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# Sexuality After Treatment of Diffuse Large B-cell Lymphoma: Patients' Experiences and Psychometric Testing of the Sexual Adjustment Questionnaire-Swedish Version II

## KEY WORDS

Factor analysis  
 Hematological malignancies  
 Instrument development  
 Lymphoma  
 Patient perspectives  
 Sexual Adjustment  
 Sexual Health  
 Sexuality  
 Statistical

**Background:** Sexuality is an important part of health-related quality of life. To ensure adequate supportive interventions, valid and reliable instruments specific to sexual changes and adjustments after cancer treatment are needed. **Objectives:** The aims of this study were to test the psychometric properties of the Sexual Adjustment Questionnaire-Swedish version II (SAQ-SII) in patients treated for diffuse large B-cell lymphoma and to describe and explore patients' experiences of sexuality after treatment. **Methods:** A cross-sectional study was conducted in 2019, using SAQ-SII and data from the National Quality Registry for Leukemia—subregistry for Lymphoma, which included 257 patients (25% response rate). An exploratory factor analysis was performed for psychometric evaluation. Internal consistency was assessed by Cronbach's  $\alpha$ . Independent *t* tests, analysis of variance, and multiple regression were used to describe patients' experiences of sexuality. **Results:** The exploratory factor analysis resulted in a 4-factor structure, explaining 65.7% of the total scale variance (SAQ-SII). The Cronbach's  $\alpha$  for the SAQ-SII was 0.88 and varied between 0.70 and 0.89 across subscales. Sexuality was affected in various ways and extent. Sexual Interest was most affected, whereas Sexual Function was least affected. Being male, of younger age, without comorbidities, and in a relationship were associated to a higher Sexual Interest. **Conclusions:** The SAQ-SII is a valid and reliable instrument to measure changes and

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The project has been funded by the Swedish Federation of Blood Cancer, 300 000 SEK (ca 30 000 US dollars).

The authors have no conflicts of interest to disclose.

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Accepted for publication May 27, 2020.

DOI: 10.1097/NCC.0000000000000866

adjustments in sexuality in patients treated for lymphoma. **Implications for Practice:** Assessments of sexuality in a broad sense should be an integrated part of cancer care to ensure timely interventions for those who need and want support.

The number of people given a diagnosis of and treated for cancer is increasing, and many of them achieve long-term survival because of early diagnosis, development of new successful treatments, and new effective supportive care interventions.<sup>1,2</sup> Surviving cancer should be a happy occurrence. However, the ever-increasing numbers of cancer survivors and people living with the consequences of cancer and its treatment frequently report that they do not return to the health status and quality of life they had before they became ill. One important part of life and a key aspect of health-related quality of life for many people is sexuality.<sup>3</sup> The World Health Organization<sup>4</sup> defines sexuality as a part of everyone's personality and states that all persons are sexual beings irrespective of age, state of health, sexual orientation, and current relationship status. Sexuality, as described by World Health Organization,<sup>4</sup> is constituted of an integration of physical, psychological, intellectual, and social aspects of the individual, which positively enriches and enhances personality, communication, and love. Sexuality may also have different meanings throughout the lifespan of an individual person.<sup>3</sup> Because cancer and cancer treatment affect not only sexual function but also sexual interest, sexual satisfaction, and sexual relationship,<sup>5-7</sup> it is important to address sexuality in its broadest sense in both clinical cancer care and research.

The research regarding sexuality in patients with hematologic malignancies is limited and has mostly focused on younger patients and/or hematopoietic stem cell transplantation in relation to fertility.<sup>8-13</sup> However, as patients with hematologic malignancies such as diffuse large B-cell lymphoma (DLBCL) are most often around or older than their 60s, the issue of fertility is usually of less importance compared with other aspects of sexuality such as communication and intimacy. Consequently, among the few studies performed, 1 qualitative study showed that these patients experienced negative effects on sexual function and sexual relationship during treatment due to the effects on strength, sexual desire, and body image.<sup>14</sup> In addition, 2 longitudinal studies showed that the importance of sexuality, sexual interest, sexual function, sexual satisfaction, and sexual relationship was negatively affected 1 month after treatment,<sup>15,16</sup> and sexual relationship was still affected after 6 months.<sup>16</sup> These studies highlight the importance of systematic assessment of sexuality to identify patients in need of support and to enable timely supportive interventions.

To guide and support patients in respect of their sexuality throughout the care trajectory, healthcare professionals need clinically relevant and theoretically based instruments to assess the patients' sexual adjustment that take into account the complex and multidimensional nature of sexuality.<sup>6,7</sup> The instruments used also have to be psychometrically tested, because valid and reliable instruments are crucial both to be able to provide reliable measures of how sexuality is affected by cancer and its treatment and to develop and evaluate supportive interventions.<sup>7</sup> This is especially true in an era when an ever-increasing number of cancer

patients put demands on the development of cancer rehabilitation and survivorship care based on their needs.

The Sexual Adjustment Questionnaire (SAQ) is an instrument developed to measure changes and adjustments in sexuality (over time) in cancer patients.<sup>7,17,18</sup> It was developed in the early 1980s based on the 1979 Oncology Nursing Society's outcome standard of sexuality<sup>19</sup> and Masters and Johnson's<sup>20</sup> definition of sexual function, which both includes the sexual aspects of desire, arousal, orgasm (ie, response cycle), and the ability to engage in sexual activity and achieve sexual satisfaction. The original SAQ was designed to assess changes and adjustment in sexuality for both women and men, with marginally different versions for each sex and which consists of items related to sexual function, sexual interest, and sexual satisfaction.

However, during recent decades, the SAQ has mostly been used in patients with prostate cancer, which also is the only patient group for which the instrument has been psychometrically tested.<sup>7,18</sup> The SAQ<sup>18</sup> was translated into Swedish (SAQ-S) by the first author with colleagues<sup>15</sup> in 2015. The translation procedure was carried out in accordance with recommended guidelines for cross-cultural adaption.<sup>21,22</sup> However, it was not possible to carry out any in-depth psychometric analyses in that study because of the limited number of participants.

As also relational aspects of sexuality are affected during cancer treatment,<sup>16</sup> items regarding intimacy and communication were added to the instrument, resulting in SAQ-Swedish version II (SAQ-SII). Therefore, the aims of this study were to test the psychometric properties of the SAQ-SII in patients treated for DLBCL and to describe and explore the patients' experiences of sexuality after treatment.

## ■ Methods

A cross-sectional study design was conducted using patient-reported data together with the SAQ-SII and data from the National Quality Registry for Leukemia-subregistry for Lymphoma (NQRL-Lymphoma).

## Data Collection

Data were collected by means of a postal alternative web-based survey in Sweden between May and July 2019. Inclusion criteria were patients given a diagnosis of DLBCL and treated with chemotherapy, chemoimmunotherapy, and/or radiotherapy. Additional criteria used for inclusion were that the patients should be 45 years or older and able to read and write in Swedish. Patients (n = 1047) given a diagnosis of and/or treated for DLBCL from January 2016 to October 2018 and registered in the NQRL-Lymphoma were invited to participate in late April 2019. Via the Swedish Population Register, we checked that potential participants were alive before invitation and distributing

the questionnaire. Written information about the aim and design of the study, voluntariness, and confidentiality together with the package of questionnaires were sent to the patients by ordinary mail. A returned questionnaire or an answered web survey together with a ticked box was considered as providing consent to participate in the study. Reminders were sent once, 1 month later, resulting in 257 participants (response rate, 25%). Stated reasons for not participating as reported by patients were that the content of the instrument was perceived as irrelevant at the present time of life, comorbidity, or advanced age (Figure 1).

## Instrument

### DEVELOPMENT OF THE SAQ-SII

The original SAQ-S exists in 2 versions, namely, 1 baseline and 1 follow-up (the latter was used in this study), and consists of 3 subscales—Sexual Interest, Sexual Function, and Sexual Satisfaction—together with a number of single items. The SAQ-S was culturally adapted to the Swedish context and modified to be used on a unisex basis, except for 3 sex-specific single items regarding sexual function by Olsson et al.<sup>15</sup> The items in the baseline version are answered in the past tense, that is, “how sexuality was experienced before diagnoses,” and the items in the follow-up version are answered in the present tense, that is, “how sexuality is experienced.” The response options are presented in a 5-point Likert scale, except for 1 item that is answered with a 6-point scale. High scores indicate more positive feelings or better functioning. There is also

the option to score “not applicable” for all items. On the basis of a study using the SAQ-S<sup>16</sup> showing that sexual relationship was affected during treatment and 1 and 6 months after treatment, together with a review of the literature,<sup>5,6</sup> a number of new items were developed. This resulted in items regarding “satisfaction with emotional closeness/intimacy in the sexual relationship” (1 item) and “if ‘having cancer’/‘undergoing cancer treatment’ changed you and your partner/partners dialogues about your sexual relationship and closeness and intimacy” (4 items). The adjusted version of SAQ-SII used in this study consisted of 25 items, of which 24 are used for men and 23 are used for women, tentatively grouped into 4 subscales.

### DEMOGRAPHIC AND MEDICAL CHARACTERISTICS OF THE PARTICIPANTS

Data regarding year of birth, date of diagnosis, details of the diagnosis, date for start of treatment, and treatment regimens were collected from the NQRL-Lymphoma. Some of these data were also provided by the patients, together with demographics regarding civil status, children living at home, educational level, and current employment/occupation.

### Statistical Analysis

Data were analyzed using IBM SPSS statistics version 25. Descriptive statistics were used to examine patients' characteristics, and independent *t* test was used for dropout analysis.

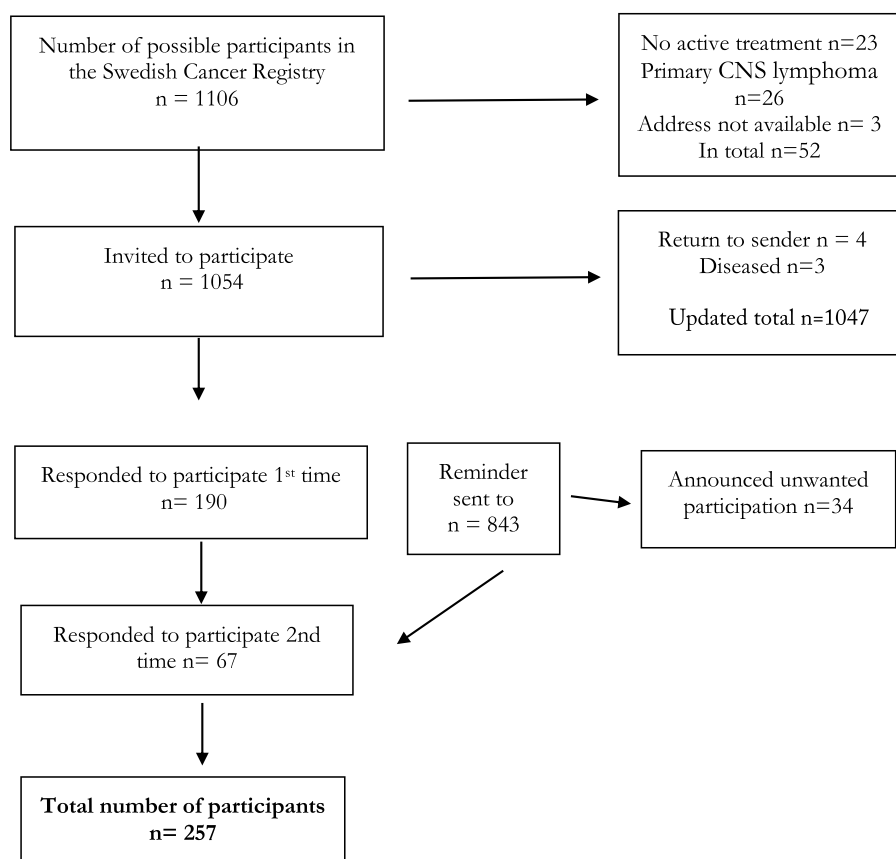


Figure ■ Flowchart of the study.

Exploratory factor analysis (EFA) using principal component analysis (PCA) was chosen for exploration of the underlying structure among the items.<sup>23</sup> Before PCA, the data's suitability for EFA was assessed using Bartlett's test of sphericity and the Kaiser-Meyer-Olkin test. To determine the number of factors to extract, the Kaiser's criterion (factors with an eigenvalue < 1.0 were deleted) together with parallel analysis and a scree test<sup>24</sup> were used. To extract the factors, a varimax rotation method with Kaiser normalization was used. Items loading at 0.4 or greater were considered as acceptable,<sup>25</sup> and the items were included in the factor where they loaded the highest. Labeling of the factors was based on the earlier EFA.<sup>7</sup> Four items were not included in the PCA: 3 items because they were sex specific and 1 item that measured frequency of sexual activity. Internal consistency of the factors was calculated with Cronbach's  $\alpha$  coefficient.<sup>23</sup> The final instrument is from now on called SAQ-SII.

Differences in SAQ-SII (scales' score and total score) regarding patients' characteristics were examined using independent  $t$  test and analysis of variance, followed by post hoc Tukey test.<sup>23</sup> We also computed the number and percentage of patients who scored negatively, less than 3, on each item/subscale in the SAQ-SII to identify the frequency in the more affected areas.

Multiple regression analyses<sup>23</sup> were carried out to explore how different characteristics explained sexual interest and overall sexuality (dependent variable). The independent variables were sex, current age, living in a relationship or not, born in Sweden or not, currently working or not, university educated or not, months since diagnosis, and self-reported comorbidities, which were entered simultaneously. In the regression analyses, participants were excluded pairwise in the SAQ-SII. All statistical tests were 2-tailed, and the statistical significance was assumed at  $P < .05$ .

## Ethical Approval

The study was approved by the Regional Ethical Review Board in Uppsala (Dnr 2018/028). Region Skåne gave permission to use data from NQRL-Lymphoma for recruiting informants and variables for research (Dnr 122/18).

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## ■ Results

### Patient Characteristics

The participants' ( $n = 257$ ) ages ranged from 45 to 94 years, with a mean (SD) age of 62.5 (10.4) years. Most of the participants (71%,  $n = 181$ ) were in a relationship. For most of them, Sweden was their country of birth (80%). All participants had DLBCL, and 47% also had 1 or more additional chronic diseases. With regard to educational level, nearly 40% had university education, and 27% were employed. Time since diagnosis ranged between 4 and 39 months, and time since treatment ended ranged between less than 1 and 39 months (Table 1).

There were no statistically significant differences in respect of time from diagnosis, sex, ongoing treatment, and treatment regimen between the responding and nonresponding groups of patients. However, there was a statistically significant difference in

age, where nonparticipants were 2.6 years older than participants ( $P = .001$ ).

## Construct Validity of the SAQ-S

Construct validity was measured by EFA using PCA (Table 2). As Bartlett's test of sphericity was significant ( $P < .05$ ), data were considered suitable for EFA.<sup>25</sup> The Kaiser-Meyer-Olkin value was 0.803, indicating that the sample should produce reliable and distinct factors.<sup>23</sup> The Kaiser's criterion suggested that the instrument consisted of 5 factors, although the parallel analysis and the scree test suggested a 4-factor solution,<sup>24</sup> which were congruent with the theoretical assumptions and therefore kept.

Subsequently, 3 factors were named in accordance with the earlier 3-factor solution by Wilmoth et al,<sup>7</sup> namely, Sexual Interest, Sexual Function, and Sexual Satisfaction, and the fourth new factor was named sexual relationship. The sex-specific items (13 Women, 14 Men, and 15 Men), together with the single item (25) regarding frequency of sexual activity, were not included in the PCA (all items are shown in Table 3). The factor solution was supported by the varimax rotation matrix and revealed strongly loaded items (>0.4) in each factor. The final instrument, SAQ-SII, had a 4-factor (subscales) structure and consisted of 21 items, which explained 65.7% of the total variance to which 1 or 2 sex-specific and 1 single item regarding sexual frequency are added in the SAQ-SII (Table 2), resulting in a 23-item questionnaire for women and a 24-item questionnaire for men.

## Reliability

Internal consistency was calculated with Cronbach's  $\alpha$  coefficient—which was for the 4 subscales, respectively: Sexual Interest, 0.89; Sexual Function, 0.70; Sexual Satisfaction, 0.75; and Sexual Relationship, 0.88—showing acceptable to good internal consistency of the subscales.<sup>26</sup> In addition, the total scale SAQ-SII had a Cronbach's  $\alpha$  coefficient of 0.88.

## Patients' Perception of Cancer and Its Treatment's Impact on Sexual Interest, Sexual Function, Sexual Satisfaction, and Sexual Relationship

In the Sexual Interest subscale, the patients scored lowest, "slightly important," for "importance of sexual activity" (mean [SD], 2.12 [1.09]); 63.6% scored less than 3. The highest score, "sometimes," was found in "important to reach orgasm" (mean [SD], 3.14 [1.43]). A slight majority, 55.1%, reported less than 3 on that subscale. In the subscale Sexual Function, they scored lowest, "sometimes," for "too tired for sexual activity" (mean [SD], 3.19 [1.30]) and highest, "almost never," for "feel any pain or discomfort during sexual activity" (mean [SD], 4.27 [1.04]). In the subscale Sexual Satisfaction, the patients scored lowest, "neutral," for "satisfied with the frequency of sexual activity" (mean [SD], 3.15 [1.16]) and highest, "almost always," for "feeling satisfied following sexual activity" (mean [SD], 4.02 [1.02]). All items in the subscale Sexual Relationship, had a mean score of less than 3, "somewhat negative impact" to "strong negative impact" (range of mean [SD], 2.46 [0.80] to 2.95 [0.77]). However, only 44.6%

Table 1 • Patient Characteristics (N = 257)

Characteristics	n	%	Mean (SD)
Sex			
Men	144	56	
Women	113	44	
Age, y			62.5 (10.4)
Range			
45–54	26	10	
55–64	49	19	
65–74	83	32.5	
75–84	78	30.5	
84–94	21	8	
Civil status			
Being in a relationship	181	71	
Single	75	29	
Children at home			
No	218	86.5	
Yes	34	13.5	
Country of birth			
Sweden	200	80	
Other	49	20	
Education level			
Elementary school	50	20	
Upper secondary school	46	18	
Vocational training	60	23.5	
University	98	38.5	
Employment			
Employed	58	23	
Employed, currently on sick leave	11	4	
Unemployed	4	1.5	
Retired	173	69	
Disability pension/long-term sick leave	6	2.5	
Additional chronic diseases, yes <sup>a</sup>	117	47	
Cardiovascular diseases	41		
Endocrine diseases	25		
Musculoskeletal diseases	18		
Hematological and autoimmune diseases	13		
Gastrointestinal diseases	12		
Pulmonary diseases	11		
Genitourinary diseases	9		
Neurological diseases	9		
Dermatological diseases	8		
Other neoplasms	7		
Mental disorders	6		
Ocular diseases	3		
Therapy (patient reported)			
Chemotherapy	248	99	
Immunotherapy	52	20	
Radiotherapy	63	25	
Other	22	9	
Months since diagnosis <sup>c</sup> (registry data <sup>b</sup> )			22.6 (9.7)
≤6	8	3	
7–12	48	19	
13–18	37	14	
19–24	49	19	
25–30	52	20	
31–36	38	15	
≥37	25	10	

(continues)

Table 1 • Patient Characteristics (N = 257), Continued

Characteristics	n	%	Mean (SD)
Months since start of treatment <sup>d</sup> (registry data <sup>b</sup> )			24.2 (9.1)
≤6	3	2	
7–12	19	11.5	
13–18	19	11.5	
19–24	40	24.5	
25–30	38	23	
31–36	26	16	
≥37	19	11.5	

<sup>a</sup>Patients could choose more than 1 option.

<sup>b</sup>Data from the NQRL-Lymphoma are based on <sup>c</sup>n = 257 and <sup>d</sup>n = 164.

reported a subscale score less than 3. Regarding the item “present frequency of sexual activity,” 36% (n = 92) answered no activity, 16% (n = 41) answered less than once a week, 17% (n = 45) answered 1 to 3 times per month, 15% (n = 39) answered once a week, 9% (n = 23) answered 2 to 3 times a week, and 2% (n = 4) answered 4 times a week or longer (a 6-point scale). The mean scores of each subscale are presented in Table 3.

## Characteristics Explaining Sexual Interest and Overall Sexual Adjustment

Multiple regression analyses were performed on the SAQ-SII Subscale Sexual Interest and the SAQ-SII total mean score. As time from diagnosis correlated strongly with time from treatment start (0.99) and time from treatment cessation (0.87), only time from diagnosis was kept for the final model. Because only 13% (n = 34) of the patients reported having children living at home, we excluded that variable. The full models for SAQ-SII SI subscale and the SAQ-SII total score are demonstrated in Table 4. For SAQ-SII Subscale Sexual Interest, being male, of younger age, and in a relationship as well as lacking comorbidities all contributed to higher sexual interest. For the SAQ-SII total score, being male and of younger age as well as lacking comorbidities contributed to a more positive sexual adjustment in patients treated for DLBCL.

## Discussion

The aims of this study were to test the psychometric properties of the SAQ-S in patients treated for DLBCL and to describe and explore the patients' experiences of sexuality after treatment.

The EFA resulted in the SAQ-SII with a 4-factor structure, explaining 65.7% of the total scale variance. The Cronbach's  $\alpha$  for the SAQ-SII was 0.88 and varied between 0.70 and 0.89 across subscales. Hence, overall, the results showed that the SAQ-SII is a valid and reliable instrument to measure changes and adjustments in sexuality in patients treated for lymphoma. In this study, sexuality was affected in various ways and extent. Sexual Interest was the most affected, whereas Sexual Function was the least affected. Being male, of younger age, without comorbidities, and in a relationship were associated to a higher Sexual Interest.

**Table 2 • The 4-Factor Structure of the 25-Item SAQ-Swedish Version II**

Items/Factors	Sexual Interest	Sexual Function	Sexual Satisfaction	Sexual Relationship
1. Importance of SA	0.764			
2. Resume SA after treatment	0.617			
3. SA pleasurable	0.825			
4. Desire for SA	0.861			
5. Greater desire than partner	0.796			
6. Initiator for SA	0.814			
7. Important to reach orgasm	0.739			
8. Too tired for SA		0.667		
9. Trouble getting aroused		0.759		
10. Pain/discomfort during SA		0.530		
11. Problem reaching orgasm		0.608		
12. Problem with SF after treatment		0.706		
16. Satisfied following SA			0.640	
17. Satisfied with frequency of SA			0.738	
18. Satisfied with emotional closeness			0.797	
19. Cancer changed SR				0.441
20. Treatment changed SR				0.569
21. Cancer changed dialogues about SR				0.840
22. Cancer changed dialogues about intimacy				0.896
23. Treatment changed dialogues about SR				0.886
24. Treatment changed dialogues about intimacy				0.855
No. items	7	5	3	6
Eigenvalue	6.998	3.355	1.996	1.446
Explained variance (total, 65.69%)	33.33	15.97	9.50	6.89
Sex-specific items <sup>a</sup>				
13. Do you experience vaginal dryness during sexual activity? (single item, women)		x		
14. Can you achieve erection when sexually aroused? (single item, men)		x		
15. Do you feel that it takes you long time to achieve an erection? (single item, men)		x		
Unisex single item				
25. SA frequency				

Abbreviations: SA, Sexual Activity; SAQ, Sexual Adjustment Questionnaire; SR, Sexual Relationship.

Extraction method: principal component analysis. Rotation method: varimax with Kaiser normalization. Rotation converged in 6 iterations.

<sup>a</sup>Three sex-specific items (13-15) and 1 item regarding frequency (25) were not included in the principal component analysis. The sex-specific items were placed in the Sexual Function factor on a theoretical basis.

The final psychometrically tested version of the SAQ-SII consists of 21 items with 4 additional items (3 sex-specific items and 1 single item), resulting in a 24-item version for men and a 23-item version for women. The EFA was computed as a PCA because the SAQ-S was modified for use in a new context. After excluding items loading at less than 0.4, the results showed that the factor structure for the subscales Sexual Interest, Sexual Function, and Sexual Satisfaction was consistent with the factor structure of Wilmoth et al<sup>7</sup> and that the added items constructed a new, well-defined factor/subscale that we named Sexual Relationship. Together with the good internal consistency of all factors, this indicates that the modified SAQ-SII is a psychometrically sound instrument<sup>23</sup> in line with proven theories and models of sexuality.<sup>5,6,20</sup>

In the subscale Sexual Relationship, the added items all had factor loadings greater than 0.8, indicating that some of them may be redundant. These questions operate with both “having cancer” and “having been treated for cancer,” which may relate to patients being unable to distinguish whether the impact on sexual relationship was due to the cancer disease or its treatment, which has been shown earlier by Olsson et al.<sup>14</sup> We argue that

this new factor, Sexual Relationship, is important, but in future studies, we will revise these questions. Within cancer care, awareness has been raised during recent decades regarding the complexity of sexuality in integrative models,<sup>5,6</sup> and the importance of addressing sexuality in its broadest sense has been stressed. In Olsson et al,<sup>14</sup> patients described sexual relationships as sharing intimacy and communication about sexuality with a loved one, in accordance with Cleary and Hegarty's<sup>5</sup> “neo-theoretical framework of sexuality” in women survivors from gynecological cancer and Bober and Varela's<sup>6</sup> interpersonal factors in “integrative biopsychosocial model for intervention.”

In addition, the item concerning the frequency of sexual activity was left out of the factor extraction. This item is answered at the interval scale level and measures an absolute frequency instead of feelings and/or function in contrast to the other items. Furthermore, frequency as such is not necessarily a proxy of overall sexual satisfaction.<sup>6,26</sup> Thus, we deemed that it was not relevant in any of the subscales but should be considered as a single item.

This group of patients given a diagnosis of and treated for DLBCL is a previously understudied group, especially regarding differences between sexes, and there are very few references in the

**Table 3 • Statistics Swedish Version II (SAQ-SII)**

Total Score, by Subscale and by Item	n	Mean (SD)	Score < 3, n (%)
<b>SAQ-SII total score</b>	<b>219</b>	<b>3.02 (0.70)</b>	<b>98 (44.7)</b>
<b>Sexual Interest</b>	<b>236</b>	<b>2.63 (1.04)</b>	<b>130 (55.1)</b>
1. What is the importance of sexual activity in your life right now?	239	2.12 (1.09)	152 (63.6)
2. How soon after your last cancer treatment did you resume sexual activity (on your own or with another person)?	244	2.40 (1.45)	146 (59.8)
3. How often is sexual activity pleasurable for you now?	246	2.88 (1.52)	103 (41.9)
4. Do you have desire for sexual activity?	242	2.77 (1.12)	82 (33.9)
5. Do you have a greater desire for sexual activity than your partner/partners?	185	2.51 (1.09)	88 (47.6)
6. Have you been the one to initiate sexual activity with your partner/partners since last cancer treatment?	188	2.62 (1.27)	77 (41.0)
7. Is it important for you to reach orgasm?	234	3.14 (1.43)	73 (31.2)
<b>Sexual Function</b>	<b>201</b>	<b>3.62 (0.92)</b>	<b>39 (19.4)</b>
8. Do you feel too tired for sexual activity?	236	3.19 (1.30)	67 (28.4)
9. Do you have problems getting sexually aroused/turned on?	189	3.62 (1.17)	32 (16.9)
10. Do you feel any pain or discomfort during sexual activity?	171	4.27 (1.04)	12 (7.0)
11. Since your cancer treatment, do you have problems in reaching orgasm or did you feel that you "come" too soon?	156	3.56 (1.13)	22 (14.1)
12. Have you experienced problems with your sexual ability since your cancer treatment?	173	3.49 (1.21)	36 (20.8)
13. Do you experience vaginal dryness during sexual activity? (single item, women)	77	3.48 (1.40)	27 (35.1)
14. Can you achieve erection when sexually aroused? (single item, men)	135	3.41 (1.30)	37 (27.4)
15. Do you feel that it takes you long time to achieve an erection? (single item, men)	128	3.18 (1.46)	26 (20.3)
<b>Sexual Satisfaction</b>	<b>237</b>	<b>3.50 (1.01)</b>	<b>44 (18.6)</b>
16. Do you feel satisfied following sexual activity?	167	4.02 (1.02)	13 (7.8)
17. Are you satisfied with the frequency of sexual activity in your life?	236	3.15 (1.16)	60 (25.4)
18. Are you satisfied with your emotional closeness in your sexual relationship/relationships?	180	3.81 (1.11)	18 (10)
<b>Sexual Relationship<sup>a</sup></b>	<b>184</b>	<b>2.72 (0.60)</b>	<b>82 (44.6)</b>
19. Has "having cancer" changed your sexual relationship with your partner(s)?	182	2.47 (0.78)	81 (44.5)
20. How has "undergoing cancer treatment" changed your sexual relationship to your partner(s)?	179	2.46 (0.80)	80 (44.7)
21. Has "having cancer" changed your and your partner's(s') dialogues about your sexual relationship?	180	2.81 (0.67)	40 (22.2)
22. Has "having cancer" changed your and your partner's(s') dialogues about your closeness and intimacy?	175	2.95 (0.79)	35 (20)
23. Has "undergoing cancer treatment" changed your and your partner's(s') dialogues about your sexual relationship?	181	2.76 (0.87)	46 (25.4)
24. Has "undergoing cancer treatment" changed your and your partner's(s') dialogues about your closeness and intimacy?	180	2.95 (0.77)	38 (21.1)
25. How often do you have sexual activity (with or without a partner)? <sup>b</sup> (single item)	244	1.48 (1.45)	

Responses range from 1 to 5 except for 1 item with a 6-point scale. Higher scores indicate more positive feelings or better function in these areas. The response alternative 0 (zero) was used when the question was not applicable, except for the item with a 6-point scale.

<sup>a</sup>Response alternative 0 (zero) within this subscale indicated no partner.

<sup>b</sup>Single item to the total scale with quantitative responses. Observe that 23 items are used for women and 24 items are used for men.

research literature.<sup>14–16,27,28</sup> For the latter part of the aim in this study, to describe and explore changes and adjustment of sexuality in cancer patients after treatment, the results showed that sexuality was somewhat affected. The lowest score, that is, most affected, was found in the Sexual Interest subscale, whereas Sexual Function was the least affected. The regression analyses showed that a higher total SAQ-SII score was associated to being male, younger, and without comorbidities, showing that younger men with no additional illnesses had a better adjustment of their sexuality.<sup>27</sup> In addition to the conditions mentioned previously, we also found that being in a relationship was associated with a greater Sexual Interest. However, in a study from Korea,<sup>27</sup> comprising a sample of non-Hodgkin lymphoma (includes DLBCL), with a population

of somewhat 10 years younger than those in this study, lacking sexual interest for women was associated to being married. Regarding sexual interest in hematological cancer survivors (15% DLBCL),<sup>29</sup> women were more than twice as likely as men to lack interest in sex, indicating that sexual interest varies between men and women. This is an interesting area that should be investigated further.

Regarding age, the results in this study showed that younger age (<62.5 years) was associated with higher sexual interest as well as with overall sexual adjustment. Older age has been associated with sexual dysfunction and a particularly low level of sexual satisfaction in earlier studies on hematological malignancies. Greaves et al<sup>29</sup> demonstrated a substantial challenge to long-term survivors, with 25% to 30% reporting a sexual dysfunction or dissatisfaction

**Table 4 • Multiple Regression Models of the SAQ-SII Subscale Sexual Interest (SI) and SAQ-SII Total Score**

Dependent Variables	SAQ-SII SI			SAQ-SII Total Score		
	Std B	t	P	Std B	t	P
Independent variables						
Sex	0.322	5.559	.000	0.210	3.194	.002
Age	-0.362	-4.334	.000	-0.239	-2.800	.006
In a relationship	0.167	2.837	.005	-0.057	-0.857	.392
Born in Sweden	0.069	-1.186	.237	-0.076	-1.165	.246
Currently working	-0.068	-0.924	.357	-0.066	-0.791	.430
University education	0.087	1.475	.142	0.046	0.495	.495
Months from diagnosis	0.053	0.907	.365	0.051	0.770	.442
Comorbidities	-0.169	-2.977	.003	-0.296	-4.599	.000
R <sup>2</sup>	0.309			0.180		
Adjusted R <sup>2</sup>	0.283			0.148		

Abbreviation: SAQ-SII, Sexual Adjustment Questionnaire-Swedish version II.

that they attribute directly to having had cancer. Together with current age, older patients were more likely to have lost interest in sex and were more dissatisfied with sex since diagnosis. On the other hand, in a study on cancer survivors, mostly given a diagnosis of breast, prostate, or colorectal cancer or melanoma, there were no differences in levels of sexual activity or sexual function between cancer survivors and persons in a control group (>50 years old).<sup>30</sup> However, the cancer survivors, both women and men, were more dissatisfied with their sex lives than controls, which could depend on deficient information and support in issues related to sexual adjustment. More research regarding sexual adjustment of all cancer survivors' wishes and needs of information and support, and especially in hematological malignancies, is needed, if we are to understand the posttreatment problems each sex faces. However, in a qualitative study by Olsson et al,<sup>14</sup> the patients described the need or wish for support related to this issue as very low during treatment, because the thoughts and interest of sexuality were overshadowed when disease and adverse effects of the treatment were experienced as severe. This highlights the challenge to identify patients who want information and supportive care related to sexuality, which also should be adjusted to each patient's needs and wishes at a time and in an individual manner in line with the person-centered care framework.

For the cancer nurse, the problem of patients with affected sexuality should be an area of possible intervention.<sup>31,32</sup> The cancer nurses need to endeavor confirmation of the subject sexuality as an area that could be impacted by cancer and its treatment. Because the patients in this study described sexuality as less important, together with earlier results that not all patients want support,<sup>14</sup> the challenge for the cancer nurses is to identify/discern the patients who experience changes in sexual interest, sexual function, sexual satisfaction, and sexual relationship as a problem and really want information and support. Nurses, who are present during the entire trajectory of care, have a key role working with holistic individual nursing care aiming to promote well-being and as high quality of life as possible for the patients. However, to be able to support the patients on a timely basis, it is important for nurses to recognize the diversity and complexity of the patients' problems, including their unmet needs, to give adequate support. Therefore, and on the basis

of patients' wishes and needs, person-centered information and support should be given.

### Limitations

The patients could answer the questionnaire either on paper (89%, n = 230) or via a web survey (11%, n = 27), which was a way to accommodate both preferences and make the sample more representative.<sup>34</sup> Interestingly, in the age of online interaction, a majority still preferred to answer on paper, which is in accordance with other studies.<sup>33,34</sup> Despite us making sure that all patients were still alive when the questionnaires were distributed, we were informed by relatives that 3 persons had died. This indicated the vulnerability of the group and likely deceased patients in the nonrespondents' group. Some patients justified their nonparticipation by highlighting their advanced age, being without a partner, or having ceased to be sexually active. These results correspond well to what Tierney<sup>3</sup> concluded in her review—that during the lifespan, sexuality may have different meanings for an individual person and advanced age reduces sexual interest.

There were no significant differences found between responders and nonresponders in this sample apart from age. However, this difference in means was 2.6 years only, which probably is of no clinical significance.

We are aware of the relatively low response rate (25%), and a second reminder could have been of value. However, as the group was frail and relatives reported that invited patients had deceased, we chose not to send out a second reminder. Regardless of the rather low response rate, we had a satisfactory basis of data to carry out an EFA because the least number of observations is 5 times the number of items analyzed.<sup>25</sup>

### Conclusion

This study has shown that SAQ-SII is a valid and reliable instrument in patients treated for lymphoma. The EFA resulted in a 4-factor structure, explaining 65.7% of the total scale variance. Cronbach's  $\alpha$  for the SAQ-S II was nearly excellent and varied



between acceptable to good across the subscales. For the participants in this study, SI was the most affected, whereas Sexual Function was the least affected. Being male, younger, without comorbidities, and in a relationship were associated to a higher score of SI.

This study contributes to a better understanding of sexuality after treatment in patients with DLBCL. However, more research is needed to understand how demographics and changes in sexuality due to cancer and its treatment impact on patients' quality of life. Further testing of the SAQ-SII in other cancer diagnoses would be valuable.

## Clinical Implication

The results are of significance for cancer nurses because these highlight that sexual adjustment needs to be considered also in older patients with hematological malignancies such as DLBCL. An important part of cancer nurses' responsibility is the timely identification of patients, regardless of sex and age, who experience sexual problems and who want support. Guided by the idea of holistic individual nursing care, one way to realize this is to organize the care in line with the framework of person-centered care. Cancer nurses must endeavor to provide information on how cancer and its treatment have the potential to affect patients' sexual interest, sexual satisfaction, sexual functioning, and sexual relationships, which can lead to the need for sexual adjustment. However, it must be stressed that, in order not to violate patients' integrity and dignity, the challenge for cancer nurses will be to identify patients who ascribe importance to sexuality and need and want information and support regarding sexuality issues. Various communication models exist to assist cancer nurses to broach the topic of sexuality and sexual adjustment with their patients, for example, BETTER.<sup>32</sup>

## ACKNOWLEDGMENTS

The authors want to gratefully thank all of the patients who participated in the study. They also thank Jari Appelgren (lic statistician) for statistical advice. Gratitude is expressed for the Blood Cancer Foundation for financial support and to Karin Ekström Smedby, MD, Associate Professor and Registry Manager, and Klaus Bjerregard, Data Manager, NQRL-Lymphoma, Region Skåne.

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