



# Health-care professionals' perspective on discussing sexual issues in adult patients after haematopoietic cell transplantation

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## Abstract

The majority of adult patients have sexual concerns after post-haematopoietic cell transplantation. Even so, health-care professionals (HCP) do not routinely discuss these problems. We, therefore, surveyed all the members of the European Society for Blood and Marrow Transplantation to evaluate the barriers and facilitators to discussing sexual issues. The 73-item web-survey was completed by 166 registered nurses (RNs) and 126 medical doctors (MDs). Sixty-eight percent reported that they seldom discussed sexual issues. Younger MDs ( $p < 0.001$ ) and those who work in non-western European countries ( $p = 0.003$ ), RNs with probably less sexual education themselves ( $p = 0.002$ ), MDs and RNs who have limited knowledge about sexual complications ( $p < 0.001$ ) and MDs and RNs who feel uncomfortable discussing sexual issues ( $p < 0.001$ ) are all less likely to discuss these matters. The major perceived barriers were that patients might be embarrassed if sexual issues were discussed in the presence of a relative (60% RNs, 67% MDs) and that professionals prefer patients to raise sexual issues themselves (54% RNs, 44% MDs). The most important perceived facilitator was for the patient to initiate discussion ( $\geq 90\%$  for RNs and MDs). Overall, haematopoietic cell transplantation survivors may not be receiving the support on sexual issues they probably need.

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## Introduction

Haematopoietic cell transplantation (HCT) is often the only curative option for many malignant and non-malignant haematological diseases. However, high-dose radiation, and the

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use of alkylating agents in treatment, can cause premature menopause [1–3], hypogonadism [2, 4, 5], polyneuropathy [6], and graft versus host disease [7–9]; all of which can result in alterations to the patient's sexual functioning and satisfaction [10–12]. Disruption of sexual function is one of the most common long-term side-effects following both allogeneic and autologous HCT [13–18] and, according to the most extended longitudinal study report, 46% of male and 80% of female patients have sexual problems 5 years post-transplantation [16]. Long-term sexual complications include changes in sexual function [17, 8] and changes, which could impact on sexuality [15, 17, 8, 19–21]. The impact of disrupted sexual function usually becomes evident 1 year after HCT, during the recovery and reintegration phases [22, 23].

Because sexuality is an important aspect of overall health and quality of life, and because many HCT patients are at risk of developing sexual problems, it is important to discuss sexual issues with patients to promote their recovery and well-being. Unfortunately, there is much evidence that cancer patients are disappointed by the information they receive regarding sexual issues. Health-care professionals (HCP) rarely routinely discuss this subject [14, 15, 17, 21, 24–26]. For instance Humphreys et al. [15] reported that nearly half of patients questioned received no information about the possible consequences of treatment on sexual function before bone marrow transplantation. This seems important as patients who did receive information reported they experienced better sexual function after transplantation [15]. Other studies have reported that only 13–33% registered nurses (RNs) [27, 28] and 25%–38% medical doctors (MDs) [27–29] discussed sexual issues with cancer patients, with many barriers to addressing patients' sexuality in oncological settings being identified. Physicians put forward a perceived lack of time as well as a lack of knowledge as the most important reasons for their not addressing such issues [27–33]. Nurses reported their own lack of comfort on the subject as well as feelings of embarrassment as being significant barriers [27, 28, 31–43].

To examine this question in more detail, we designed and distributed an online survey among the medical staff involved with such patients. Our main aim was to investigate how often HCP throughout Europe discuss sexual issues with their adult patients. In addition, barriers and facilitators to discussing sexual issues with patients were determined.

## Subjects and methods

### Design: Cross-sectional survey

#### Subjects

Between March and July 2014, we sent an online questionnaire to all 3127 members (physicians, principal

investigators, nurses) of the 193 centres of the European Society for Blood and Marrow Transplantation (EBMT). The centres were requested to further distribute the questions to those caring for HCT patients.

### Study-specific questionnaire

A self-administered questionnaire, previously devised by Moore et al. [37] for use among oncology nurses of men diagnosed with testicular cancer, was adapted for use with HCT staff [39]. The adapted questionnaire (available as Supplemental Material) consisted of 73 items divided into seven sections namely:

1. Demographics (gender, age, religion, country)
2. Work experience, additional education/training following registration, plus previous education specifically taken in the field of sexuality
3. Discussing sexual issues with patients (frequency of discussing sexual issues)
4. Perceived barriers to discussing sexual issues with patients
5. Perceived facilitators to discussing sexual issues with patients
6. Self-reported knowledge about sexual issues and comfort level relating to discussing sexual issues and
7. Comments (free text).

The response format of the items in Sections 4 and 5 was a 5-point Likert scale (range: strongly agree—strongly disagree, or very comfortable—very uncomfortable). Current clinical practice surrounding the discussion of sexual issues with patients was evaluated by means of a single item added to the study-specific questionnaire: “In the last 6 months, how frequently have you informed patients that you were available to discuss their sexual concerns?” (never/occasionally or frequently/very frequently/with all patients).

The perceived knowledge and comfort when discussing sexual issues were evaluated with 11 items; barriers to discussing sexual issues were evaluated using 28 items, subdivided into environmental barriers (6 items), patient barriers (11 items), and other potential barriers (11 items). Facilitators for discussing sexual issues with patients were evaluated with 10 items. To obtain insight into which factors are the most relevant, we compared perceived knowledge of sexual issues, comfort when discussing sexual issues, and barriers and facilitators to discussing sexual issues among HCP who rarely discussed sexual issues, with those who discussed sexual issues routinely.

The questionnaire was available in French, German, Dutch, Italian and English languages.

#### Statistical analyses

All statistical analyses were performed using SPSS version 21 (IBM Corp. Armonk, NY). Demographics are described

using frequencies and percentages and comparisons between groups (i.e., complete responders versus incomplete responders and frequency of discussing sexual issues) via Chi-square or Fisher's exact tests. Except for age (categorised in clinically relevant blocks) and sexual education (categorized in hourly blocks), all other variables were dichotomised as follows:

1. Geographic distribution (western European/ non-western European)
2. Religion (religious/not religious or not practising)
3. Academic qualification (received post graduate education (yes/no))
4. Time working in HCT (more/less than 5 years)
5. Current clinical setting (only inpatient/other)
6. Barriers and facilitators ((strongly) agree/neutral or (strongly) disagree)
7. Questions about the frequency of discussing sexual health (none or occasionally/(very) frequently or with

all patients)

8. Self-reported knowledge levels ((strongly) agree/neutral or (strongly) disagree)
- 9) Self-reported comfort levels ((very) comfortable/neutral or (very) uncomfortable).

Chi-square tests or Fisher's exact tests were used to examine statistically significant differences between groups.

*P*-values < 0.05 were considered to be significant, *p*-values < 0.1 were considered to indicate a trend.

## Results

### Demographic data

In total, 426 EBMT members responded (14% response rate). Responses from 59 RNs and 44 MDs were excluded because of incomplete or missing data. Thirty-one HCP (16

**Table 1** Demographics characteristics of the study population who did and did not complete the questionnaire

	Registered nurses				<i>p</i> -value	Medical doctors				<i>p</i> -value
	Completed ( <i>N</i> = 166)		Not completed ( <i>N</i> = 52)			Completed ( <i>N</i> = 126)		Not completed ( <i>N</i> = 37)		
	<i>n</i>	%	<i>n</i>	%		<i>n</i>	%	<i>n</i>	%	
Gender					0.33					0.75
Male	21	12.7	4	7.7		61	48.4	19	51.4	
Female	145	87.3	48	92.3		65	51.6	18	48.6	
Religion					0.001*					0.003*
Religious	73	44	37	71.2		72	57.1	31	83.8	
Not practising or not religious	93	56	15	28.8		54	42.9	6	16.2	
Academic qualification					0.006*					<0.001*
Registration	38	22.9	22	42.3		9	7.1	14	37.8	
Post graduate education	128	77.1	30	57.7		117	92.9	23	62.2	
Years working in HSCT <sup>a</sup>					0.77					0.38
0–5 years	35	21.1	10	19.2		13	10.3	6	16.7	
More than 5 years	131	78.9	42	80.8		113	89.7	30	83.3	
Current practice area <sup>a</sup>					0.26					0.029*
Haematology inpatient	91	55.2	24	46.2		37	29.4	18	48.6	
In and/or outpatient	74	44.8	28	53.8		89	70.6	19	51.4	
sexual health education pre- and or post graduate					0.50					0.088
None/unsure	58	34.9	25	48.1		54	42.9	26	70.3	
0–1 h	23	13.9	7	13.5		19	15.1	4	10.8	
1–5 h(s)	52	31.3	14	26.9		28	22.2	5	13.5	
6–10 h	18	10.8	2	3.8		11	8.7	1	2.7	
11–15 h	5	3	1	1.9		4	3.2	0	0	
>15 h	10	6	3	5.8		10	7.9	1	2.7	

\**p* < 0.05

<sup>a</sup>Missing values

**Table 2** Discussing sexual issues in relation to characteristics of the registered nurses and the medical doctors

	Registered nurses ( <i>N</i> = 166)					Medical doctors ( <i>N</i> = 126)				
	In the last 6 months, how frequently have you informed patients that you were available to discuss their sexual concerns?									
	Never/occasionally		(Very) frequently/with all my patients			Never/occasionally		(Very) frequently/with all my patients		
	<i>n</i>	%	<i>n</i>	%	<i>p</i> -value	<i>n</i>	%	<i>n</i>	%	<i>p</i> -value
	112	67.5	54	32.5		85	67.5	41	32.5	
Age in years <sup>a</sup>					0.81					<0.001*
20–35	32	71.1	13	28.9		9	81.8	2	18.2	
36–55	69	65.7	36	34.3		68	75.6	22	24.4	
55+	11	68.8	5	31.3		8	32.0	17	68.9	
Gender <sup>a</sup>					0.93					0.14
Male	14	66.7	7	33.3		45	73.8	16	26.2	
Female	98	67.6	47	32.4		40	61.5	25	38.5	
Geographic distribution					0.17					0.003*
Western European	103	66.0	53	34.0		69	62.7	41	37.3	
Non-western European	9	90.0	1	10.0		16	100.0	0	0.0	
Religion <sup>a</sup>					0.80					0.58
Religious	50	68.5	23	31.5		50	69.4	22	30.6	
Not practising or not religious	62	66.7	31	33.3		35	64.8	19	35.2	
Academic qualification <sup>a</sup>					0.35					0.72
Registration	28	73.7	10	26.3		7	77.8	2	22.2	
Post graduate education	84	65.6	44	34.4		78	66.7	39	33.3	
Years working in HSCT <sup>a</sup>					0.33					0.55
0–5 years	26	74.3	9	25.7		10	76.9	3	23.1	
More than 5 years	86	65.6	45	34.4		75	66.4	38	33.6	
Current practice area <sup>a</sup>					0.21					0.66
Haematology inpatient	65	71.4	26	28.6		26	70.3	11	29.7	
In and/or outpatient	46	62.2	28	37.8		59	66.3	30	33.7	
Sexual education received					0.002*					0.078
None	43	74.1	15	25.9		36	66.7	18	33.3	
0–1 h	18	78.3	5	21.7		14	73.7	5	26.3	
1–5 h(s)	34	65.4	18	34.6		23	82.1	5	17.9	
6–10 h	14	77.8	4	22.2		7	63.6	4	36.4	
11–15 h	1	20.0	4	80.0		1	25.0	3	75.0	
>15 h	2	20.0	8	80.0		4	40.0	6	60.0	

\**p* < 0.05<sup>a</sup>missing values

RNs, 15 MDs) who only worked with children or adolescents did send completed data but, as sexual issues were rarely or never discussed (94% of RNs and 80% of MDs) these responses were excluded from the factor analysis. The final analyses were carried out on the remaining 292 responses (equivalent to 9% response rate).

The study population, therefore, consisted of 166 RNs and 126 MDs, from 34 countries. The majority of RNs and MDs came from European countries; the Netherlands (RNs 36 (22%), MDs 14 (11%)), Belgium (RNs 35 (21%), MDs 6 (5%)), United Kingdom (RNs 23 (14%), MDs 18 (14%))

and Italy (RNs 19 (11%), MDs 23 (18%)). The demographic data are described in Table 1.

We compared the demographic data of respondents who completed the questionnaire and respondents from whom responses on barriers and facilitators were missing (Table 1). Differences between HCP who did complete the questionnaire with those who did not, included self-reported religious affiliation; RNs 44%/71%, *p* = 0.001; MDs 57%/84%, *p* = 0.003, and a lack of post graduate education; (RNs 23%/42%, *p* = 0.006; MDs 7%/38%, *p* < 0.001.

**Table 3** Percentage of registered nurses and medical doctors who reported to never/occasionally discussed sexual issues, compared with those who reported to frequently discuss them. Results also presented for competence barriers, perceived comfort, potential barriers and facilitators to discussion

	Registered nurses (N = 166)					Medical doctors (N = 126)				
	Never/occasionally		(Very) frequently/with all my patients			Never/occasionally		(Very) frequently/with all my patients		
	n	%	n	%	p-value	n	%	n	%	p-value
<i>In the last 6 months, how frequently have you informed patients that you were available to discuss their sexual concerns?</i>	112	67.5	54	32.5		85	67.5	41	32.5	
<b>Knowledge</b>										
<i>I have the knowledge to talk to patients about ....</i>										
The impact of HSCT on the patients body image	94	83.9	50	92.6	0.12	69	81.2	39	95.1	0.036*
The impact of HSCT on the patients' male sexual function	64	57.1	44	81.5	0.002*	59	69.4	38	92.7	0.004*
The impact of HSCT on the patients' female sexual function	65	58.0	45	83.3	0.001*	60	70.6	40	97.6	<0.001*
The option of preservation of fertility	63	56.3	38	70.4	0.081	75	88.2	38	92.7	0.44
The impact of vaginal dryness/atrophy	48	43.2	42	77.8	<0.001*	52	61.2	35	85.4	0.006*
The impact of an erectile dysfunction.	75	67.0	49	90.7	0.001*	60	70.6	36	87.8	0.034*
The impact of low sexual desire	65	58.0	49	90.7	<0.001*	53	63.1	36	87.8	0.004*
Concerns regarding fertility	73	65.2	45	83.3	0.016*	73	85.9	36	90.0	0.52
Concerns regarding future sexual relationships	69	62.2	45	83.3	0.006*	47	55.3	36	87.8	<0.001*
Concerns to talking to their partner about sexual function	58	52.3	44	81.5	<0.001*	40	47.1	36	87.8	<0.001*
Responding to a patient who misinterprets the intentions of my questions	69	61.6	41	75.9	0.068	53	62.4	25	61.0	0.88
<b>Comfort</b>										
<i>I am comfortable talking to patients about ....</i>										
The impact of HSCT on the patients body image	86	76.8	49	90.7	0.031*	60	71.4	33	80.5	0.28
The impact of HSCT on the patients' male sexual function	35	31.3	39	72.2	<0.001*	48	56.5	31	77.5	0.023*
The impact of HSCT on the patients' female sexual function	40	37.0	46	88.5	<0.001*	48	57.8	29	76.3	0.050*
The option of preservation of fertility	54	48.6	42	77.8	<0.001*	70	83.3	32	78.0	0.47
The impact of vaginal dryness/atrophy	37	33.6	38	70.4	<0.001*	45	52.9	30	73.2	0.030*
The impact of an erectile dysfunction.	39	35.1	46	85.2	<0.001*	44	51.8	27	67.5	0.098
The impact of low sexual desire	43	38.7	46	85.2	<0.001*	39	45.9	29	70.7	0.009*
Concerns regarding fertility	62	55.9	47	87.0	<0.001*	70	82.4	34	82.9	0.94
Concerns regarding future sexual relationships	47	42.0	44	83.0	<0.001*	41	48.8	31	75.6	0.004*
Concerns to talking to their partner about sexual function	46	41.4	42	80.8	<0.001*	44	51.8	32	78.0	0.005*
Responding to a patient who misinterprets the intentions of my questions	43	38.4	35	64.8	0.001*	41	48.2	21	53.8	0.56
<b>Environmental barriers</b>										
<i>I do not talk to patients about their sexual concerns because....</i>										
Of a heavy workload and a lack of time	34	30.6	8	14.8	0.029*	32	38.6	8	20.0	0.040*
There is no private environment	37	33.3	11	20.4	0.085	21	25.3	9	22.5	0.73
There is a lack of support from colleagues/managers	18	16.2	0	0.0	0.002*	11	12.9	2	4.9	0.16
There is a lack of services to refer patients to	40	35.7	8	14.8	0.005*	37	43.5	8	20.0	0.011*
Patients are only in hospital/outpatient clinic for a Short period so there is no time to discuss sexual issues	17	15.2	5	9.4	0.31	27	31.8	2	4.9	0.001*
Patients sexual concerns are too private to document in the notes	27	24.1	2	3.7	0.001*	16	18.8	3	7.3	0.091
<b>Other potential barriers</b>										
<i>I would be reluctant to discuss sexuality concerns because....</i>										
Patients would get embarrassed/offended if I initiated a conversation about the impact of cancer on their sexuality	37	33.0	5	9.3	0.001*	26	30.6	7	17.1	0.11

Table 3 (continued)

	Registered nurses (N = 166)					Medical doctors (N = 126)				
	Never/occasionally		(Very) frequently/with all my patients			Never/occasionally		(Very) frequently/with all my patients		
	n	%	n	%	p-value	n	%	n	%	p-value
Patients would get embarrassed/offended if I initiated a conversation about the impact of cancer on their sexuality if a family member or relative were present	67	59.8	21	38.9	0.011*	57	67.1	16	39.0	0.003*
Patients might misinterpret my questions as a sexual advance or a seductive gesture	2	1.8	0	0.0	0.32	5	5.9	1	2.4	0.40
Patients would refuse to answer my questions if I asked them about their worries about the impact of the cancer on their sexuality	18	16.1	0	0.0	0.002*	9	10.6	1	2.5	0.12
Patients do not want to talk to nurses/doctors about sexual concerns as they consider it is their role	26	23.2	1	1.9	<0.001*	12	14.1	1	2.4	0.043*
Other colleagues would think I was infringing in the patients right to privacy if I raised a discussion on sexual issues	5	4.5	0	0.0	0.11	6	7.1	1	2.4	0.29
The patients family/significant others would not want nurses/doctors* to talk to patients about their sexual concerns	12	10.7	4	7.5	0.52	12	14.1	4	9.8	0.49
Patients do not want to talk about sexual issues, as it is the furthest thing from their minds when they have just been through HSCT	34	30.4	8	14.8	0.031*	25	29.4	4	9.8	0.014*
Patients prefer nurses/doctors to wait until they raise their concerns	60	53.6	19	35.2	0.026*	37	43.5	7	17.1	0.004*
Patients would get emotionally distressed if I initiated a conversation about the impact of HSCT on their sexuality	18	16.2	5	9.3	0.23	30	35.3	9	22.5	0.15
Talking to patients about the impact of HSCT on sexuality is the role of the specialist	34	30.4	16	29.6	0.92	27	31.8	16	39.0	0.42
<b>Patient barriers</b>										
<i>I would be reluctant to ....</i>										
Talk to a patient younger than me about the impact of HSCT on their sexuality	18	16.1	2	3.7	0.022*	6	7.1	4	9.8	0.60
Talk to a patient older than me about the impact of HSCT on their sexuality	16	14.4	2	3.8	0.045*	7	8.3	3	7.3	0.84
Talk to a patient about the impact of HSCT on their sexuality if they were single	13	11.6	2	3.7	0.096	6	7.1	4	9.8	0.60
Talk to a patient about the impact of HSCT on their sexuality if they have a different sexual orientation	29	26.1	3	5.6	0.002*	15	17.6	6	14.6	0.67
Raise a discussion about the impact of HSCT on their sexuality with a patient who is of a different culture	34	30.4	3	5.6	<0.001*	19	22.4	6	14.6	0.31
Raise a discussion about the impact of HSCT on their sexuality with a patient who is of a different religion	31	27.7	12	22.2	0.45	20	23.5	10	24.4	0.92
Raise a discussion about the impact of HSCT on their sexuality with a patient who I know has a mental health problem	27	24.3	6	11.3	0.052	28	32.9	6	14.6	0.030*
Raise a discussion about the impact of HSCT on their sexuality with a patient who I know is anxious	24	21.4	10	18.5	0.66	20	23.8	9	22.0	0.82
Raise a discussion about the impact of HSCT on their sexuality with a patient who I know has a progressive disease	23	20.5	5	9.3	0.069	25	29.4	6	14.6	0.071
Raise a discussion about the impact of HSCT on their sexuality with a patient who I know has GVHD	13	11.6	3	5.6	0.22	11	12.9	5	12.2	0.91
Talk to patients of the opposite gender about the impact of HSCT on their sexuality	15	13.4	1	1.9	0.018*	15	17.9	4	9.8	0.24
<b>Facilitators</b>										
<i>The following would facilitate me to talk to patients about their sexual concerns.</i>										
Being told by another professional that the patient had concerns	90	81.1	48	88.9	0.20	70	83.3	28	70.0	0.088
Being asked questions by the patient regarding their sexuality	109	98.2	53	98.1	0.98	81	96.4	36	90.0	0.15

**Table 3** (continued)

	Registered nurses ( <i>N</i> = 166)					Medical doctors ( <i>N</i> = 126)				
	Never/occasionally		(Very) frequently/ with all my patients			Never/occasionally		(Very) frequently/ with all my patients		
	<i>n</i>	%	<i>n</i>	%	<i>p</i> -value	<i>n</i>	%	<i>n</i>	%	<i>p</i> -value
Being prompted by a care plan	66	59.5	35	64.8	0.51	62	73.8	22	55.0	0.036*
Having standard operating procedures/ policies on how to address sexual issues	78	70.3	28	51.9	0.021*	48	57.1	18	45.0	0.21
Having received relevant communication workshops/ training	98	89.1	46	85.2	0.47	58	69.0	28	70.0	0.91
Having a private environment to have such discussion	90	82.6	52	96.3	0.014*	71	84.5	32	82.1	0.73
Having sufficient time to sit and talk to patients	93	85.3	51	94.4	0.088	77	91.7	30	78.9	0.048*
To have known the patient for 2–3 weeks and have developed a good rapport	89	80.2	38	70.4	0.16	72	85.7	31	77.5	0.25
Having observed an example of a team member talking to patients about sexual issues	53	48.6	18	33.3	0.061	34	40.5	9	23.7	0.072
Having knowledge on the sexual difficulties HSCT patients experience	99	90.0	47	87.0	0.57	72	85.7	27	69.2	0.032*

HSCT haematopoietic stem cell transplantation, GVHD graft-versus host disease

\* $p < 0.05$

### Frequency and associated factors related to discussing sexual issues

The majority of RNs and MDs did not, or only occasionally, discussed sexual issues with individual patients; RNs (68%), MDs (68%), see Table 2, perceived knowledge and comfort are shown in Table 3. Younger MDs ( $p < 0.001$ ) and those who work in non-western European countries ( $p = 0.003$ ), plus RNs who have received less sexual education ( $p = 0.002$ ), as well as MDs and RNs with limited knowledge about the long-term sexual complications of HCT ( $p < 0.001$ ), or feel uncomfortable discussing sexual issues ( $p < 0.001$ ) or work with a paediatric / teenage population are all less likely to discuss sexual issues.

#### Perceived knowledge on sexual issues

RNs and MDs who infrequently discussed sexual issues reported a significantly lower knowledge level in 8 of the 11 areas related to the impact of HCT on sexual issues (Table 3). Seven out of 8 areas were concordant between RNs and MDs. RNs only differed from MDs in that RNs who never/occasionally discussed sexual issues perceived less knowledge to talk to patients about concerns regarding fertility ( $p = 0.016$ ), whereas MDs who never/occasionally discussed sexual issues reported less knowledge talking to patients about the impact of HCT on patients' body image ( $p = 0.036$ ).

#### Comfort in discussing sexual issues

RNs/ MDs who infrequently discussed sexual issues felt significantly less comfortable in 10 and in 6 of the 11 areas,

respectively (Table 3). Averages were calculated and showed that 44% of RNs who rarely discussed sexual issues felt comfortable in all areas, compared to 81% of RNs who routinely discussed these subjects ( $p < 0.001$ ). For MDs these percentages were 59% and 74%, respectively, ( $p < 0.001$ ). Six areas were concordant between RNs and MDs; RNs only differed from MDs in that RNs who never/occasionally discussed sexual issues felt significantly less comfortable compared with RNs who routinely discussed sexual issues, in all areas except for the impact of HCT on body image.

#### Barriers

The main barrier perceived by HCP (>50%) who never/occasionally discussed sexual issues was the perception that patients would feel embarrassed if these subjects were discussed in the presence of a family member (RNs 60%/MDs 67%); this was significantly higher than among HCP routinely discussing sexual issues; (RNs 39% ( $p = 0.011$ )/MDs 39% ( $p = 0.003$ )) (Table 3). Furthermore, 54% of RNs and 44% of MDs who never/occasionally discussed sexual issues, felt that patients would prefer the HCP to wait until the patient initiates the discussion and/or raises a concern. This was in contrast to 35% of RNs and 17% of MDs who routinely discussed sexual issues ( $p = 0.026$  and  $p = 0.004$ , respectively). In HCP routinely discussing sexual issues, none of the barriers were present in >50% of responses.

Fifteen of 28 barriers were found to be significantly different between RNs who rarely discussed sexual issues and RNs who routinely discussed sexual issues.

Significantly different barriers, reported by > 30% of respondents who never/occasionally discussed sexual issues were; a heavy workload/lack of time (31%/15%), a lack of services to refer the patient to (36%/15%), the perception that patients would feel embarrassed discussing sexual issues either alone (33%/9%), or in the presence of a third person (60%/39%), that patients do not want to discuss sexual issues (30%/15%) and that patients prefer nurses to wait for the patient to initiate the discussion (54%/35%). For MDs, significantly different barriers reported by those > 30% of respondents who never/occasionally discussed sexual issues were: a heavy workload/lack of time (39%/20%), a lack of services to refer the patient to (44%/20%), the perception that the patients' time in (outpatient) clinic was too short (32%/5%), that patients would feel embarrassed discussing sexual issues in the presence of a third person (67%/39%), that patients would prefer doctors to wait for the patient to initiate the discussion (44%/20%) and an awareness by the physician that the patient is suffering from a mental health issue (33%/15%).

### Facilitators

The majority of RNs and MDs felt that almost all facilitators were helpful, often in more than 80% of the respondents. "Having observed a team member discussing sexual issues with a patient" was perceived as a significant facilitator in 49%/41% of RNs/MDs who rarely discussed sexual issues compared to 33%/24% of RNs/MDs, respectively, who routinely discussed sexual issues (Table 3).

Two perceived facilitators were found to be significantly different between RNs who rarely, and those who regularly, discussed sexual issues. Those who rarely discussed sexual issues reported more often that "Having a private environment to discuss sexual issues" as helpful (96%/83%), while "Having standard operating procedures/policies on how to address sexual issues significantly" was reported as a facilitator much less often (52%/70%).

There were three facilitators showing significant differences between MDs who rarely, and those who routinely, discussed sexual issues namely: being prompted by a care plan (74%/55%), having sufficient time to sit and talk to patients (92%/79%), and having knowledge of the sexual difficulties HCT patients experience (86%/69%). These were all reported more frequently by MDs who never or only occasionally discussed sexual issues.

### Discussion

It is generally recognised that many patients have sexual problems following HCT and it is also probable that adequate information helps or even improves sexual function.

Even so, talking to those staff involved suggests that sexual issues are still not routinely discussed among the HCP community.

We, therefore, performed a survey supported by the EBMT of its members, to determine the number of RNs and MDs who routinely discuss sexual issues with their patients and to explore the potential barriers and facilitators to discussions among those who do not have such conversations.

An analysis of this survey indicates that two-thirds of respondents rarely discuss sexual issues with their patients. A lack of knowledge, and being uncomfortable with the topic, both contribute to HCP avoiding such talks. Many factors are leading to these problems, such as a reluctance to do so by MDs working in non-western European countries, or of MDs being younger, while a lack of training as to the long-term sexual complications of HCT influenced RNs. Furthermore, HCP who never, or only occasionally, discussed sexual issues with their patients reported their own lack of knowledge about sexual issues as being relevant. In addition, feeling uncomfortable while talking about sexual issues appeared important. Factors influencing comfort are unknown, however, the fact that younger and non-western European MDs, plus RNs with less sexual education, tended not to discuss sexual issues, suggests that cultural differences and experience play an important role. Moreover, it was noted that fewer respondents who reported themselves as religious, completed the questionnaires. This suggests that barriers to discussing sex might be linked to religious beliefs.

Further analyses of the barriers and facilitators involved, showed that the most frequent barrier, even for HCP who did routinely hold such discussions, was the perception that patients would become embarrassed if sexual issues were discussed especially if a relative was present during the consultation. These feelings of embarrassment have been previously described in relation to HCP caring for gynaecological and colorectal patients [31, 36, 38, 39, 44]. Moreover, in the recent literature, the presence of a third party during consultation was mentioned by HCP as causing embarrassment [39, 40].

Many HCP felt that it would be more appropriate if the patients themselves initiated the discussion on sexual issues. Indeed, the patient initiating discussion of the topic was the major facilitator for nearly all HCP. Leaving the initiative to the patient is understandable, as for some patients knowing that sex and reproduction are affected is sufficient, and they do not always want help for their sexual problems [39]. Nevertheless, patients need to be informed about the impact that HCT can potentially have on both sexuality and sexual function and they need to know whether treatment or support is available. Additionally, patients would surely benefit from knowing that sexual issues are common problems. In fact, having this confirmation is sometimes sufficiently



helpful. However, without preparatory information it is more difficult for the patient to initiate discussions (for instance on such issues as the possible effect on (new) sexual relationships) [24]. Earlier work has shown that education is an important factor in this arena and Humphreys et al. [15] reported that patients who received information regarding the consequences of treatment on sexual function before bone marrow transplantation reported better sexual function post-transplantation. Crucially, sexual problems need to be identified in order to obtain adequate support [41].

Our study is limited by the low response rate, which is not uncommon for large surveys and we realise that the results might, therefore, not be representative of a larger cohort. Participation bias is also a possible limitation, which is difficult to exclude. Overall, it is also possible there was an overrepresentation from HCP interested in the subject matter and, as a consequence, fewer RNs and MDs who do not routinely discuss sexual issues in clinical practice responded. Even so, this would indicate that the problem of not discussing sexual concerns may have been underestimated.

In spite of these limitations, this survey clearly shows that there is a lack of routine clinical assessment of this subject and it seems obvious that better support information would be useful. A questionnaire assessing sexual function, followed up by discussions of the results appears to be an effective intervention/strategy for promoting patient-physician communication [43, 45–47]. Furthermore, the routine implementation of a simple validated screening tool used at scheduled time-points, could determine the need for such a discussion. The Brief Sexual Symptom Checklist for Men/Women is one such checklist that consists of four simple questions, and addresses not only patients' level of satisfactions with sexual function but also assesses duration, identification of the type of sexual problems, and importantly, the willingness of the patient to discuss the problem with an HCP [39, 48–50]. If the patient has concerns and is willing to talk about problems, the use of the step based model (PLISSIT model) can be useful to properly intervene, from providing information to referral to a dedicated specialist [51]. Furthermore, although previous studies have reported that more education does not necessarily lead to improved ability to incorporate discussions surrounding sexuality into usual care, it has also been shown that additional sexuality-related education does help HCP to feel more comfortable discussing this subject [21, 34, 52, 53]. The results presented here would appear to further validate this theory. Therefore, in our opinion, appropriate education about the impact of HCT on male and female sexuality should be included in education programmes for HCP who follow-up patients after HCT [54].

In conclusion, this study shows that while many HCT survivors experience sexual problems, the majority do not routinely discuss them with staff and advisors. Embarrassment, or at least a discomfort about discussing sexual concerns, and a lack knowledge and relevant education on the side of the medical staff side, are major barriers for HCP initiating such discussions; the discomfort is such that initiation of discussions on this topic usually originates from the patient.

## Future research

Research to develop a more detailed understanding of patients' requirement for information regarding sexual concerns, and how best to communicate them, would complement the work presented in this paper. Future investigations might also consider the training needs of HCP to facilitate comfortable and competent discussions, manage patient expectations, provide information and deal with issues when they arise, and allow referral where appropriate.

Finally, this study has highlighted the fact that children and teenagers are rarely included in discussions about sexuality and sexual problems. This is of concern as, while the topic may not be relevant today, it will be later in the patient's life. We plan to address this in future studies.

## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

## References

1. Haukvik UK, Dieset I, Bjørø T, Holte H, Fosså SD. Treatment-related premature ovarian failure as a long-term complication after Hodgkin's lymphoma. *Ann Oncol.* 2006;17:1428–33.
2. Levine J, Canada A, Stern CJ. Fertility preservation in adolescents and young adults with cancer. *J Clin Oncol.* 2010;28:4831–41.
3. van der Kaaij MA, Heutte N, Meijnders P, Abeilard-Lemoisson E, Spina M, Moser EC, et al. Premature ovarian failure and fertility in long-term survivors of Hodgkin's lymphoma: a European Organisation for Research and Treatment of Cancer Lymphoma Group and Groupe d'Etude des Lymphomes de l'Adulte Cohort Study. *J Clin Oncol.* 2012;30:291–9.
4. Howell SJ, Shalet SM. Testicular function following chemotherapy. *Hum Reprod Update.* 2001;7:363–9.
5. Behringer K, Breuer K, Reineke T, May M, Nogova L, Klimm B, et al. German Hodgkin's Lymphoma Study Group. Secondary amenorrhea after Hodgkin's lymphoma is influenced by age at treatment, stage of disease, chemotherapy regimen, and the use of oral contraceptives during therapy: a report from the German Hodgkin's Lymphoma Study Group. *J Clin Oncol.* 2005;23:7555–64.
6. Podnar S, Vodušek DB. Sexual dysfunction in patients with peripheral nervous system lesions. *Handb Clin Neurol.* 2015;130:179–202.

7. Mueller SM, Haeusermann P, Rovó A, Halter JP, Passweg J, Itin P, et al. Genital chronic GVHD in men after hematopoietic stem cell transplantation: a single-center cross-sectional analysis of 155 patients. *Biol Blood Marrow Transplant.* 2013;19:1574–80.
8. Wong FL, Francisco L, Togawa K, Kim H, Bosworth A, Atencio L, et al. Longitudinal trajectory of sexual functioning after hematopoietic cell transplantation: impact of chronic graft-versus-host disease and total body irradiation. *Blood.* 2013;122:3973–81.
9. Ciavattini A, Clemente N. Female genital tract chronic graft-versus-host disease: review of the literature. *Anticancer Res.* 2015;35:13–7.
10. Tierney DK. Sexuality following hematopoietic cell transplantation. *Clin J Oncol Nurs.* 2004;8:43–7.
11. Mosher CE, Redd WH, Rini CM, Burkhalter JE, DuHamel KN. Physical, psychological, and social sequelae following hematopoietic stem cell transplantation: a review of the literature. *Psychooncology.* 2009;18:113–27.
12. Tierney DK. Sexuality: a quality-of-life issue for cancer survivors. *Semin Oncol Nurs.* 2008;24:71–9.
13. Watson M, Wheatley K, Harrison GA, Zittoun R, Gray RG, Goldstone AH, et al. Severe adverse impact on sexual functioning and fertility of bone marrow transplantation, either allogeneic or autologous, compared with consolidation chemotherapy alone: analysis of the MRC AML 10 trial. *Cancer.* 1999;86:1231–9.
14. Claessens JJ, Beerendonk CC, Schattenberg AV. Quality of life, reproduction and sexuality after stem cell transplantation with partially T-cell-depleted grafts and after conditioning with a regimen including total body irradiation. *Bone Marrow Transplant.* 2006;37:831–6.
15. Humphreys CT, Tallman B, Altmaier EM, Barnette V. Sexual functioning in patients undergoing bone marrow transplantation: a longitudinal study. *Bone Marrow Transplant.* 2007;39:491–6.
16. Syrjala KL, Kurland BF, Abrams JR, Sanders JE, Heiman JR. Sexual function changes during the 5 years after high-dose treatment and hematopoietic cell transplantation for malignancy, with case-matched controls at 5 years. *Blood.* 2008;111:989–96.
17. Thygesen KH, Schjødt I, Jarden M. The impact of hematopoietic stem cell transplantation on sexuality: a systematic review of the literature. *Bone Marrow Transplant.* 2012;47:716–24.
18. Majhail NS, Rizzo JD. Surviving the cure: long term followup of hematopoietic cell transplant recipients. *Bone Marrow Transplant.* 2013;48:1145–51.
19. Katz A. The sounds of silence: sexuality information for cancer patients. *J Clin Oncol.* 2005;23:238–41.
20. Hordem A. Intimacy and sexuality after cancer: a critical review of the literature. *Cancer Nurs.* 2008;31:E9–17.
21. Kotronoulas G, Papadopoulou C, Patiraki E. Nurses' knowledge, attitudes, and practices regarding provision of sexual health care in patients with cancer: critical review of the evidence. *Support Care Cancer.* 2009;17:479–501.
22. Bevans M. Health-related quality of life following allogeneic hematopoietic stem cell transplantation. *Hematol Am Soc Hematol Educ Program.* 2010;2010:248–54.
23. Braamse AM, van Meijel B, Visser O, Huijgens PC, Beekman AT, Dekker J. Distress, problems and supportive care needs of patients treated with auto- or allo-SCT. *Bone Marrow Transplant.* 2014;49:292–8.
24. Hughes MK. Sexuality and the cancer survivor: a silent coexistence. *Cancer Nurs.* 2000;23:477–82.
25. Thaler-DeMers D. Intimacy issues: sexuality, fertility, and relationships. *Semin Oncol Nurs.* 2001;17:255–62.
26. Park ER, Norris RL, Bober SL. Sexual health communication during cancer care: barriers and recommendations. *Cancer J.* 2009;15:74–7.
27. Bober SL, Recklitis CJ, Campbell EG, Park ER, Kutner JS, Najita JS, et al. Caring for cancer survivors: a survey of primary care physicians. *Cancer.* 2009;115:4409–18.
28. Bekker M, Beck J, Putter H, van Driel M, Pelger R, Lycklama, et al. The place of female sexual dysfunction in the urological practice: results of a Dutch survey. *J Sex Med.* 2009;6:2979–87.
29. Lindau ST, Surawska H, Paice J, Baron SR. Communication about sexuality and intimacy in couples affected by lung cancer and their clinical-care providers. *Psychooncology.* 2011;20:179–85.
30. Ussher JM, Perz J, Gilbert E, Wong WK, Mason C, Hobbs K, et al. Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. *Psychol Health.* 2013;28:1370–90.
31. Vermeer WM, Bakker RM, Stiggelbout AM, Creutzberg CL, Kenter GG, ter Kuile MM. Psychosexual support for gynecological cancer survivors: professionals' current practices and need for assistance. *Support Care Cancer.* 2015;23:831–9.
32. Wilson ME, Williams HA. Oncology nurses' attitude and behaviors related to sexuality of patients with cancer. *Oncol Nurs Forum.* 1988;15:49–53.
33. Gamel C, Hengeveld M, Davis B. Informational needs about the effects of gynaecological cancer on sexuality: a review of the literature. *J ClinNurs.* 2000;9:678–88.
34. Magnan MA, Reynolds KE, Galvin EA. Barriers to addressing patient sexuality in nursing practice. *Medsurg Nurs.* 2005;14:282–9.
35. Zeng YC, Li Q, Wang N, Ching SS, Loke AY. Chinese nurses' attitudes and beliefs toward sexuality care in cancer patients. *Cancer Nurs.* 2011;34:E14–20.
36. Zeng YC, Liu X, Loke AY. Addressing sexuality issues of women with gynaecological cancer: Chinese nurses' attitudes and practice. *J Adv Nurs.* 2012;68:280–92.
37. Moore A, Higgins A, Sharek D. Barriers and facilitators for oncology nurses discussing sexual issues with men diagnosed with testicular cancer. *Eur J Oncol Nurs.* 2013;17:416–22.
38. Oskay U, Can G, Basgol S. Discussing sexuality with cancer patients: oncology nurses attitudes and views. *Asian Pac J Cancer Prev.* 2014;15:7321–6.
39. Traa MJ, De Vries J, Roukema JA, Rutten HJ, Den Oudsten BL. The sexual health care needs after colorectal cancer: the view of patients, partners, and healthcare professionals. *Support Care Cancer.* 2014;22:763–72.
40. Krouwel EM, Nicolai MP, van Steijn-van Tol AQ, Putter H, Osanto S, Pelger RC, et al. Addressing changed sexual functioning in cancer patients: A cross-sectional survey among Dutch oncology nurses. *Eur J Oncol Nurs.* 2015;19:707–15.
41. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, Lin L, Shelby RA, et al. Patient experiences with communication about sex during and after treatment for cancer. *Psychooncology.* 2012;21:594–601.
42. Sauermann H, Roach M. Increasing web survey response rates in innovation research: An experimental study of static and dynamic contact design features. *Res Policy.* 2013;42:273–86.
43. Hartmann U, Burkart M. Erectile dysfunctions in patient-physician communication: optimized strategies for addressing sexual issues and the benefit of using a patient questionnaire. *J Sex Med.* 2007;4:38–46.
44. Stead ML, Brown JM, Fallowfield L, Selby P. Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *Br J Cancer.* 2003;88:666–71.
45. Berry DL, Blumenstein BA, Halpenny B, Wolpin S, Fann JR, Austin-Seymour M, et al. Enhancing patient-provider

- communication with the electronic self-report assessment for cancer: A randomized trial. *J Clin Oncol*. 2011;29:1029–35.
46. Reese JB, Keefe FJ, Somers TJ, Abernethy AP. Coping with sexual concerns after cancer: The use of flexible coping. *Support Care Cancer*. 2010;18:785–800.
  47. Reese JB. Coping with sexual concerns after cancer. *Curr Opin Oncol*. 2011;23:313–21.
  48. Hatzichristou D, Rosen RC, Broderick G, Clayton A, Cuzin B, Derogatis L, et al. Clinical evaluation and management strategy for sexual dysfunction in men and women. *J Sex Med*. 2004;1:49–57.
  49. Hatzichristou D, Rosen RC, Derogatis LR, Low WY, Meuleman EJ, Sadovsky R, et al. Recommendations for the clinical evaluation of men and women with sexual dysfunction. *J Sex Med*. 2010;7:337–48.
  50. Zhou ES, Nekhlyudov L, Bober SL. The primary health care physician and the cancer patient: tips and strategies for managing sexual health. *Transl Androl Urol*. 2015;4:218–31.
  51. Annon JS. The PLISSIT model: a proposed conceptual scheme for the behavioral treatment of sexual problems. *J Sex Ed & Ther*. 1976;2:1–15.
  52. Butler L, Banfield V. Oncology nurses' views on the provision of sexual health in cancer care. *J Sex Reprod Med*. 2001;1:35–9.
  53. Lavin M, Hyde A. Sexuality as an aspect of nursing care for women receiving chemotherapy for breast cancer in an Irish context. *Eur J Oncol Nurs*. 2006;10:10–8.
  54. Hautamäki K, Miettinen M, Kellokumpu-Lehtinen PL, Aalto P, Lehto J. Opening communication with cancer patients about sexuality-related issues. *Cancer Nurs*. 2007;30:399–404.