Cancer and sexual health: The continuum of care

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Chapter 7: Exploring communication about intimacy and sexuality: what are the preferences of adolescents and young adults with cancer and their healthcare professionals?

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Introduction

Psychosexual formation and evolvement of romantic relationships are fundamental developmental milestones of adolescents and young adults (AYA) in normal health(1, 2). In case malignancies occur during this phase of life, cancer can interfere with normal sexual development(3-7).

Cancer treatment has multiple physical side effects which may have an impact on sexuality. Chemotherapy and pelvic radiotherapy, for example, are known to cause problems with lubrication, vaginal atrophy in women and erectile dysfunction in men(5, 8-10). Surgery could cause permanent body changes, with issues with body image and sexual desire as result (11, 12). General treatment complications as pain, fatigue and nausea hinder sexual activity as well (13). Besides, psychological effects of having cancer, like low self-esteem, poorer mental health and body image concerns are associated with a negative impact on sexuality (5). Psychological aspects are described to have a greater effect on sexual quality-of-life than physiological aspects(12). Both physical and psychological effects affect sexual arousal, pleasure and satisfaction. Moreover, sexual quality-of-life after cancer is strongly related to relationship status. Unpartnered AYAs reported less satisfaction with their sexual life than partnered AYAs. They experience distress of sexuality and fear more about their sexual attractiveness(12).

Prevalence of sexual problems is about 50% two years after diagnosis(5, 6). AYAs report several unmet psychosexuality needs, like inadequate support and information regarding sexuality(3, 14, 15). In a survey among AYAs, 82.2% reported the need for information and counselling related to sexuality as being unmet(16). Nonetheless, in a survey assessing oncology providers perceptions on AYAs' unmet needs, only 29.4% of them reported that sexuality and intimacy needs went unmet(17).

Communication about intimacy and sexuality between healthcare professionals (HCPs) and patients is challenging(18). Literature reveals mismatched expectations between HCPs and AYAs. HCPs consider sexuality as non-relevant issue for single AYAs and avoid the topic(19). As a result, single AYAs feel embarrassed to initiate a discussion about sexuality(10, 19). Besides, HCPs are more likely to discuss sexuality with patients with reproductive cancer(19). However, it is known both reproductive and non-reproductive cancers affect sexuality. Equal levels of sexual satisfaction are reported in both groups(12).

Specific knowledge on preferences of AYAs regarding communication about intimacy and sexuality is needed.(20-22). Moreover, to be able to integrate sexual healthcare into practice the view of HCPs is needed. This survey-based study focused on the perspective of AYAs who were diagnosed with cancer between 15-39 years of age and their HCPs. The aim of this study was to determine preferences of AYAs regarding communication about intimacy and sexuality and examine discrepancies between AYA and HCP. We aimed to identify which sexuality-related items are important to discuss, who is held responsible for bringing up sexuality, which barriers AYAs and HCPs face to discuss sexuality and what would help them to enhance communication regarding sexuality. The study outcomes can provide recommendations for HCPs to anticipate AYAs' healthcare-related sexuality and intimacy needs.

Methods

Realisation
In the Netherlands a national AYA-healthcare network was established. This National AYA "Young-and-Cancer" Platform provides an optimal collaborating environment for knowledge translation, scientific research coordination on 'cancer at the AYA-age' and education of state of the art care for AYAs (23). The need to improve care and information related to intimacy and sexuality was emphasized by the network. In association with the department Urology of the Leiden University Medical Center (LUMC), the '*National AYA dreamteam intimacy and sexuality*' was created. This innovative and blended projectgroup, consisting of HCPs, AYAs and researchers was created to investigate shortcomings of provided attention and improve this specific AYA-care. AYA-care in the Netherlands is nurse-led(24). The nurse and oncologist/haematologist are the first contact an AYA has when diagnosed with cancer.

Questionnaire design
The questionnaires were constructed by the dreamteam in collaboration with the authors and based on previous studies of the research group of the LUMC since no validated questionnaire for the aim of our study was available. The department conducted multiple studies using a self-developed questionnaire based on literature and expert review in the past, investigating communication about sexuality in healthcare(25-28). The questionnaire of the current study was adjusted to AYAs based on a search of AYA specific literature and input of the '*National AYA dreamteam intimacy and sexuality*'. A draft version of both questionnaires was sent to a test panel of 6 AYAs and 3 HCPs for evaluation. The HCPs included a urologist-sexologist, sexologist with sexual oncology as field of interest and a psychologist specialized in psychosocial care for AYAs. The pilot panel reviewed the questionnaire with regard to relevance, integrity, structure, lay-out and spelling; some questions were reformulated and open-ended options as well as specific questions about the presence of parents and starting a relationship were added.
The final questionnaires for the AYAs and HCPs contained 39 questions (Appendix 8+9).

Study design
A cross-sectional survey was conducted among AYAs (15-39 years) and HCPs in the Netherlands (29). The distribution of the questionnaire (on paper) for the AYAs happened during the annual Dutch AYA congress in March 2018. This congress is attended by patients, their fellows, HCPs and researchers. During this congress, different important themes regarding AYA-care were discussed and developments were presented.
The questionnaire was also distributed via the online AYA community for private members (AYAs only), facilitated by the National AYA Platform. When members agreed to participation, they were sent a personal link through the online secured system Castor Electronic Data Capture (EDC). After eight weeks a reminder was sent. Exclusion criteria were patients diagnosed under the age of 15 and above the age of 39. There were no restrictions based on cancer type or time from diagnosis(5).

The questionnaire for HCPs was distributed during (1) the congress and (2) a digitalised version of the questionnaire was sent to HCPs who signed up for the congress (n=178). They were sent a personal link through the EDC. The HCPs who already participated during the congress were requested not to contribute again. A reminder to participate was

sent after eight weeks. Exclusion criteria were HCPs who did not work with AYAs. Both paper-based and web-based questionnaires were used to optimize response rate(30).

Privacy
Data were anonymously obtained and processed. Only researchers of the projectgroup had access to the questionnaire data.

Statistical analysis
The data were analysed using IBM SPSS Statistics23. Because of relatively low missing data we performed complete case analysis. Demographic information and answers to the survey were analysed using descriptive statistics. Equality of proportions between groups was tested with Pearson's chi-square test.
For the list of complaints (table 3) we tested for each complaint separately whether the percentage of AYAs with the complaint was equal to the percentage of HCPs that discussed the complaints. This comparison was done using Pearson's chi-square test; amounts were weighted by number. The same analyses was performed for the list of responsible HCPs (table 4). Each answer option (different HCPs) was tested separately. A two-sided P-value <0.05 was considered statistically significant.

Ethical considerations
Data were collected anonymously and there was no doctor-patient relationship. After consultation with the Medical Ethics Committee of the LUMC, this study appeared not to fall under its jurisdiction and did not require its approval (Number:G19.052).

Results

The survey was administered among 145 AYAs (congress=80, online=65) and 178 HCPs. A total of 61 questionnaires were completed by AYAs (response rate 42.1%) and 54 by HCPs (response rate 30.3%). Five AYA respondents did not meet the inclusion criteria due to a cancer diagnosis before the age of 15; 56 respondents were included for analysis. Two respondents of the HCP-survey were excluded, since they did not meet the criteria of being a HCP to come in contact with AYAs; 52 surveys were included. Demographic and clinical characteristics of the AYAs and HCPs are presented in **Table 1 and Table 2**.

Table 1: Demographic characteristics and clinical variables of the AYAs (n=56)

	n (%)
Age (years)	
Mean 29.4 (SD 5.0, range 20-41)	56 (100.0)
Gender	
Male	12 (21.4)
Female	44 (78.6)
Relationship status	
Single	19 (33.9)
Relationship	31 (55.4)
Married	6 (10.7)
Duration of relationship (years)	
Median 6.5 (range 0.4 – 21)	
Having children	
Yes	10 (17.9)
No	46 (82.1)
Education	
Lower vocational education (VMBO/MAVO/LBO)	1 (1.8)
Intermediate vocational education (MBO)	15 (26.8)
Higher secondary education (HAVO/VWO)	5 (8.9)
Higher education (HBO/WO)	35 (62.5)
Employment	
Yes	28 (50.0)
No, job-seeking	4 (7.1)
No, not able due to disease	15 (26.8)
No, student	9 (16.1)
Cancer type[a]	
Hematological cancer	16 (28.6)
Breast cancer	12 (21.4)
Gynaecological cancer	6 (10.7)
Testicular cancer	5 (8.9)
Brain cancer	4 (7.1)
Sarcoma	4 (7.1)
Thyroid cancer	4 (7.1)
Skin cancer	3 (5.4)
Colorectal cancer	1 (1.8)
Other[b]	2 (3.6)
Type of treatment[c]	
Operation	43 (76.8)
Chemotherapy	43 (76.8)
Radiotherapy	32 (57.1)
Hormonal therapy	8 (14.3)
Immunotherapy	8 (14.3)
Other[d]	8 (14.3)
Age at diagnosis (years)	
Mean 26.0 (SD 5.2, range 15 – 36)	
Time since diagnosis	
3-6 months	4 (7.1)
6 months – 1 year	6 (10.7)
1-2 years	16 (28.6)
2-4 years	17 (30.4)
5-10 years	9 (16.1)
10 years or more	4 (7.1)

a) One respondent reported two cancer types.

b) Anal cancer (n=1), adrenocortical cancer (n=1).

c) Most respondents reported multiple types of treatment.

d) Stem cell transplantation (n=4), brachytherapy (n=1), radioactive iodine (n=1), missing (n=2)

Table 2: Demographic characteristics and clinical variables of the health care providers (n=52)

	n (%)
Age (years)	
Mean 41.2 (SD 11.8, range 21-62)	52 (100.0)
Gender	
Male	3 (5.8)
Female	49 (94.2)
Function[a]	
Oncology nurse	25 (48.1)
Nurse practitioner	8 (15.4)
Medical specialist	8 (15.4)
Nurse specialized in AYA care	7 (13.5)
Social worker	3 (5.8)
Other[b]	5 (9.6)
Clinical setting[c]	
University hospital	30 (57.7)
District general teaching hospital	16 (30.8)
District general hospital	2 (3.8)
Independent extramural practice	1 (1.9)
Other[d]	6 (11.5)
Time of practice	
1-2 years	3 (5.8)
3-5 years	13 (25.0)
6-10 years	12 (23.1)
11-15 years	10 (19.2)
>15 years	14 (26.9)
Followed course on sexuality	
Yes, specifically for AYAs	2 (3.8)
Yes, about cancer and sexuality in general	22 (42.3)
No	28 (53.8)

a) Four respondents reported multiple functions.

b) Occupational therapist (n=2), nurse practitioner in training (n=1), coordinator (n=1), missing (n=1)

c) Three respondents reported multiple settings.

d) Rehabilitation center (n=2), hospice (n=1), Care for Cancer Foundation (n=1), home based guidance (n=1)

The influence of disease on sexuality

The majority of the AYAs (75.0%, n=42) indicated that cancer had negative influence on their sexuality. The AYAs were asked in a multiple choice question, containing thirteen possible items, how their sexuality was influenced. The HCPs, who did discuss sexuality with AYAs, were asked which of the same items they discussed with AYAs during a conversation about sexuality. The results are presented in **Table 3**. Both AYA and HCP considered "less sexual desire" (resp. 73.8% and 69.5%), "fatigue" (resp. 64.3% and 65.3%) and "lower lubrication" (in women) (resp. 58.3% and 62%) as most important items. A difference between answers of AYAs and HCPs was found on the item "fear around sex" (resp. 23.8% and 45.3%, p=0.017); HCPs discussed this item more often than AYAs experienced fear around sex.

Table 3

Items[a] that negatively influenced sexuality in AYAs[b] (n=42, women = 36, men = 6)
Items[a] of sexuality that HCPs discussed in female patients (n=50) and male patients (n=45)

	AYA n (%)	HCP n (%)	Significance
Less sexual desire	31 (73.8)	66 (69.5)	NS
Fatigue	27 (64.3)	62 (65.3)	NS
Lower lubrication[c]	21 (58.3)	31 (62)	NS
Self-uncertainty due to changed appearance	24 (57.1)	43 (45.2)	NS
Self-uncertainty due to changed self-image	18 (42.9)	48 (50.5)	NS
Pain during intercourse	18 (42.9)	41 (43.2)	NS
No more pleasure from sex	15 (35.7)	27 (28.4)	NS
Fear around sex	10 (23.8)	43 (45.3)	p = 0.017
Difficulty with orgasm	10 (23.8)	29 (30.5)	NS
Emotional lability	9 (21.4)	33 (34.7)	NS
Erectile dysfunction[d]	1 (16.7)	26 (57.8)	NS

a) Respondents did or did not check the box for each item
b) Most respondents reported multiple items
c) Percentage within women
d) Percentage within men

AYAs' and HCPs' view on sexual healthcare

Nearly all AYAs (91.1%, n=51) and HCPs (98.0%, n=50) considered communication about sexuality as (very) important. Half of the HCPs (47%, n=24) reported to discuss sexuality always or in more than half of the cases. HCPs with training in sexual oncology discussed the topic more often than HCPs without training (63% vs. 45%; $p<0.05$). Less than half of the AYAs (41.1%, n=23) reported to have received information from a HCP. The majority of 79% (n=44) of the AYAs was not satisfied with the manner the information on intimacy and sexuality was provided. Given reasons for not being satisfied were related to the nature of information as being too general (43.2%, n=19), their expectation that HCPs should have initiated the discussion on the topic (38.6%, n=17) and the opinion that information should have been given earlier (25.0%, n=11).

Answering the question on which HCP would be most suited to discuss intimacy and sexuality according to the AYA, nurse practitioner (61.8%, n=34) and sexologist (49.1%, n=27) were most frequently mentioned. HCPs held the physician (84.3%, n=43) and nurse practitioner (84.3%, n=43) responsible for initiating the topic. Responsibility according to the HCPs and preferences of the AYAs allocated to possible HCP to discuss sexuality with are displayed in **Table 4**. Slightly more than half of the HCPs (56.9%, n=29) mentioned the AYA to be the one to take the initiative to discuss sexuality; no difference was seen between HCPs with training in sexual oncology and HCPs without training (p=0.17). At the same time, HCPs reported that 76.0% of the AYAs never or in less than half of the cases initiate discussion about sexual problems on their own initiative.

Table 4
AYA: options on who would be most suited on discussing sexuality (n=55) [ab]
HCP: options on who should take the initiative on discussing sexuality (n=51) [ab]

	AYA n (%)	HCP n (%)	Significance
Physician	23 (41.8)	43 (84.3)	p < 0.005
Nurse practitioner	34 (61.8)	43 (84.3)	p < 0.005
The AYA	n/a	29 (56.9)	n/a
Social worker	9 (16.4)	16 (31.4)	NS
Sexologist	27 (49.1)	12 (23.5)	p = 0.006
Psychologist	21 (38.2)	10 (19.6)	p = 0.036

a) *Missing (n=1)*
b) *Most respondents mentioned multiple options*

AYAs' and HCPs' barriers to discuss sexuality
Of all AYAs, 26.8% (n=15) felt like the HCP sufficiently discussed sexuality. Not asking for additional information on their own initiative had mostly to do with feelings of shame (34.2%, n=13) or absence of a romantic relationship (23.7%, n=9). All barriers to discuss sexuality experienced by the AYA are displayed in **Table 5**. Thirty-three percent of the HCPs (n=17) stated to always discuss sexuality with a newly diagnosed AYA. They reported the presence of a third party (52.9%, n=17) and lack of training (42.3%, n=22) as most important barriers for not discussing sexuality with the AYA. HCPs discussed sexuality less often when parents were present (p<0.05). All barriers are displayed in **Table 6**.

Table 5: AYAs' barriers to initiate a conversation about sexuality (n=38)

	n (%)
Feeling of shame	13 (34.2)
I do not have a partner	10 (26.3)
Intimacy and sexuality are not my priority	8 (21.0)
Intimacy and sexuality are private	7 (18.4)
The health care professional does not initiate the conversation	7 (18.4)
Lack of privacy, my parents were present during the conversation	6 (15.8)
I rather discuss it with my partner	5 (13.2)
The health care professional is from the opposite gender	5 (13.2)
I am too sick to discuss intimacy and sexuality	4 (10.5)
The health care professional is too busy	3 (7.9)
Nothing can be done about it	2 (5.3)
The health care professional does not seem open to this	2 (5.3)
The age of the health care professional	2 (5.3)
Lack of privacy, my partner was present during the conversation	2 (5.3)
I don't want to talk about it	1 (2.6)
This is no task for the health care professional	0
Lack of privacy, other health care professionals were present during the conversation	0

Table 6: Reasons for the healthcare professional not to discuss sexuality with an AYA. (n=52)[a]

	Agree/strongly agree *n (%)*	Partly disagree/ agree *n (%)*	Strongly disagree/disagree *n (%)*
Presence of a third party	27 (52.9)	18 (35.3)	6 (11.8)
Lack of training	22 (42.3)	14 (26.9)	16 (30.8)
AYA's parents were present	18 (36.7)	22 (44.9)	9 (18.4)
Lack of knowledge	17 (32.7)	13 (25.0)	22 (42.3)
Reasons related to language/ethnicity	16 (31.4)	18 (35.3)	17 (33.3)
Reasons related to culture/religion	14 (27.5)	18 (35.3)	19 (37.3)
Lack of time	10 (19.6)	19 (37.3)	22 (43.1)
No angle or reason for asking	10 (19.6)	13 (25.5)	28 (54.9)
My workspace is not quiet	8 (15.7)	6 (11.8)	37 (72.5)
AYA is too ill	6 (11.8)	15 (29.4)	30 (58.8)
I feel uncomfortable	5 (9.6)	16 (30.8)	31 (59.6)
AYA is not ready	3 (6.0)	16 (32.0)	31 (62.0)
Sexuality is a private matter	3 (5.9)	14 (26.9)	34 (66.7)
Not feeling a connection with the AYA	2 (3.9)	11 (21.6)	38 (74.5)
AYA has no sexual problems	2 (4.0)	9 (18.0)	39 (78.0)
Age difference between you and AYA	2 (3.9)	5 (9.8)	44 (86.3)
Afraid to offend the AYA	2 (3.8)	4 (7.7)	46 (88.5)
AYA doesn't have a partner	1 (2.0)	7 (13.7)	43 (84.3)
It's someone else's task	1 (2.0)	4 (7.8)	46 (90.2)
AYA is the opposite gender	-	9 (18.0)	41 (82.0)
No resources to refer the AYA	-	2 (3.9)	49 (96.1)

a) Not all percentages are equal due to missing data

What do they need to discuss sexuality?
According to AYAs, the best way for providing information is through a website (66.1%, n=37) or via a conversation with a HCP (64.3%, n=36). Their preferences according to different ways for information supply are displayed in **Figure 1**. As to the AYAs preferred moment of getting information, they mentioned the following options: before treatment (64.3%, n=36), followed by during treatment (51.8%, n=29) and after treatment (50.0%, n=28).

Frequently mentioned ways by HCPs that may help them discuss sexuality with AYAs were leaflets about sexuality to give to the AYA (75%, n=39) and training to improve skills on discussing the matter (71.2%, n=37), easy ways to refer the AYA to the department of sexology (32.7%, n=17) and more time with the patient (32.7%, n=17). HCPs without training in sexual oncology were more interested in the leaflets about sexuality than the HCPs with training ($p<0.05$).

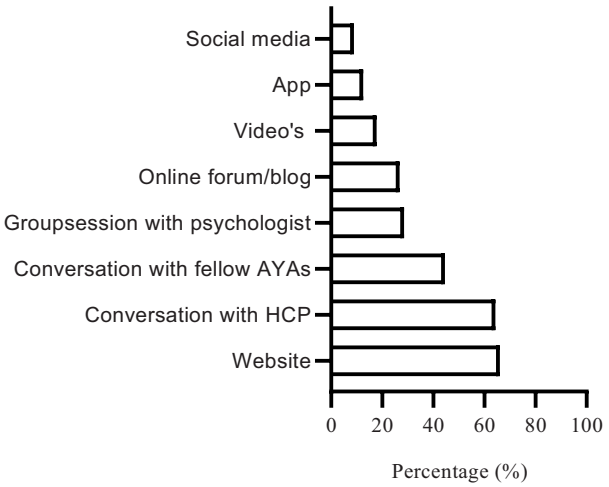

Figure 1: The best way for providing information about intimacy and sexuality according to the AYAs. (AYAs: adolescents and young adults; HCPs: health care professionals)

Discussion

The purpose of this study was to determine preferences of AYAs regarding communication about intimacy and sexuality and examine discrepancies between AYA and HCP. AYAs and HCPs almost unanimously agreed that communication about sexuality is important. However, approximately half of the AYAs and HCPs reported not to discuss sexuality in the consultation room. When sexuality is discussed, HCPs seem to discuss the relevant items according to the AYA. AYAs preferred to discuss sexuality with a nurse practitioner or sexologist. However, HCPs held physicians and nurse practitioners responsible. To enhance communication about sexuality, HCPs would like to have leaflets about sexuality to give to the AYA and additional training. AYAs would prefer to get information before start of treatment via a website and HCP.

According to our study, detailed provision of information before treatment is necessary. Early information provision may contribute to realistic expectations of the impact of cancer treatment on sexuality and may reduce possible distress due to sexual problems(20). Besides, further evaluation of sexuality related needs should come to pass during follow-up since problems with sexuality can arise after treatment(31). Dobinson et al. showed similar results, proposing that intimacy and sexuality should be discussed on several occasions throughout the treatment trajectory and sexual healthcare should be incorporated in survivorship care plans (3).

As our findings, previous research emphasized AYAs' need for support from HCPs regarding sexual concerns(3, 18). HCPs reported barriers to discuss sexuality in the current study are similar to barriers reported by adult oncology HCPs, namely lack of training and feeling of embarrassment(6, 32-34). In concordance with existing literature, presence of a third party was mentioned as specific barrier for HCPs in AYA-care(35). It is known that most patients will not initiate a discussion about sexuality by themselves(15). For the responding AYAs this had mostly to do with feelings of shame or the present of the parents(18). Moreover, AYAs might not be aware that their issues with sexuality are related to cancer treatment due to limited sexual self-knowledge or sexual immaturity(15). Cancer threats normal sexual development. Limited sexual-health knowledge can be caused by developmental age, reduced contact with pears and reduced contact at school due to the cancer(3, 36). Therefore it is important that HCPs address the issue and not rely on the initiative of AYAs. Taking in mind AYAs' and HCPs' barriers, it would be helpful if HCPs routinely offer AYAs some time alone with them(18). In addition, training for HCPs on effective communication strategies to initiate and facilitate a discussion about sexuality may lead to better comfort by both AYA and HCP(35). Moreover, according to our survey HCPs would be helped with the availability of written material to give to the AYA.

In our survey a discrepancy was seen in which HCP AYAs considered as most suitable for discussing sexuality with and to whom HCPs allocate the responsibility within their oncology team to discuss sexuality. AYAs preferred to discuss sexuality with a sexologist. A conversation with a sexologist is not part of standard care in the Netherlands. To deliver optimal sexual healthcare, clear defined roles within the oncological team are required(37). For example, physicians could name sexual side effect and check for these side effects during treatment and follow-up. The nurse practitioner, or if needed a sexologist, could support patients with sexual changes due to cancer (37). These findings indicate a role for

practical training for HCPs to create awareness for sexual problems, be able to provide information or else know about referral options(14).

This study was the first Dutch nation-wide survey on sexuality related care for AYAs. The design made it possible to conduct the study from the perspective of AYAs and HCPs. The study confirms some results of existing literature on discussion about sexuality, but distinguished itself by involving both AYAs and HCPs and examine discrepancies between them. Some limitations should be taken into account when interpreting the results. In spite of the considerable response rate to a patient survey with a sensitive topic (42.1%), the study population consisted of 56 AYAs. This is comparable with other surveys among patient about communication in sexuality(26, 38). This response rate is slightly higher in comparison with surveys with other topics among AYAs in the Netherlands (29%) (39, 40). The response ratio of the HCPs was low, yet comparable to the response rate of other questionnaires among HCPs(25, 34, 41). Selection bias could have been present. People attending a cancer symposium or actively respond to an online questionnaire request are not necessarily a representative sample of the AYA population or HCPs who work with AYAs. Previous research examined AYAs' sexual satisfaction and reported women to having sex less often post-cancer and lower levels of satisfaction with their sexual lives than men(6, 42). This might be an explanation for the male/female ratio of 20/80 in our survey whereas the male/female ratio among AYAs in the Netherlands is about 40/60 (29). Moreover, the unequal distribution can be explained by recruitment via an online forum. 71% of the members of the forum are women(43). It could be that women are more likely to seek online support(44). They may therefore be more prepared to fill out the questionnaire, but also more likely to be user of information about sexuality(43, 45). There could also be question of recall bias. This survey-based study relied on the memory of participants. The majority of AYAs was diagnosed over one year ago. However, sexual problems are likely to continue on the long-term and many cancer survivors do not feel prepared for sexual issues(10). Therefore experiences of respondents diagnosed some time ago are of importance. Furthermore, we used a non-validated questionnaire since there were no validated questionnaires available for the aim. Questionnaires were designed in co-creation with AYAs and HCPs to highlight relevant issues. Further research could focus on improving existing information and educate HCPs. Our results could give guidance on the areas that need enhancement and serve as pilot for further research.

Conclusion

According to the AYAs, sexuality and intimacy is not being discussed enough by HCPs and existing information is not sufficient. It is recommended to address the topic by trained HCPs on multiple occasions throughout the cancer trajectory and information on websites needs to be more focussed on AYAs. The discrepancy between AYAs and HCPs illustrates the importance of patient participation to prioritize their own care according to their needs on intimacy and sexuality.

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