

PAPER

Sexual and romantic challenges among young Danes diagnosed with cancer: Results from a cross-sectional nationwide questionnaire study

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Abstract

Objective: The negative impact of malignant disease on sexual and relational functioning is well documented among adults but scarcely investigated among adolescents and young adults. This study explored the body image, self-perceived attractiveness, and sexual/romantic experiences of Danes diagnosed with cancer at the age of 15 to 29 years. It also aimed to clarify whether self-perceived needs for counseling were in fact met by health care providers.

Methods: All Danes who had been diagnosed with cancer at the age of 15 to 29 years during the period 2009 to 2013 were included in a cross-sectional nationwide questionnaire study. Eight hundred twenty-two questionnaires were returned, yielding a response rate of 45%.

Results: More than half of the respondents (53.8%) reported that cancer had altered their body image negatively, while 44.6% felt that disease had lowered their feeling of being attractive. Nearly one-third (31.3%) and one-fourth (23.6%), respectively, had experienced a negative impact on their desire to have sex or to flirt/date/have a partner. Female responders were more affected than males on most variables, and breast cancer patients were approximately 4 times more at risk for sexual and romantic adversities than patients with melanoma of the skin. Although more than 80% indicated a need to discuss issues of sexuality and intimacy with a health professional, 49.5% and 61.7%, respectively, had talked little or not at all with professionals during hospitalization and follow-up consultations.

Conclusions: Young cancer patients experience sexual and romantic challenges along with a lack of self-perceived attractiveness. Their substantial need for dialogue and counselling should be met in health care settings.

KEYWORDS

adolescent and young adults, body image, cancer and oncology, counselling, sexuality

1 | BACKGROUND

Young people go through a period of physical and psychosocial changes, and during adolescence and early adulthood, comprehensive

renegotiations of identity and interpersonal relations occur. Sexual, emotional, and romantic positioning constitutes an integral part of this individuation-separation process, and it is well known from research and clinical experience that cancer represents a threat to both

biological, psychological, and relational development.¹⁻⁷ During a cancer trajectory, adolescent and young adult (AYA) patients may experience fear, sadness, and depression that can decrease their ability to attain age-appropriate autonomy.^{5,6,8} Further, AYA patients might feel left behind by peers, resulting in diminished social participation. Finally, AYA cancer patients face various degrees of body image disturbances, and treatment-induced complications and side effects often add to feelings of insecurity and lowered self-esteem.^{1,2,5,6,9-12} The same may be true for worries about future fertility.^{6,13}

Not surprisingly, problems concerning self-confidence and social competencies might negatively influence AYA cancer patients' readiness and ability to engage in romantic relationships or sexual activities,^{1,2,9,11,14,15} as it has also been described in adult patients.^{16,17} In addition, erotically active AYA patients can experience cancer-related sexual problems such as erectile dysfunction or anorgasm. It has also been demonstrated that chronically ill AYA face more risky situations concerning sexually transmittable infections and sexual abuse than their peers.^{7,15,18} However, the significance of sexual/romantic issues in oncological youth care has only been insufficiently investigated, and the clinical implications of such themes remain poorly understood.

Based on a nationwide cross-sectional questionnaire study, this article contributes to an underprioritized research area by exploring the impact of disease on the body image and sexual/romantic life of cancer patients aged 15 to 29 at diagnosis and to establish possible factors associated with cancer-related adversity. Further, we seek to clarify whether professional conversations about sexuality-related issues are requested by patients and provided by doctors and nurses during treatment and follow-up care.

2 | METHODS

2.1 | Setting

The Danish health care system is publicly funded with free access to health services for all citizens. Neither adolescent medicine nor adolescent oncology are medical specialties in Denmark, and only few specialized youth units within oncology exist.

2.2 | Study design and population

The study was a nationwide cross-sectional population-based questionnaire survey, and its sample was identified through the Danish Cancer Registry.¹⁹ All patients diagnosed with cancer (except for basal cell carcinoma) at the age of 15 to 29 years from January 1, 2009, to December 31, 2013, were invited to join the study ($n = 2480$). Two hundred four individuals had died, and an additional 51 were lost to follow-up. Those with an unattainable address ($n = 82$) were excluded and so were patients registered with benign or unspecified tumours ($n = 312$). These exclusions yielded a study population of 1831 patients.

All participants were invited via postal mail including an invitation letter, a printed questionnaire, a prepaid return envelope, and a leaflet explaining the aims of the study. Participants could fill out a paper version of the questionnaire (66% did so) or respond electronically

via a website (33% did so) or by a telephone interview (1% did so). Nonresponders received a single reminder after 3 weeks. A total of 822 questionnaires were returned (response rate, 45%). The age range of participants was 17 to 36 years (mean, 27.9), and the mean age at diagnosis was 23.9. The time span from diagnosis to study inclusion ranged from 1 to 7 years (mean, 3.9). A response analysis revealed no differences between responders and nonresponders regarding age and time since diagnosis. However, responders were more likely to be women, and consequently, breast cancer was more frequent among responders (Table 1).

The overlaying aim of the survey was to evaluate health care services and survivorship issues seen from AYA patients' perspective. A questionnaire was developed, based on previous research and following an iterative process of item generation and validation. Adolescent and young adult cancer patients were involved throughout the entire process alongside a professional advisory board of oncologists and youth researchers. The final questionnaire contained 151 closed- and open-ended items.²⁰

2.3 | Variables and data analyses

The topics of main interest to this study were body image, sexuality, and romantic capability. The questionnaire contained 5 items related to bodily self-perception and intimate relations (ie, body image, attractiveness, desire to flirt/date/have a partner, sexual desire, and partnership), and the outcome variables measured respondents' assessment of how cancer had affected these areas, using a 5-point Likert scale. The variables were dichotomized and included as dependent variables in the analysis (Table 3), classifying "somewhat negatively"/"very negatively" as a negative impact and "somewhat

TABLE 1 Population characteristics and response analysis

| | Respondents n, % | Nonrespondents n, % | Test of Difference ^a |
|----------------------|---------------------|------------------------|------------------------------------|
| Total | 822 (45) | 1009 (55) | ... |
| Sex | | | $P < .0001$ |
| Male | 317 (37) | 533 (63) | |
| Female | 505 (51) | 476 (49) | |
| Age at diagnosis, y | | | $P = .15$ |
| 15-19 | 146 (43) | 195 (57) | |
| 20-24 | 259 (43) | 340 (57) | |
| 25-29 | 417 (47) | 474 (53) | |
| Year of diagnosis | | | $P = .28$ |
| 2009 | 140 (40) | 212 (60) | |
| 2010 | 176 (47) | 196 (53) | |
| 2011 | 174 (47) | 193 (53) | |
| 2012 | 157 (43) | 209 (57) | |
| 2013 | 175 (47) | 199 (53) | |
| Cancer type | | | $P = .0032$ |
| Melanoma of the skin | 236 (45) | 291 (55) | |
| Genital cancers | 212 (42) | 294 (58) | |
| Breast cancer | 38 (68) | 18 (32) | |
| Other cancers | 336 (45) | 406 (55) | |

^a P value, χ^2 test.

positively"/"very positively"/"neither/nor" as a positive impact/no impact. Responses of "not relevant to me" were excluded from the analyses.

Two items were categorized and included as dependent variables (Table 4) to identify factors associated with respondents' need to discuss intimate concerns with health professionals and to establish, whether these needs were in fact met. The responses "Yes, to a great extent"/"Yes, to some extent" were condensed and interpreted as an accommodated need. Likewise, the responses "To a lesser extent"/"Not at all" were condensed and interpreted as an unmet need. The response "Have had no need" was treated as a separate category, and all other responses were interpreted as a "need."

Information about current sexual functioning was attained through 3 questions: During the past week, "Did you have problems obtaining an orgasm?" (both genders), "Did you have difficulty gaining or maintaining an erection?" (males only), and "Did you experience vaginal dryness during sexual activity?" (females only). The responses of these 3 items were dichotomized, and any response of "A little"/"Quite a bit"/"Very much" was classified as "Sexual problem during past week." The questionnaire offered no specific indication of sexual inactivity.

Information about partnership status was registered at the time of filling out the questionnaire. For analytical reasons and based on the existing literature, the cancer types were operationalized in 4 categories: (1) melanoma of the skin, (2) genital cancers (predominantly c. testis and c. cervix uteri), (3) breast cancer, and (4) other cancers (predominantly haematological cancers, thyroid cancer, and sarcomas). Male and female genital cancers were pooled, as sensitivity analyses revealed no significant difference.

Logistic regression analyses were performed to identify factors independently associated with the perceived impact of cancer and needs for conversations with a health professional regarding sexual/romantic issues. Adjusted odds ratio estimates with calculated 95% confidence intervals (CI) were reported. $P < .05$ was considered statistically significant. All analyses were performed using SAS version 9.4 (SAS, Institute Inc, Cary, North Carolina).

2.4 | Ethics

Potential participants were informed in writing that the study was voluntary and anonymous. The study was approved by the Danish Data Protection Agency. Under Danish law, questionnaire studies are not subject to review by The Ethics Committee System.

3 | RESULTS

As depicted in Table 2, the participants were asked to what extent cancer had altered their body image and feeling of being attractive. More than half (53.8%) responded that they viewed their physical appearance more negatively after their diagnosis, while 44.6% stated that cancer had made them feel less attractive. As depicted in Table 3, female respondents were significantly more at risk of being negatively affected than male responders concerning these 2 items. Patients with genital cancers were significantly less likely than patients with

TABLE 2 Frequency distribution of questionnaire variables

| How has cancer affected your ... | N, % |
|---|------------|
| View of your own body? | |
| Positively | 90 (12.0) |
| Negatively | 405 (53.8) |
| Neither/nor | 258 (34.2) |
| Feeling of being attractive? | |
| Positively | 62 (8.3) |
| Negatively | 335 (44.6) |
| Neither/nor | 354 (47.1) |
| Desire to flirt, date, or have a partner? | |
| Positively | 102 (15.9) |
| Negatively | 151 (23.6) |
| Neither/nor | 388 (60.5) |
| Desire to have sex? | |
| Positively | 65 (9.0) |
| Negatively | 226 (31.3) |
| Neither/nor | 431 (59.7) |
| Relationship with your partner/spouse? | |
| Positively | 231 (40.6) |
| Negatively | 125 (22.0) |
| Neither/nor | 213 (37.4) |
| Has a professional at the hospital talked with you about how your illness or treatment might affect your love life or sex life? | |
| Yes, to great/some extent | 248 (32.5) |
| To lesser extent/not at all | 378 (49.5) |
| No need | 137 (18.0) |
| During follow-up consultations, did a doctor or a nurse talk with you about whether you had problems in relation to being in love, partners or sex? | |
| Yes, to great/some extent | 156 (21.0) |
| To lesser extent/not at all | 460 (61.7) |
| No need | 129 (17.3) |
| Relationship ^a | |
| Yes | 576 (69.4) |
| No | 242 (29.6) |
| Sexual problem during the past week ^b | |
| Yes | 173 (22.3) |
| No | 603 (77.7) |

^aRelationship status at the time of completion of survey, self-reported in questionnaire.

^bHave you had problems gaining orgasm (both genders), gaining or maintaining erection (males), or vaginal dryness during sexual activity (females)?

melanoma to have experienced a negative impact on their body image and self-perceived attractiveness. No significant age-group differences were observed.

Regarding the patients' desire to flirt/date/have a partner, most respondents (60.5%) reported no change after the cancer diagnosis. However, almost one-quarter (23.6%) stated that the disease had had negative consequences (Table 2). Breast cancer patients were 4 times more likely to experience disruptions in romantic aspirations than patients with melanoma (Table 3).

Asked about their desire to have sex, nearly one-third (31.3%) had experienced an adverse effect (Table 2). As seen in Table 3, female

TABLE 3 Multivariate analysis of responses concerning adverse effects on body image, relational, and sexual issues

| | Cancer Has Negatively Affected your ... | | | | |
|---|---|-----------------------------------|---|--|-----------------------------------|
| | View of Your Own Body? | Feeling of Being Attractive? | Desire to Flirt, Date, or Have a Partner? | Relationship with Your Partner/Spouse? | Desire to Have Sex? |
| | OR Adjusted (95% CI) ^a | OR Adjusted (95% CI) ^a | OR Adjusted (95% CI) ^a | OR Adjusted (95% CI) ^a | OR Adjusted (95% CI) ^a |
| Sex | | | | | |
| Male | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| Female | 2.5 (1.78-3.66) | 1.99 (1.38-2.87) | 1.02 (0.63-1.63) | 1.26 (0.74-2.16) | 1.67 (1.10-2.55) |
| Age at diagnosis | | | | | |
| 15-19 y | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| 20-24 y | 0.93 (0.53-1.53) | 1.02 (0.62-1.69) | 1.38 (0.74-2.55) | 1.05 (0.48-2.28) | 1.54 (0.84-2.84) |
| 25-29 y | 1.03 (0.63-1.67) | 1.06 (0.65-1.74) | 1.41 (0.76-2.63) | 1.33 (0.63-2.80) | 1.62 (0.89-2.96) |
| Cancer type | | | | | |
| Melanoma of the skin | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| Genital cancers | 0.54 (0.33-0.88) | 0.47 (0.28-0.77) | 1.41 (0.72-2.84) | 1.76 (0.85-3.63) | 3.54 (1.95-6.43) |
| Breast cancer | 1.00 (0.43-2.36) | 1.60 (0.68-3.74) | 4.49 (1.70-11.83) | 3.95 (1.43-10.93) | 4.10 (1.71-9.78) |
| Other cancers | 0.74 (0.49-1.13) | 0.74 (0.50-1.12) | 1.87 (1.05-3.35) | 1.95 (1.04-3.67) | 2.70 (1.60-4.55) |
| Relationship status | | | | | |
| No relationship | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| Relationship | 0.81 (0.56-1.17) | 0.84 (0.58-1.21) | 0.21 (0.13-0.32) | 0.19 (0.11-0.34) | 0.91 (0.59-1.39) |
| Sexual problem during past week | | | | | |
| No | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| Yes | 1.87 (1.25-2.86) | 2.38 (1.59-3.56) | 2.07 (1.24-3.44) | 1.40 (0.83-2.37) | 4.49 (2.94-6.87) |
| Conversations with health professionals about problems related to sex/love during follow-up consultation | | | | | |
| Yes, to great/some extent | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| To lesser extent/not at all | 1.09 (0.71-1.68) | 1.15 (0.74-1.79) | 2.1 (1.15-3.67) | 1.37 (0.77-2.45) | 1.66 (1.03-2.67) |
| No need | 0.55 (0.31-0.99) | 0.67 (0.37-1.23) | 0.72 (0.29-1.77) | 0.34 (0.11-1.03) | 0.67 (0.31-1.47) |

Abbreviation: OR, odds ratio.

^aEach variable adjusted for all other factors listed.

responders were significantly more at risk for lowered sexual desire than male responders, and the odds ratios for a negative sexual impact were around 4 times higher in patients with genital cancer or breast cancer compared with melanoma patients. No difference between singles and those in a relationship was observed. During the past week, 22.3% of all respondents had encountered a sexual problem (Table 2). As seen in Table 3, the risk of reporting a negative impact from cancer on body image, attractiveness, and the desire to flirt/date/have a partner/have sex was significantly increased, if a current sexual problem was present.

At the time of the investigation, 69.4% of the respondents were in a partnership; 22.0% of respondents reported that the disease had impacted negatively on their current or previous couple relationship, while 40.6% reported that cancer had affected their partnership positively. Around one-third (37.4%) reported no relational impact (Table 2). Again, breast cancer patients were approximately 4 times more at risk of a negative impact than patients with melanoma (Table 3).

The participants were also asked if a professional had ever addressed the possible sexual/romantic ramifications of their disease during the period of their hospitalization. Half of the respondents (49.5%) reported that this was not or to a lesser extent the case, while 18.0% had not felt any need to discuss such matters (Table 2). As seen

in Table 4, the reported need of having such discussions during hospitalization was more than 20 times higher among patients with genital cancer or breast cancer than among melanoma patients. Conversely, patients with genital/breast cancer were significantly less at risk for reporting unmet needs than patients with melanoma. The need to discuss sexual issues displayed no gender differences, but female patients' risk of having unmet needs was twice that of male patients.

At follow-up consultations, 61.7% of respondents were not or to a limited degree invited by a health professional to discuss the sexual/romantic aspects of their disease, while 17.3% had not felt any need to discuss such issues (Table 2). Again, patients with genital or breast cancer expressed markedly more need for such talks than melanoma patients. Also, their risk of having unmet needs was significantly lower than patients with melanoma. Female patients were more at risk of having unaccommodated needs than male patients. Finally, the need for counselling during a follow-up session was significantly increased for patients who expressed current sexual problems (Table 4).

As depicted in Table 3, patients who had not or to a lesser extent discussed sexual and romantic topics during follow-up consultations were twice as likely to have experienced a negative impact on their desire to flirt, date, or have a partner. A similar trend was seen for the desire to have sex.

TABLE 4 Multivariate analysis of conversations about sex/love during hospitalization and follow-up consultations

| | Conversations About Sex/Love with a Professional During Hospitalization | | Conversations About Sex/Love with a Professional During Follow-up Consultations | |
|---------------------------------|---|-----------------------------------|---|--|
| | Had Need | Had Unmet Need | Had Need | Had Unmet Need |
| | Adjusted OR (95% CI) ^a | Adjusted OR (95% CI) ^a | Adjusted OR (95% CI) ^a | Adjusted OR ^a (95% CI) ^a |
| Sex | | | | |
| Male | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| Female | 0.73 (0.44-1.23) | 2.1 (1.43-3.09) | 0.88 (0.55-1.42) | 1.7 (1.10-2.69) |
| Age at diagnosis, y | | | | |
| 15-19 | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| 20-24 | 1.24 (0.65-2.35) | 1.04 (0.60-1.81) | 2.25 (1.21-4.21) | 1.20 (0.64-2.26) |
| 25-29 | 1.88 (0.99-3.54) | 1.11 (0.65-1.89) | 1.50 (0.84-2.70) | 1.02 (0.55-1.90) |
| Cancer type | | | | |
| Melanoma of the skin | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| Genital cancers | 20.51 (8.43-49.94) | 0.17 (0.09-0.32) | 8.09 (3.86-16.90) | 0.04 (0.02-0.13) |
| Breast cancer | 24.36 (3.25-182.75) | 0.12 (0.05-0.29) | 15.20 (2.02-114.90) | 0.09 (0.03-0.34) |
| Other cancers | 7.80 (4.68-13.01) | 0.26 (0.14-0.48) | 3.28 (2.02-5.30) | 0.11 (0.04-0.31) |
| Relationship status | | | | |
| No relationship | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| Relationship | 0.98 (0.59-1.61) | 0.76 (0.51-1.14) | 1.07 (1.14-4.29) | 1.39 (0.88-2.19) |
| Sexual problem during past week | | | | |
| No | 1 (ref) | 1 (ref) | 1 (ref) | 1 (ref) |
| Yes | 1.69 (0.91-3.14) | 0.89 (0.59-1.35) | 2.22 (1.14-4.30) | 0.74 (0.46-1.19) |

Abbreviation: OR, odds ratio.

^aEach variable adjusted for all other factors listed.

4 | CONCLUSIONS

Our study revealed adverse effects of cancer on the body image and sexual/romantic capability of AYA. In correspondence with other studies among young cancer patients,^{1,9-11} around half of our participants reported that cancer had lowered their appraisal of their own appearance or feeling of attractiveness (Table 2).

We expected the negative impact of cancer to be significantly associated with core patient characteristics, but no significant differences between age groups could be detected, and it made no difference whether patients were currently in a relationship or not. On the other hand, female respondents were significantly more at risk for most cancer-induced adversities than males (Table 3). This is in line with studies suggesting that young women with cancer are more vulnerable to psychosocial distress than young men.⁵ Genital cancer patients were significantly less at risk for lowered body image or self-perceived attractiveness than melanoma patients, possibly due to the visible scars of the latter (Table 3).

In correspondence with the American AYA HOPE study,¹ nearly one-fourth of our respondents reported that cancer had had a negative impact on their readiness to flirt/date/being romantically engaged (Table 2). This number seems to be almost unaffected by gender and age, whereas patients with breast cancer were markedly more at risk than other cancer patients (Table 3). Adolescent and young adult breast cancer patients also had increased risk of relational disturbances and lowered sexual desire, and this corresponds well with studies that focus on the sexual and romantic ramifications of

this cancer type in young women.²¹ Likewise, it is hardly unexpected that patients with genital cancers expressed significantly increased risk of having a disturbed sexual drive compared with melanoma patients. Women were affected by loss of sexual drive more frequently than men (Table 3), and to our knowledge, this gender difference has not previously been demonstrated in AYA cancer patients.

Importantly, AYA patients also reported positive effects of their disease, as cancer may put other life challenges into perspective or prompt the patient to live healthier or more intensively.^{2,5} Approximately 40% of our respondents stated that cancer had affected their romantic partnership in a positive way. This finding, obviously, does not imply the absence of disease-correlated problems, but it reminds us that cancer-related distress is contextual and that AYA patients cope with disease differently. Similarly, in a study among Danish cancer survivors, nearly one-fifth (19%) experienced a better quality-of-life than pre-morbidly.²²

Previous research has described ramifications of cancer on AYA's romantic and sexual lives, but most studies deal with childhood cancer survivors,²³⁻²⁸ where disease was not present during the bio-psycho-social development of adolescence and young adulthood. However, on the basis of our findings, health care professionals should be aware that up to one-third of patients diagnosed with cancer as adolescents or young adults feel that disease has had a negative impact on their desire to have sex, and that more than one-fifth may experience current sexual problems. Moreover, cancer can inflict not only bodily self-confidence problems in adult

patients but also in up to half of AYA patients. Finally, health care providers should keep in mind that very few (less than one-fifth in this study) declare no need to talk about sexual/romantic issues during hospitalization and follow-up consultations.

Existing research has emphasized the importance of enhancing self-esteem and positive coping of AYA cancer patients.^{2,9,11,29-32} Our study suggested that talks about intimate matters might be an important key to resilience and self-efficacy in AYA cancer patients, as dialogues about such issues were significantly associated with the patients' desire to flirt/date/have a partner/have sex (Table 3). Furthermore, it could be hypothesized that the capacity for intimacy and sexuality can provide existential vigor and serve as a vehicle of normality in an otherwise chaotic situation.³³ However, the underlying causal mechanisms should be further investigated, as the possible quality-of-life benefits of AYA patients' sexual and romantic empowerment are clearly multifactorial and complex.

In adults, studies have pointed to the failing efforts of the health care system to acknowledge and accommodate the requirements for sexual information and counselling of cancer patients.^{16,17} Research suggests similar needs among AYA patients,^{2,9,11,14,15,31,34} and in our study, less than 1 in 5 reported no need for talks about their intimate life during their cancer treatment and rehabilitation (Table 2). Reversely, more than 80% of AYA cancer patients in Denmark have felt a need to discuss matters related to sexuality, love, and relationships. It is, however, noteworthy that 50% to 60% of patients were not or to a limited degree invited to talk about sexual/romantic issues by health professionals during hospitalization or follow-up. Further, it is notable that females reported significantly more unmet need for counselling than males (Table 4). This finding probably reveals an all-together larger counselling need among female patients, but it may also reflect male patients' reluctance to admit counselling requirements concerning intimate matters.

Adolescent and young adult cancer patients have previously lamented the silence surrounding sexual and romantic domains in the health system^{2,10,24,35} and a recent Danish study showed that staff members reported more activity than young patients when asked how often sexuality was mentioned in outpatient clinics.³⁴ Correspondingly, a survey among American oncologists revealed that less than half believed that AYA patients needed counselling on sexuality/intimacy/body image disturbances.³⁶ Several studies have emphasized that young cancer patients request a direct, frank, and honest dialogue with health providers about all dimensions of their disease.^{2,6,31,32,37} However, sexuality still seems to be a taboo in youth oncology, as is also the case for health maintenance visits aimed at young people in general.³⁸

This study provided evidence that cancer might have a negative effect on AYA patients' bodily self-perception and on their readiness and ability to initiate sexual/romantic activities. It also revealed that a substantial part of AYA cancer patients required professional dialogue about their intimate life. Although such needs may be considered an integral part of a youth-friendly practice, our study showed that they were often unmet by health care providers, and it confirmed the barriers to discuss intimate matters described by

others. Health professionals should therefore be aware of these overlooked aspects of AYA's lives and remember to proactively address sexuality, love, and partnership to provide youth-relevant services and ultimately strengthen the resilience and survivorship skills of AYA patients.

4.1 | Study limitations

The national cohort format and the thorough validation process of the questionnaire constitute major strengths of this study. However, a response rate of 45% makes it susceptible to selection bias, and the missing voices of deceased and severely ill patients may result in falsely low rates of cancer-induced challenges. The gender asymmetry among responders may further invalidate the study's generalizability. Although the mean period from diagnosis to study inclusion was less than 4 years, recall bias cannot be ruled out. The lack of clinical information (including treatment regime and disease stage) decreases the accuracy of the study. Also, the prevalence of sexual problems was calculated among all participants, and as sexually inactive respondents will likely report no problems, the frequencies of problems must be considered minimum numbers. Finally, it weakens the study that information about partnership was collected at the time of the survey and not during active disease.

4.2 | Clinical implications

Youth clinicians have delivered useful recommendations concerning the "2-way taboo" that seems to surround sexual issues in the health sector.^{2,9,11,15,29,31} Some have even presented suggestions for intervention programmes to provide psychosexual support for AYA cancer patients and thereby prevent knowledge gaps, social, and emotional alienation and risky behaviour.^{9,29,30,39,40} Such interventions can be based upon a psychoeducational approach towards the patient and his/her eventual partner, or they can employ peer groups of AYAs. For a limited group of young patients, intensive psychological or psychiatric intervention is warranted.³⁰

Above all, health care providers in youth oncology should routinely address sexual and romantic issues, as they might constitute important aspects of coping and survivorship.

CONFLICT OF INTEREST

None of the authors have any conflict of interest to declare.

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REFERENCES

1. Wettergren L, Kent EE, Mitchell SA, et al. Cancer negatively impacts on sexual function in adolescents and young adults: the AYA HOPE study. *Psycho-Oncology*. 2016;26(10):1632-1639.
2. Moules NJ, Estefan A, Laing CM, et al. "A tribe apart": sexuality and cancer in adolescence. *J Pediatr Oncol Nurs*. 2017;34(4):295-308.
3. Zebrack B, Isaacson S. Psychosocial care of adolescent and young patients with cancer and survivors. *J Clin Oncol*. 2012;30(11):1221-1226.

4. Abrams AN, Hazen EP, Penson RT. Psychosocial issues in adolescents with cancer. *Cancer Treat Rev*. 2007;33(7):622-630.
5. Sansom-Daly UM, Wakefield CE. Distress and adjustment among adolescents and young adults with cancer: an empirical and conceptual review. *Translational Pediatrics*. 2013;2(4):167-197.
6. Quinn GP, Goncalves V, Sehovic I, et al. Quality of life in adolescent and young adult cancer patients: a systematic review of the literature. *Patient Related Outcome Measures*. 2015;6:19-51.
7. Morgan S, Davies S, Palmer S, Plaster M. Sex, drugs, and rock 'n' roll: caring for adolescents and young adults with cancer. *J Clin Oncol*. 2010;28(32):4825-4830.
8. Hølge-Hazelton B, Sperling CD, Graugaard C, et al. Perhaps I will die young. Fear and concerns regarding illness and death among young adults with cancer, a cross-sectional multi method national study. *Support Care Cancer*. 2016;24:47-37.
9. Aubin S, Perez S. The clinician's toolbox: assessing the sexual impacts of cancer on adolescents and young adults with cancer (AYAC). *Sexual Medicine*. 2015;3(3):198-212.
10. Tindle D, Denver K, Lilley F. Identity, image, and sexuality in young adults with cancer. *Semin Oncol*. 2009;36(3):281-288.
11. Evan EE, Kaufman M, Cook AB, Zeltzer LK. Sexual health and self-esteem in adolescents and young adults with cancer. *Cancer Supplement*. 2006;107(S7):1672-1679.
12. Larouche SS, Chin-Peuckert LC. Changes in body image experience by adolescents with cancer. *J Pediatr Oncol Nurs*. 2006;23(4):200-209.
13. Benedict C, Thom B, Friedman D, et al. Young adult female cancer survivors' unmet needs and reproductive concerns contribute to decisional conflict regarding posttreatment fertility preservation. *Cancer*. 2016;122(13):2101-2109.
14. Dobinson KA, Hoyt MA, Seidler ZE, Beaumont AL, Hullmann SE, Lawsin CR. A grounded theory investigation into the psychosexual unmet needs of adolescent and young adult cancer survivors. *Journal of Adolescent and Young Adult Oncology*. 2016;5:135-145.
15. Murphy D, Klosky JL, Reed DR, Termuhlen AM, Shannon SV, Quinn GP. The importance of assessing priorities of reproductive health concerns among adolescent and young adult patients with cancer. *Cancer*. 2015;121(15):2529-2539.
16. Reese JB. Coping with sexual concerns after cancer. *Curr Opin Oncol*. 2011;23(4):313-321.
17. Hordern A. Intimacy and sexuality after cancer. *Cancer Nurs*. 2008;31:E9-E17.
18. Suris JC, Resnick MD, Cassuto N, Blum RWM. Sexual behavior of adolescents with chronic disease and disability. *J Adolesc Health*. 1996;19(2):124-131.
19. Gjerstorff ML. The Danish Cancer Registry. *Scand J Public Health*. 2011 Jul;39(7 Suppl):42-45.
20. Sperling CD, Petersen GS, Hølge-Hazelton B, et al. Being young and getting cancer: development of a questionnaire reflecting the needs and experiences of adolescents and young adults with cancer. *J Adolesc Young Adult Oncol*. 2016;6:171-177.
21. Fobair P, Stewart SL, Chang S, D'Onofrio C, Banks PJ, Bloom JR. Body image and sexual problems in young women with breast cancer. *Psycho-Oncology*. 2006;15(7):579-594.
22. Grønvold M, Pedersen C, Jensen CR, et al. *Kræftpatientens verden. [The Cancer Patient's World]*. Kræftens Bekæmpelse: København; 2006.
23. Jacobs LA, Pucci DA. Adult survivors of childhood cancer: the medical and psychosocial late effects of cancer treatment and the impact on sexual and reproductive health. *Journal of Sexual Medicine*. 2013;10(suppl. 1):120-126.
24. Thompson AL, Long KA, Marsland AL. Impact of childhood cancer on emerging adult survivors' romantic relationships: a qualitative account. *Journal of Sexual Medicine*. 2013;10:65-73.
25. Sundberg KK, Lampic C, Arvidson J, Helström L, Wettergren L. Sexual function and experience among long-term survivors of childhood cancer. *Eur J Cancer*. 2011;47(3):397-403.
26. Zebrack BJ, Foley S, Wittmann D, Leonard M. Sexual functioning in young adult survivors of childhood cancer. *Psycho-Oncology*. 2010;19(8):814-822.
27. Van Dijk EM, van Dulmen-den Broeder E, Kaspers GJL, et al. Psychosexual functioning of childhood cancer survivors. *Psycho-Oncology*. 2008;17(5):506-511.
28. Gerhardt CA, Vannatta K, Valerius KS, et al. Social and romantic outcomes in emerging adulthood among survivors of childhood cancer. *J Adolesc Health* 2007;40. 462:e9-e15.
29. Kelly D. Developing age appropriate psychosexual support for adolescent cancer survivors: a discussion paper. *Journal of Sexual Medicine*. 2013;10(suppl. 1):133-138.
30. Bolte S, Zebrack B. Sexual issues in special populations: adolescents and young adults. *Semin Oncol Nurs*. 2008;24(2):115-119.
31. D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young cancer survivors. *Cancer*. 2011;117(S10):2329-2334.
32. Siembida EJ, Bellizzi KM. The doctor-patient in the adolescent cancer setting: a developmentally focused literature review. *Journal of Adolescent and Young Adult Oncology*. 2015;4(3):108-117.
33. Graugaard C. Sexuality as a health-promoting factor—theoretical and clinical considerations. *Nat Rev Urol*. 2017;14(10):577-578.
34. Boisen KA, Hertz PG, Blix C, Teilmann G. Is HEADS in our heads? Health risk behavior is not routinely discussed with young patients. *Int J Adolesc Med Health*. 2016;28(4):429-435.
35. Drybrough K, Frid W, Vitko K, Vlach A, D'Agostino N. Walking two worlds—adolescent and young adult oncology. *Cancer Supplement*. 2006;107(S7):1659-1662.
36. Kirschhoff AC, Fowler B, Warner EL, et al. Supporting adolescents and young adults with cancer: oncology provider perceptions of adolescent and young adult unmet needs. *J Adolesc Young Adult Oncol*. 2017;6(4):519-523.
37. Hølge-Hazelton B. Inquiries of discomfort: cancer experiences in young adulthood. *Qualitative Studies*. 2011;2:118-130.
38. Alexander SC, Fortenberry D, Pollak KI, et al. Sexuality talk during adolescent health maintenance visits. *JAMA Pediatr*. 2014;168(2):163-169.
39. Canada AL, Shover LR, Li Y. A pilot intervention to enhance psychosexual development on adolescents and young adults with cancer. *Pediatric Blood & Cancer*. 2007;49:824-828.
40. Winterling J, Wiklander M, Obol CM, et al. Development of a self-help web-based intervention targeting young cancer patients with sexual problems and fertility distress in collaboration with patient research partners. *JMIR Res Protocols*. 2016;e60:5.

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