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# Designing Sexuality and Intimacy Care for Adolescents and Young Adults (AYAs) with Cancer

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**ABSTRACT** Adolescents and Young Adults (AYAs) with Cancer are making the transition from childhood to adulthood while handling the burden of cancer. During this extraordinarily challenging time in their growth and development, sexuality and intimacy, an important aspect of AYAs' wellbeing, are often insufficiently addressed by the healthcare providers, and AYAs are dissatisfied with the available information. The objective of this study was to develop objectives that could help design properly address sexuality and intimacy in AYA care along with a design prototype. The research investigated the big picture of sexuality and intimacy care for AYAs in the Netherlands and looked into AYAs' unmet needs through literature study, interviews with AYA using the Q-sort method and interviews with healthcare providers. The list of design objectives was proposed based on the interviewees' opinions and insights, along with an iterative prototype designed by the researcher that reflected the objectives. Through a cyclic interview process, the list of design objectives was revised, and the prototype was refined as a possible solution in the end. Finally, a conclusion on the research findings and the design objectives is provided.

Keywords: Adolescents and young adults (AYAs) with cancer; human-centred design; sexuality and intimacy; sexual health; online intervention

## Introduction

'AYA' stands for Adolescents and Young Adults (AYAs) with Cancer diagnosed at the age between 15 and 39 years old. When the burden of cancer is added during the transition from childhood to adulthood, it becomes part of a challenging time in AYAs' growth and development. The challenges present problems that neither paediatric nor adult-treating oncologists are fully comfortable in managing (Bleyer et al. 2017). The cancer as a disease, the diagnosis and the therapies can all have a negative effect on the quality of life on both the patient and the partner. The impact tends to cause a decline in the patients' level of functioning and their ability to maintain intimacy and a healthy sex life with their partner. On the patients' part, this will continue for many years even after the cancer treatment has come to an end (Reisman and Gianotten 2017).

While the impacts of cancer diagnosis and treatment are widely recognized and have been investigated in multiple studies (Dobinson et al. 2016; Olsson et al. 2018; Wettergren et al. 2016), inadequate support from physicians and lack of information regarding sexuality-related issues may contribute to AYAs' unmet needs. A national cross-sectional survey about sexuality and intimacy among AYAs in the Netherlands was conducted in 2018 among 56 AYAs. Nearly half of the respondents expressed that the subject of intimacy and sexuality is not sufficiently discussed by the healthcare providers, and there is dissatisfaction among AYAs about the information supplied (Albers et al. 2019).

To date, very few studies have been published that focus on finding solutions to fulfil the unmet needs of AYAs and that can help reduce the negative impacts on sexuality and intimacy. It is a missing part of the puzzle of the comprehensive AYA care in the Netherlands.

## Research Aim and Methods

The purpose of the current study was to develop a list of design objectives that can properly address sexuality and intimacy in AYA care. The study investigated the big picture of sexuality and intimacy care for AYAs in the Netherlands and AYAs' unmet needs throughout the cancer trajectory, and translated the findings into a list of design objectives.

A literature study and interviews were conducted in parallel. Two books were the main reference: (1) *Cancer, Intimacy and Sexuality - A Practical Approach* (Reisman and Gianotten 2017) and (2) *Cancer in Adolescents and Young Adults* (Bleyer et al. 2017). Additional literature about roles of different healthcare providers, psychoeducation and the sexual healthcare intervention model was also studied.

Five interviews with two sexologists, two interviews with two oncology nurses and seven interviews with five AYAs were conducted in the period between March and June 2019. The AYAs were recruited from the National AYA 'Young & Cancer' Congress in March 2019. All interviews were recorded and transcribed for analysis. The Q-sort method (Brown 1996), a popular qualitative research approach, was used to understand the unmet needs of AYAs. With sexologists and oncology nurses, the patient-healthcare provider interaction and referral pathway were discussed.

The list of design objectives was developed in a dynamic way throughout the research process. An iterative prototype reflected the design objectives, and was shown to interviewees to generate discussions on the list of design objectives and further refine it.

## Research Findings

### ***The Big Picture of Sexuality and Intimacy Care in the Netherlands***

The big picture view includes the possible intervention throughout the cancer trajectory regarding sexual consequences, the healthcare providers involved in AYA care and the referral pathway, as well as barriers and opportunities in the communication between the AYAs and healthcare providers.

Reisman and Gianotten (2017) listed the seven phases of the cancer trajectory and discussed the main sexual consequences in each phase. A summary of sexual consequences regarding AYAs and their partners in each phase is shown in Figure 1. In addition, in the interviews with Dutch sexologist Woet Gianotten, the possible interventions in an ideal situation throughout the cancer trajectory were discussed and summarized in Figure 1.

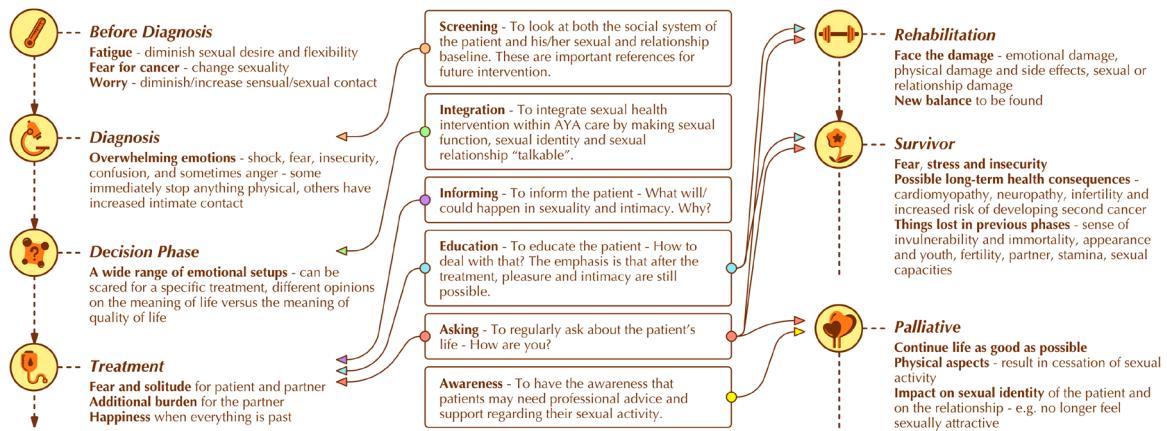


Figure 1: Sexual consequences in the seven phases of cancer trajectory and possible interventions

In the initial phases, it is important that the healthcare providers screen the baseline of the social system and relationship of the patient. It works as an important reference for future interventions where the patients should be routinely informed of what could happen, why and how to deal with this. Throughout the cancer trajectory, it is beneficial to integrate sexual health interventions within AYA care from making the topic 'talkable' (open for conversation) to regularly asking the patients 'How are you?'.

The Dutch healthcare system has the resources to address a variety of concerns and disturbances that AYAs may face. It is provided by both 'primary contact' healthcare providers, the ones that AYAs always talk to, and the 'continuing support', those that the patients can be referred to. But AYAs do not always have the referral to address sexual concerns. Figure 2 maps out the different healthcare providers that may be involved throughout the cancer trajectory, along with the

referral pathway from 'primary contact' to 'continuing support'. A referral here can be the recommendation or guidance to reach a relevant and reliable resource in any form, not necessarily a referral letter.

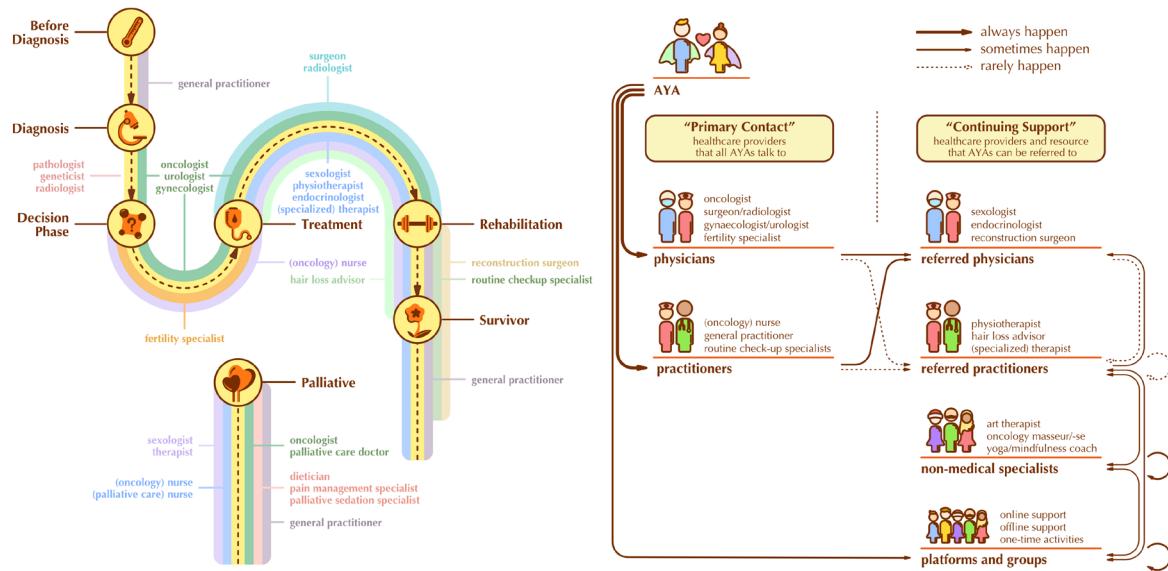


Figure 2: Different healthcare providers in different phases and in referral pathway in the Netherlands

In the referral pathway, AYAs are sometimes referred to physicians, such as a reconstruction surgeon in case of breast cancer. When AYAs communicate with the referred physician, they tend to talk more about sexuality and intimacy, and are sometimes further referred to other practitioners or non-medical specialists, where more referrals are available. When this pathway is unclear, it can take AYAs a lot of time to figure out how to approach the right expert, or even block them from finding support.

Sexuality and intimacy care is frequently not addressed by the oncology healthcare providers (Flynn et al. 2010) who are part of the 'primary contact'. On the topic of possible omissions in the attention paid to sexual functioning in oncology care in the Netherlands, three papers revealed the barriers to discussions about sexuality and intimacy (Krouwel et al. 2015; Krouwel et al. 2015; Krouwel et al. 2015). The PLISSIT model is used as the structure to list the barriers found in these papers. This model Permission (P), Limited Information (LI), Specific Suggestions (SS), and Intensive Therapy (IT) was developed by the American clinical psychologist Jack S. Annon (1976) for the purpose of introducing the topic of sex into clinical conversations. Figure 3 summarizes the barriers in each layer of intervention in 'primary contact'.

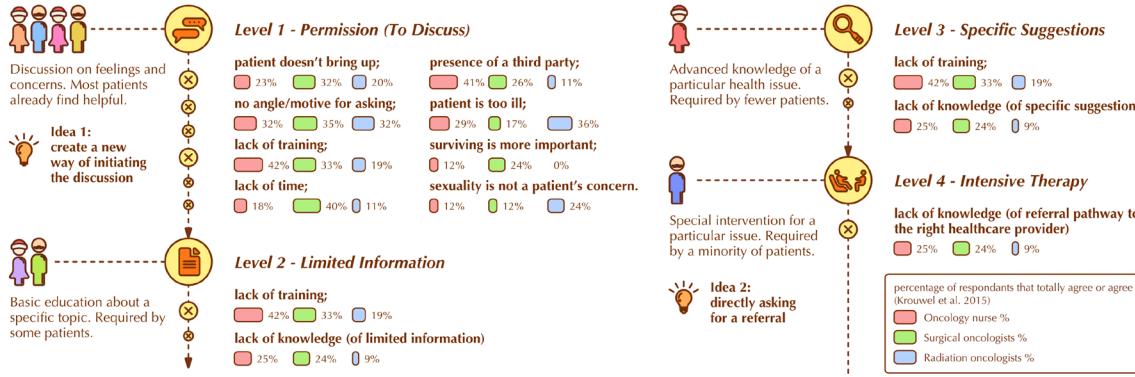


Figure 3: Barriers for oncology healthcare providers in addressing sexuality and intimacy in 'primary contact'

It is worth mentioning that most barriers can block the intervention at level 1 (Permission), that is, the basic discussion on feelings and concerns, which most patients would already benefit from. Some patients need further interventions, where the main barriers are a lack of training and a lack of knowledge. Oncology healthcare providers are not specifically educated to provide sexuality and intimacy care. Experts in 'continuing support' do have this specialized training and knowledge, but as discussed above, the referral from 'primacy contact' does not always happen, leaving AYAs' concerns and disturbances unaddressed.

#### *Ideas about Crossing the Communication Barriers to Reach More Resource*

To sum up, the main problem in the big picture of sexuality and intimacy care in the Netherlands is a lack of an effective referral pathway that bridges the gap between AYAs and experts specialized in sexual health. The ideal interventions are not offered by the healthcare providers that AYAs usually talk to because of various communication barriers, and they rarely refer AYAs to specialized experts.

If a new way of initiating the conversation can be created from the AYAs' side, and if AYAs can ask for a specific referral, they can get closer to the support they need. On the healthcare providers' side, instead of being asked to offer sexual health intervention proactively, responding to the question and request of AYAs poses less burden on them.

#### ***The unmet needs of AYAs in sexuality and intimacy care***

Research that studies the unmet psychosexual needs of AYAs seeks to understand what a design should provide through interviews. Dobinson et al. (2016) categorized these unmet needs into six categories: fertility concerns, sexual communication, dealing with side effects, dating and disclosure, relating to other AYAs, and reconciling identity conflicts. Albers et al. (2019) listed AYAs' satisfaction with received information of eight items concerning sexuality and intimacy care. Based on these two resources, the unmet needs in sexuality and intimacy care for AYAs were clustered and rephrased into ten items as a material to facilitate discussion in the interview.

Figure 4 shows the ten unmet needs and the Q-sort board used in the interviews with AYAs.

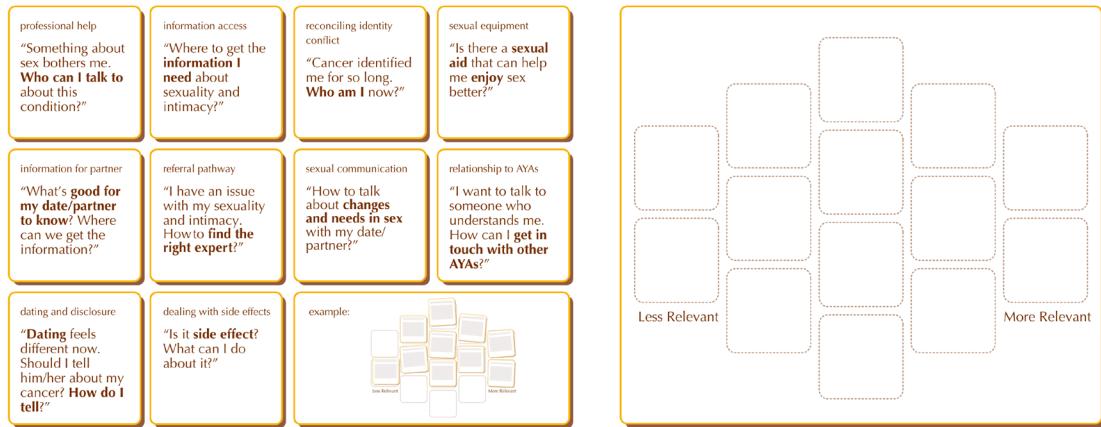


Figure 4: Material used for discussing AYAs' unmet needs using Q-sort method

Based on the thoughts and experience shared by the AYA interviewees, a summary of the insights is drawn below.

### Needs for Reassurance

The feeling of reassurance is fundamental when AYAs try to reach support. They want to be reassured that seeking help about sexuality and intimacy is an appropriate action to improve the quality of life, not overreacting, it is normal to have disturbances, and that there is always someone or something that can help them.

Emotional support throughout the cancer trajectory is crucial. Some AYAs feel lost after the treatment. For them, it is reassuring to hear that other AYAs went through similar hardships.

### Needs for Reaching Professional Help

The need for professional help is unmet in AYAs' 'primary contact'. Because the feeling of reliance is important, nurses with whom they have extensive contact with are extra important for addressing sexual health, but they can find this a topic that is difficult to discuss. Short conversations would already be helpful, but this rarely happens. The AYAs do not know where to go to, or which expert to find for their concerns. With so much uncertainty, the first step of reaching for help is already a serious hurdle to take.

### Insight about Current Information Supply

During treatment, AYAs sometimes feel uninformed about the sexual consequences. Meanwhile, the real impact on sexuality and intimacy starts *after* the treatment. But most information supplied to AYAs about sexuality and intimacy, if any, only focuses on problems *during* treatment.

Practical tips are important. For example, it is hard to find the right products that help AYAs to deal with sexual problems, such as lubricants that are safe for patients undergoing chemotherapy.

### *Insight about Online Information Resource*

When trying to find information online, AYAs could not find what they need. There is limited practical information about disturbances. Moreover, the information that is available, is sometimes too medical, not reliable, and matching the individuals' particular situation in terms of age group, type of cancer, etc. In addition, searching in the poorly organized pool of information takes a lot of energy and requires a high baseline of prior knowledge.

## **Design Objectives and a Proposed Solution – New Me. New We.**

The list of design objectives was developed throughout the research process and reviewed with the experts and AYAs in the interviews. Table 1 lists the final design objectives and a possible design solution.

Table 1. Consideration, design objectives and possible design solution

Consideration	Design objectives	Possible design solution
A) Reassurance	A-1) Convince users that seeking help is appropriate, having disturbances is normal, and there is always something/someone who can help. A-2) 'Light-hearted' vibe.	- 'Love notes' where AYAs can receive and write heart-warming words and share personal stories. - 'Expert words' that suggests there is always a way to get better. - Easy language with a personal touch.
B) Content structure	B-1) Intuitive and clear. Direct users to the information about the right expert or resource. B-2) Low barrier and personalization.	- Interactive eHealth platform. - Website provides one-time searching. - Mobile application provides tailored information.
C) Closing information gap	C-1) Address concerns in biological, psychological and social layers and information suits age group. C-2) Provide basic intervention of problem explanations.	- 'Body map' for information on biological and psychological disturbances. - 'Directory' for communication with partner, healthcare providers and fellow AYAs.
D) Communication	D-1) Prepare user to initiate discussion with healthcare provider. D-2) Help the user to ask for specific support.	- Explicitly show users how they can ask the question in text. - Show possible support on screen that can help users to discuss with their healthcare provider.

'New Me. New We.' is an application that was developed to meet the design objectives (Figure 5 and 6). For details of the design, see: <https://vimeo.com/377685171>

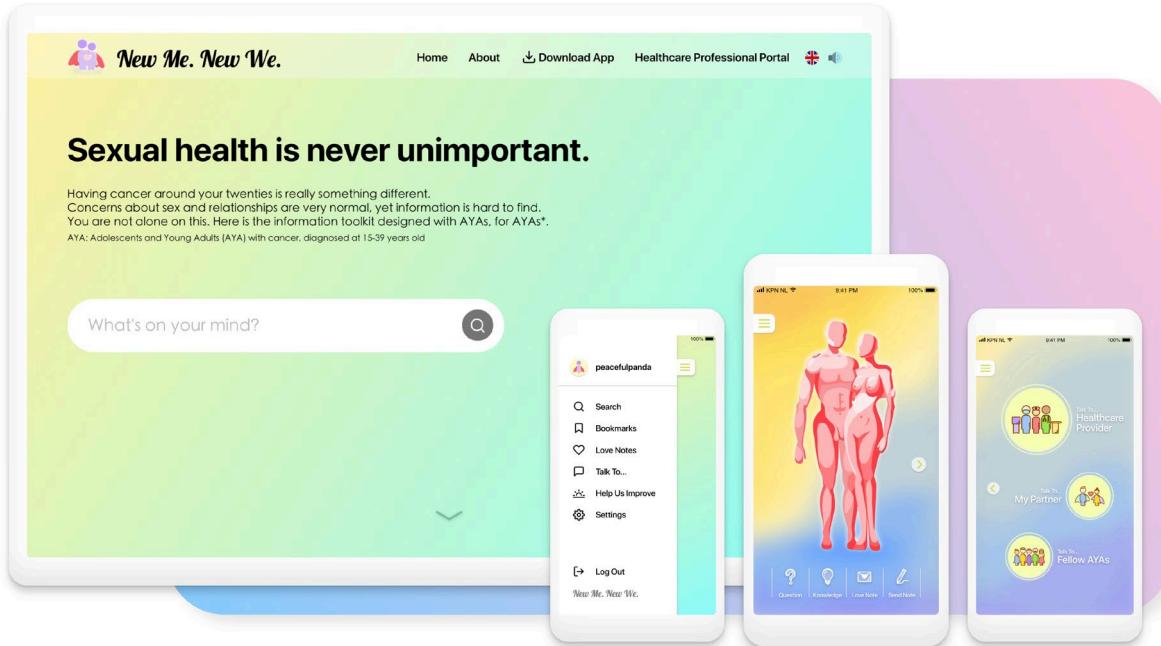


Figure 5: Interface design of New Me. New We.

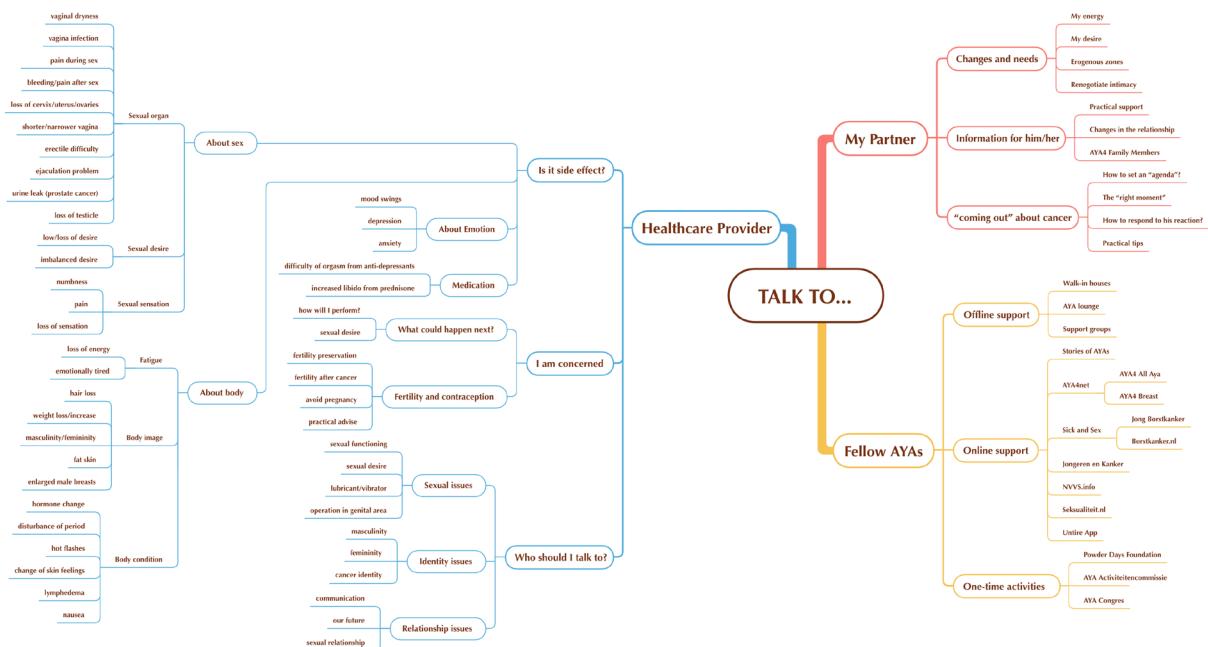


Figure 6: Information architecture of the directory of New Me. New We.

## Conclusion

The study investigated the big picture of sexuality and intimacy care for AYAs in the Netherlands, where the main problem is the lack of an effective referral pathway to the right experts and resources. Based on the findings, we propose that AYAs can be encouraged to initiate the discussion and ask for specific support from the healthcare providers in their 'primary contact'. We also delved into the unmet needs of AYAs, and found that the need for reassurance and reaching professional help are fundamental. The gained insights about the current information supply and online resource were translated to a set of eight design objectives, including reassurance, content structure, closing information gap and communication. Finally, an application was presented that aims to meet the design requirements.

Some limitations of the research should be noted. Due to the small number of AYA interviewees and their above-average educational background, the insights and feedbacks may not fully represent the entire AYA group. Homosexuality, transgender people and polyamory were also not taken into account in the prototyping process.

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