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Experiences of Peer Communities in a Cancer Smartphone App Among Adolescents and Young Adults With Cancer

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ABSTRACT

Objectives: Adolescents and young adults (AYAs) with cancer have identified connection to online communities of same-age peers to be essential for psycho-social support. In this study, the aim was to explore AYAs with cancers' and AYA cancer survivors' use of the Kræftværket cancer app's social forum and experiences of peer communities in the forum. Differences due to gender and treatment status were investigated.
Data Sources: In all, 85 AYAs aged 15-29 were recruited: 46 on and 39 off cancer treatment. The use of the social forum was assessed by a questionnaire, which were analyzed using descriptive statistics, and telephone interviews were analyzed thematically by the Framework Method.
Conclusion: Some AYAs assessed the social forum to be more valuable at time of diagnosis, while others experienced meaningful peer-support after cancer. Women were more active and diligent users than men. The following themes were found: 1) Common understanding of each other's challenges; 2) Other AYAs' stories increase the feeling of comfort but can also be difficult to accommodate; 3) A temporary and unwanted community; and 4) The interaction is personal but quickly stalls.
Implications for Nursing Practice: The results are relevant to the development of AYA cancer apps, with a view to strengthening peer-to-peer relationships. Although the use of the Kræftværket app was temporary, it presented a meaningful community for AYAs with cancer. The community feeling reduced loneliness and increased the sense of togetherness. The app met AYAs' needs and wishes for peer-to-peer age-appropriate cancer support, which can be implemented and provided by nurses.

Introduction

In Denmark, approximately 600 adolescents and young adults (AYAs) aged 15 to 29 years are diagnosed with cancer annually.[1] It can be a huge challenge to face a life-threatening disease while going through a significant psychosocial phase of development. The creation of an individual identity (eg, sense of self, sexual identity), independence (eg, employment, autonomy from parents, decision-making about the future), and peer relationships (eg, intimate relationships, peer-to-peer support) are key psychosocial factors that impact AYAs.[2] In the cancer trajectory and return to a normal life, it is essential that AYAs receive psychosocial support.[3,4] AYAs with cancer have identified that links to patient communities with same-age peers are of the utmost importance because such communities allow for discussions of relevant issues in confidence and with a shared understanding.[5,6]

AYAs' widespread use of mobile technology means that online communities have become very common. Of all Danish AYAs aged 16 to 24 years, 96% have access to a smartphone for private use, and they are diligent and experienced users of social media.[7] Several social media channels offer AYAs with cancer peer-to-peer support,[8] thus meeting their needs for online communities to socialize and form peer communities with others of the same age affected by cancer.[9,10] However, the vast majority of online communities are targeted to people with cancer in general or people with specific cancer diagnoses.[8,11,12] Besides shared understanding and support between AYAs with cancer,[13,14] engaging in online support groups has also

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been shown to increase the feeling of empowerment and to reduce depression, cancer–related trauma, and perceived stress.[15–17] Furthermore, peer-to-peer support between AYA members of online cancer forums may have a psychosocial effect, for example, in terms of a strengthened sense of normality and identity.[9] Across age ranges, online peer-to-peer support has been shown to increase patients' empowerment, health literacy, and physical, mental, and emotional well-being, and to strengthen their illness management.[18]

Besides the many benefits of social media-based peer-to-peer patient support, some challenges have also been reported, including that strangers easily get access to open groups, which may feel like a threat to privacy and may complicate the unique connectedness and trust between people with cancer.[10,19] Even though closed groups are preferable, lack of data security is still a concern for AYAs with cancer.[20] Also, there are not always moderators to monitor the groups, and in their absence, appropriate language use, behavior, and evidence-based information on cancer are not guaranteed.[12,18] Additionally, not all social media communities offer full anonymity, which has been shown to be a high priority to some AYAs.[21] Such issues are to be considered when designing solutions for and introducing online communities to AYAs with cancer.

The development of eHealth apps has gained ground in recent years, and in European countries—including Denmark where this study is carried out—apps are subject to state legislation in relation to cyber security (the General Data Protection Regulation [GDPR]) to protect users' personal information.[22] Besides the obvious benefit of data protection, a significant advantage of eHealth app development is that closed user access can be chosen. This: (1) makes it possible to target the app at specific ages and diseases, (2) supports the confidentiality among community members, given that only the target group has access, and (3) supports anonymity because user access is not linked to a general social media profile. Thus, app communities seem to be ideal for patient use, and in line with this, research has shown that AYAs with chronic illness are pleased to share thoughts and experiences with like-minded people via app chat features.[23]

The Kræftværket Social Forum

To meet AYAs' with cancer and AYA cancer survivors' needs and wishes for online peer-to-peer-support, we created the Kræftværket app in a co-creation process with the target group.[24] The Kræftværket app met a need for a digital platform addressing the peer support needs of AYAs with cancer and AYA cancer survivors to connect with like-minded.[25] The app was developed in 2017 among AYAs with cancer from the physical youth support center "Kræftværket" at Rigshospitalet, Copenhagen University Hospital in Denmark (AYAs aged 15–29 years). Thus, those AYAs in isolation because of treatment or those living far away from the hospital in other parts of the country unable to use the support center, would be given the opportunity to join the social forum in the app. The full content of the app is described in detail in previously published articles.[21,24,25] Except for a moderator from the Danish Cancer Society's AYA department "UngKræft," only AYAs with cancer were given access to the app. The app was launched nationwide in June 2020, and by June 2022 it had 735 users.

Aim of the Study

In this study, we wanted to explore AYAs' with cancer and AYA cancer survivors' use of the Kræftværket app's social forum and experiences of peer communities in the forum through (1) a questionnaire, which was analyzed in terms of gender and treatment status, and (2) follow-up telephone interviews to gain deeper insights from the AYAs.

TABLE 1
Demographic and Clinical Information of the Participants.

	Initially enrolled participants (n = 85)	Final participants (n = 75)
Gender, n		
Male	42	34
Female	43	41
Age (y), median (range)	24 (16–29)	24 (16–29)
Treatment, n		
On treatment	46	40
Off treatment	39	35
Type of cancer		
Brain	2	2
Breast	4	4
Cervix	2	2
Gastrointestinal	2	2
Leukaemia	11	11
Lymphoma	35	29
Malignant melanoma	1	1
Neuroendocrine	1	1
Ovarian	4	4
Sarcoma	4	4
Testicular	15	13
Thyroid	1	1
Unknown primary tumour	2	–
Uterus (mola)	1	1

Methods

Participants

The app was invented for AYAs aged 15 to 39 years. However, to align this study with our previous Kræftværket app research, which included only members of the physical youth support center Kræftværket aged 15 to 29 years,[21,24,25] inclusion criteria were AYAs with cancer and AYA cancer survivors between 15 and 29 years of age. They should all have access to a smartphone. We aimed for 50% newly diagnosed with cancer (within the preceding 30 days) and 50% in follow-up after cancer treatment (within the past 5 years). Exclusion criteria were AYAs who had participated in the app co-creation development process, those who had participated in the pilot studies,[21,24,25] and those unable to read and write in Danish. In all, 85 AYAs were recruited to the study, 46 on treatment and 39 off treatment. Five AYAs dropped out of the study. Reasons for drop out were "did not hand in questionnaires" (n = 3), "could not download the app" (n = 1), and "died" (n = 1). Three AYAs were excluded after enrollment. The reasons for exclusion were "participation in the app development process" (n = 1), "missing signature on the written informed consent" (n = 1), and "older than 29 at time of recruitment" (n = 1). Additionally, two AYAs withdrew their consent after project start (n = 2). Thus, the study consists of data from 75 AYAs. Please see Table 2 for participants' demographic and clinical information.

Settings and Recruitment

This study was a national trial. The participants were recruited from the five university hospitals in Denmark that treat AYAs who have cancer. The hospitals are located in the five Danish regions. Recruitment of AYAs was calculated on the basis of the annual number of AYAs diagnosed with cancer in each region[1]: 35%, Capital Region of Denmark; 21%, Region of Southern Denmark; 21%, Central Denmark Region; 14%, Region Zealand; and 9%, North Denmark Region. The study was anchored in the youth support center 'Kræftværket', Copenhagen University Hospital – Rigshospitalet. The collaboration partners in recruitment of participants and conduct of the study were Department of Oncology and Department of Blood Diseases, Odense University Hospital; Department of Oncology and Department of Blood Diseases, Aarhus University Hospital;

TABLE 2
Frequency of App Use.

How often did you use the app during the 6-week period?	Several times a day %	Once a day %	A couple of times per week %	Once per week %	Once or twice during the 6 weeks %	Not at all %
Male (n = 34)	3	3	32	21	32	9
On treatment (n = 18)	6	—	28	28	22	16
Off treatment (n = 16)	—	6	37.5	12.5	44	—
Female (n = 41)	2	12	42	17	22	5
On treatment (n = 22)	5	9	41	27	9	9
Off treatment (n = 19)	—	16	42	5	37	—
All on treatment (n = 40)	5	5	35	27.5	15	12.5
All off treatment (n = 35)	—	11	40	9	40	—
All participants (n = 75)	3	8	37	18	27	7

Department of Hematology, Zealand University Hospital Roskilde; and Department of Hematology, Aalborg University Hospital. The participants were recruited between September 2020 and March 2022 by local nurses from each hospital who were either working as youth coordinators or with special interest in AYA oncology (authors MH, ABS, MT, MBB, and DØG). The nurses distributed the personal app code to the participants and introduced them to the research project, which implied use of the app for a 6-week test period. They introduced the participants to the app features, but they did not give the participants any specific instructions on frequency or individual use of the app. The nurses also obtained written informed consent and questionnaires from the participants.

Data Collection and Measuring Tools

The measuring tools consisted of (1) a questionnaire with questions about participants' use of the social forum and experiences of the peer communities, and (2) a telephone interview. In all, 75 completed the questionnaire and 74 completed the telephone interview, as one participant was too ill to complete the telephone interview (Table 1).

The questionnaire

After the 6-week test period, the participants completed the questionnaire. The purpose of the questionnaire was to get a thorough insight into the importance of peer communities during and after the cancer trajectory, as well as insights into the frequency of app use, with a view to assessing the need for the social forum. The questionnaire was developed on the basis of theory on social communities[26] and knowledge from our pilot study on the app.[21,25] It consisted of 22 questions. The first was about frequency of app use during the 6-week test period (see Table 2 in Results). The other 21 questions were constructed with the answer options "yes/no/don't know." Five questions were for internal use, focusing on experiences of the entire app (eg, use of the tracker and the information bank and interaction between them). The remaining 16 questions, presented in this article, were about experiences of peer communities and use of the social forum (see Table 3 in Results). The questionnaire was developed in paper format, which was either handed physically or emailed to the participants immediately after the 6-week period (depending on whether the participants were hospitalized or at home at time of distribution).

Telephone interviews

No later than two weeks after receiving the completed questionnaire from the nurse, SH conducted a qualitative telephone interview with the participants, which gave them the opportunity to elaborate on their experiences of using the social forum. Additionally, the participants were asked individually tailored questions, depending on their questionnaire responses. For example: "Can you elaborate on how you experienced the peer communities with the other AYAs in the app that you did not experience with your own peers?" or "What did it mean to you that the other users of the social forum were your own age?" The purpose of this telephone interview was to get deeper into experiences of the peer communities in the app. The 74 telephone interviews lasted between 1 and 16 minutes (average 4 minutes), which led to a total of 210 minutes of audio data.

Data Analysis

The questionnaire data were analyzed using descriptive statistics. Qualitative data from the telephone interviews were analyzed thematically through the Framework Method, which is suitable for analysis of shorter interviews connected to surveys.[27] The method consists of seven stages, which were performed in a joint process between SH and HP (except for stage 1, the transcriptions, which was done by SH after each interview). The stages were (1) transcriptions, (2) familiarization with the interviews and noting the first ideas for possible codes, (3) codes relevant to the research question were identified after reading and rereading the transcripts, (4) developing a "working analytical framework" by grouping codes together into categories, (5) applying the analytical framework by organizing all the codes, (6) charting data into the framework matrix by using a spreadsheet to summarize the data by category from each transcript, and (7) interpreting the data and writing up the findings.[27]

Theoretical Lens

As a theoretical lens in the analysis of the AYAs' sense of belonging to a social community, we applied sociologist Michel Maffesoli's theory on everyday communities.[26] The theory is about everyday communities in situations and moments called "neo-tribalism." The theory was used to shed light on the meaning and value the app might add to the AYAs' lives during and after their cancer trajectory, how they experienced the peer community, whether they became part of sub-communities (eg, in relation to specific diagnoses, gender, age, or other factors), and how strong their commitment to the peer community seemed to be.

The theory is about young people's search for identity-forming communities, so-called neo-tribes. Young people join and leave neo-tribes, which are therefore temporary, fluid, and occasional. Even though the affiliation to a neo-tribe is strong and the members experience a strong sense of togetherness, the community is noncommittal and nonbinding, and thus easy to leave.[26] In recent decades, social media communities have made their entrance, and neo-tribes, such as youth cultures, subcultures, and interest groups have a new platform. Research has shown that patients share knowledge, exchange medical information and life experiences related to their illness on social media platforms, which constitutes a type of neo-tribal storytelling.[28] Through this storytelling, members of the community can ask questions and suggest solutions to other people. Virtual communities—or social media neo-tribes—have clear advantages in terms of being time and space independent, and because the communities

TABLE 3
Participants' Use and Assessment of the Social Forum.

Questions	Male in total	Male on treatment	Male off treatment	Female in total	Female on treatment	Female off treatment	All on treatment	All off treatment	Participants in total
Have you read other AYAs' posts in the social forum?									
Yes	90.3	86.7	93.8	97.4	100	94.7	94.3	94.3	94.3
No	9.7	13.3	6.3	2.6	—	5.3	5.7	5.7	5.7
Don't know	—	—	—	—	—	—	—	—	—
Have you written questions or answers in the social forum?									
Yes	32.3	26.7	37.5	41	45	36.8	37.1	37.1	37.1
No	67.7	73.3	62.5	59	55	63.2	62.9	62.9	62.9
Don't know	—	—	—	—	—	—	—	—	—
Have you used the social forum to correspond with AYAs from other places in Denmark than where you live?									
Yes	9.7	—	18.8	15.4	15	15.8	8.6	17.1	12.9
No	87.1	93.3	81.3	77	80	73.7	85.7	77.1	81.4
Don't know	3.2	6.7	—	7.7	5	10.5	5.7	5.7	5.7
Do you use/have you used cancer communities on Facebook to find answers to questions about your illness?									
Yes	19.4	13.3	25	30.8	35	26.3	25.7	25.7	25.7
No	77.4	80	75	69.2	65	73.7	71.4	74.3	72.9
Don't know	3.2	6.7	—	—	—	—	2.9	—	1.4
(*if yes in the above-mentioned question*)									
Is the social forum tailored to your needs as young and ill compared to the cancer communities you know from Facebook?									
Yes	50	—	75	66.7	71.4	60	55.6	66.7	61.1
No	—	—	—	8.3	—	20	—	11.1	5.6
Don't know	50	100	25	25	28.6	20	44.4	22.2	33.3
Has it mattered to you that the other users of the social forum were your own age?									
Yes	64.5	53.3	75	77	85	68.4	71.4	71.4	71.4
No	19.4	26.7	12.5	12.8	10	15.8	17.1	14.3	15.7
Don't know	16.1	20	12.5	10.3	5	15.8	11.4	14.3	12.9
Is/was the social forum relevant during treatment?[*]									
Yes	60	60	—	70	70	—	65.7	—	65.7
No	—	—	—	10	10	—	5.7	—	5.7
Don't know	40	40	—	20	20	—	28.6	—	28.6
Is/was the social forum relevant after cancer treatment[†]									
Yes	56.3	—	56.3	63.2	—	63.2	—	60	60
No	31.3	—	31.3	26.3	—	26.3	—	28.6	28.6
Don't know	12.5	—	12.5	10.5	—	10.5	—	11.4	11.4
Did you experience a sense of community with the other AYAs in the social forum?									
Yes	58.1	53.3	62.5	77	75	79	65.7	71.4	68.6
No	25.8	33.3	18.8	15.4	15	15.8	22.9	17.1	20
Don't know	16.1	13.3	18.8	7.7	10	5.2	11.4	11.4	11.4
Did you experience a sense of community with the other AYAs in the social forum that you did not experience with your own peers?									
Yes	42	26.7	56.3	69.2	70	68.4	51.4	62.9	57.1
No	35.5	40	31.3	23.1	25	21.1	31.4	25.7	28.6
Don't know	22.6	33.3	12.5	7.7	5	10.5	17.1	11.4	14.3
Did users of the social forum help each other with tips and advice?									
Yes	90.3	86.7	93.8	94.9	95	94.7	91.4	94.3	92.9
No	—	—	—	2.6	5	—	2.9	—	1.4
Don't know	9.7	13.3	6.3	2.6	—	5.3	5.7	5.7	5.7
Was it possible to communicate with AYAs with the same diagnosis in the social forum?									
Yes	38.7	33.3	43.8	35.9	25	47.4	28.6	45.7	37.1
No	9.7	13.3	6.3	25.6	25	26.3	20	17.1	18.6
Don't know	51.6	53.3	50	38.5	50	26.3	51.4	37.1	44.3
Have you got one or more close relationships with anyone in the social forum?									
Yes	—	—	—	2.6	5	—	2.9	—	1.4
No	100	100	100	94.9	95	94.7	97.1	97.1	97.1
Don't know	—	—	—	2.6	—	5.3	—	2.9	1.4
Can you recognize anything from other AYAs' stories in the social forum that has made you more comfortable during your cancer trajectory?									
Yes	45.2	40	50	69.2	70	68.4	57.1	60	58.6
No	32.3	33.3	31.3	15.4	25	5.3	28.6	17.1	22.9
Don't know	22.6	26.7	18.8	15.4	5	26.3	14.3	22.9	18.6

(*continued*)

TABLE 3 (*Continued*)

Questions	Male in total	Male on treatment	Male off treatment	Female in total	Female on treatment	Female off treatment	All on treatment	All off treatment	Participants in total
I have become part of a community in the app that will continue after treatment/follow-up care									
Yes	16.1	6.7	25	23.1	20	26.3	14.3	25.7	20
No	54.8	60	50	56.4	50	63.2	54.3	57.1	55.7
Don't know	29	33.3	25	20.5	30	10.5	31.4	17.1	24.3
I have become part of a community that will continue privately after I have deleted the app									
Yes	–	–	–	2.6	5	–	2.9	–	1.4
No	64.5	66.7	62.5	76.9	75	78.9	71.4	71.4	71.4
Don't know	35.5	33.3	37.5	20.5	20	21.1	25.7	28.6	27.1

[*] Question only for AYAs currently receiving treatment.

[†] Question only for AYAs in follow-up care.

The table presents answers from AYAs who used the app during the 6-week period: male in total (n = 31), male on treatment (n = 15), male off treatment (n = 16), female in total (n = 39), female on treatment (n = 20), female off treatment (n = 19), all participants on treatment (n = 35), all participants off treatment (n = 35), and participants in total (n = 70).

enable long-distance peer-to-peer support, they also benefit people living far away from the hospital.

Ethics

Permission to conduct the study was given by the local Data Protection Agency (P-2020-317). Under Danish law, the study was exempt from review by an institutional review board or ethical authority. However, we followed the principles indicated in the Helsinki II Declaration. The participants were given a short project description that was handed before recruitment. The project description introduced the participants to the test period of the app, informed them of the aim of the study, that they were guaranteed anonymity, and that the telephone interviews would be recorded electronically. Written informed consent was obtained both for all participants and for the parents of participants younger than 18 years.

Results

The results are divided into two parts: a presentation of (1) questionnaire responses, and (2) themes from the thematic analysis of follow-up telephone interviews.

Questionnaire Responses

Themes

The themes that emerged from the thematic analysis are presented in Table 4.

Theme 1: Shared understanding of each other's challenges. The participants described the peer community as special because everyone was in the same boat; they had the same challenges, and thus had a common understanding of each other. The participants explained that everyone was going through something terrible and chaotic, and that compassion and trust in each other helped to strengthen the community feeling. They felt that, even though they did not know each other in real life, they cared for each other in a different way than they did for their own peers and family. Several explained that it sometimes felt as if they were the only young person in the world who had been affected by cancer, but in the social forum they discovered that there were others around the country in the same situation who felt the same way, and it both increased a sense of normalcy and prevented loneliness:

> "I did not feel so alone in the situation, it reassured me that okay, it is normal to feel like that, others have also experienced it and their trajectory has also been like that, so I'm not a single weird case." (AYA7)

Many participants experienced that the peer community in the app was very different from communities with their own peers. They could ask questions in the social forum that did not make sense to ask their own peers, as they did not have the necessary experience to be able to answer. Some participants even found it hard to talk with their own peers about having cancer because they were not really able to understand how it was:

> "Other like-minded people understand me better than my own friends. My old friends do not understand anything. They do not know what it is because they have not felt it on their own body, so it is nice to talk to someone who knows the special fatigue that you can feel, which is not just a fatigue you can sleep away. Old friends can't talk about hair loss and wigs, they do not understand." (AYA65)

However, primarily some of the male participants said that they had a strong network of peers, who offered them great support, and for that reason the social forum was less relevant to them. It was also noted that there was a common understanding across cancer diagnoses. Regardless of the diagnosis, the AYAs knew well what it was like to have, for instance, a headache or treatment-related nausea. Yet, some thought the app would become more targeted if they could relate to someone with exactly the same diagnosis, and they lacked easy pathways to relevant threads in the social forum:

> "It was nice to be able to read a bit about the hair and such things, but in relation to my disease, I could not. . .it is very rare, so I could not really see myself reflected in so much of it that was written in there." (AYA45)

Thus, the social forum offered the AYAs access to many more people of same age than they had the opportunity to meet at, for example, their hospital ward or in social organizations for cancer patients. This was important because most participants found that the common understanding for each other's challenges was based on being young. One described the peer community as a "community of age." Age mattered because they faced the same challenges in life, such as the significance of lost fertility and the importance of appearance in, for example, the case of having lost a breast. Also, they had similar experiences with interrupted schooling and education, delay in entering the labor market, and relationships with friends and family:

> "The elderly of 50–60 years of age have lived most of their life and hopefully had children and maybe grandchildren, they can't relate to the fact that my life has not started properly yet. Also, they

TABLE 4
Themes From the Thematic Analysis.

Themes	Summary of content
Shared understanding of each other's challenges	• Going through the same situation reinforces the understanding • Different understanding than from own peers • Specific diagnoses matter to some AYAs • Being of the same age increases the community feeling
Other AYAs' stories increase the feeling of comfort but can also be difficult to accommodate	• The AYAs received reassurance that they would get back to normal • Others' stories are sometimes scary
A temporary and unwanted peer community	• Participation was more out of need than out of desire • The acquaintances were short-lived • Anonymity led to a superficial relationship
The interaction is personal but quickly stalls	• Supporting and caring tone • You must have had a special experience to describe in the thread • The social forum reached a saturation point

> can't relate to studying and having just entered the labor market." (AYA64)

Theme 2: Other AYAs' stories increase the feeling of comfort but can also be difficult to accommodate. Most participants learned that others' stories could increase their confidence of returning to a normal life after their cancer trajectory, especially if they were newly diagnosed. Many had unanswered questions and experienced a high degree of uncertainty, and others' responses to their questions could provide answers to some of their many questions, thus increasing their sense of security. Several participants searched for certainty that specific symptoms and side effects would disappear again, and it gave peace of mind to learn that others were experiencing the same and that symptoms were not forever. There were also some who drew comfort from concrete advice from others, for example, about interrupted studies and the opportunity to re-sit examinations. It was reassuring to know that there was a safety net to pick one up after the disease. At the existential level, several expressed being afraid of not surviving. They could lean on other people's stories about having gone through a difficult time and come through well:

> "It gives an awareness that you have to get through no matter how hard it is at times. Some have been through something worse, and they have managed it, so even though it is not the same thing we have been exposed to, it gave peace to know that you can get through it and get well on the other side and get started in life again." (AYA2)

Some of the participants thought that reading about others' illness experiences in the social forum could have a negative effect on them. Some were scared to hear about side effects that they had not had themselves, and about others who had relapses. A few completely avoided to read scary information about cancer because it made them uncomfortable. To distance themselves from the disease, they stopped reading the threads in the social forum:

> "I could not stop, every time I opened it, to read about all sorts of gloomy things, and I was not ready to deal with that. So, every time I opened the app, I thought 'no, I also have to see what something else happens,' and then things appeared I was not happy about. It was like I had to distance myself from the app to distance myself from this community." (AYA58)

Theme 3: A temporary and unwanted peer community. Several participants said that they felt a kind of belonging and a togetherness with others in the social forum. However, even though they greatly appreciated the peer support and the feeling of being together with like-minded people, the forum could be conflicting to use. It felt like a social club you would never dream of being a member of because no one ever wishes to get cancer. Thus, the social forum was different from other social communities they were part of; participation was more out of need than out of desire, and many wished to put their cancer experiences behind them as far as possible:

> "I have not used the app after the 6 weeks because I try to get out on the other side, I try to get to a situation where it does not burden me too much." (AYA55)

Therefore, it was also in the minds of the participants that when they had finished their treatment, they wanted to leave the illness experience behind them as soon as possible and move on with life. Thus, many of the participants in follow-up care thought that the social forum would have been more relevant to them during the treatment course. They were either further on in life or experienced that there was only a little content that was relevant to them. However, some of the participants in follow-up care still appreciated the peer communities as a great support:

> "You can still get a stomachache before the checkups and get worried, and I have written with someone who was almost done with his controls, which has been a huge support. I have been in doubt about many things in the process after cancer." (AYA66)

Most participants took for granted that the peer community was purely virtual and confined to the app, and they felt it was important that it remained in the app. Therefore, they were not interested in getting to know the others in a physical meetup, to know where in the country others lived, or to hook up with others on other platforms. In line with this, there were also some who chose to join the social forum with an anonymous profile. However, there were divided opinions on whether anonymity was a good idea. Some liked not to reveal who they were, whereas some felt that anonymity maintained a more superficial relationship with others so they could not really get to know people properly. Most of the participants preferred that members did not choose anonymity because it weakened the sense of community:

> "It matters that people are anonymous, then the community will not be as strong." (AYA23)

Theme 4: The interaction is personal but quickly stalls. Most participants experienced that the interaction in the social forum was characterized by great helpfulness between the AYAs. Once they had written a question or comment, they could usually expect an answer, and often from several people. The AYAs wrote nicely to each other, and the tone was supportive and caring. Very personal experiences were shared, and some of the AYAs were brave to share existential thoughts about life and death. All questions and posts were usually well received:

> "The community in the app is characterized by the helpfulness among the young people who respond to each other's messages. It's cool that it's not only one person who gives an answer, others also add an answer—even though it is the same answer." (AYA61)

However, most of the participants only read other AYAs' posts; they did not write either questions or answers to others. There were two main reasons for this. First, some thought that they should have something to offer, for example, a specific experience of having cancer or exactly the same cancer experience, to answer people's questions sufficiently:

> "Many of those who wrote in there were longer in the process [...] I did not know what to answer because I did not have the experience yet." (AYA6)

Second, many participants experienced that the threads in the social forum reached a saturation point, so that practically all topics had been covered. This made the forum more like an information source, which many valued higher than traditional information from the hospital. Several of the participants said that they were able to find whatever they wanted to read about in the threads. Thus, there was no reason to ask the same question again, and the interaction therefore diminished over time:

> "I haven't used it that much, but I mainly read the old threads where people had written something, and then people have answered it. I used it once a week in the beginning, but after reading all the threads, my use of it decreased. There weren't that many new things in there so often, so I didn't really have a need to go in there and read." (AYA49)

Additionally, the declining interaction made several of the participants think that the social forum was too quiet and nondynamic. Thus, some of those who were affiliated with a hospital ward with its own closed Facebook group preferred to use those groups instead. They were described as more vibrant and active, and the tone was more relaxed and characterized by everyday speech, more than formalized answers and questions.

Discussion

In this study, we explored AYAs' with cancer and AYA cancer survivors' use of the Kræftværket app's social forum and experiences of peer communities in the forum. The study builds on results of questionnaire responses and short follow-up telephone interviews.

Frequency of app use showed that "a couple of times per week" got the highest score, ticked by 37% participants, followed by "once or twice during the 6-week test period" reported by 27% participants. Only 11% used it one or more times per day. This indicates that, to most participants, the app was not an everyday tool, which is in line with previous findings.[25] There was a clear tendency for female participants to use the app more than male participants. The difference in app use between young men and women was a clear tendency throughout most of the responses in the questionnaire; women were more active users than men. Similar gender differences in use of eHealth technology and engagement in app communities are confirmed by other studies.[29,30]

In terms of treatment status, no clear differences were registered regarding participants currently receiving treatment versus those receiving follow-up care. In most cases, the differences were less than 10%. One exception, however, was assessment of the social forum's relevance, where only 5% of AYAs on treatment rated it as not relevant compared with 29% of AYAs in follow-up care. This is in accordance with findings from the telephone interviews, where several participants in follow-up care explained that the forum would have been more relevant to them at time of diagnosis.

In turn, major differences were seen in the group in follow-up care—40% used the app only once or twice during the 6-week period, while another 40% used it a couple of times per week. Also, regarding assessment of the social forum's relevance, those in follow-up care had divided opinions: 29% rated it as not relevant; however, the other 60% rated it as relevant. This difference may reflect findings from the telephone interviews, which pointed to a discrepancy between, on the one hand, AYA cancer survivors' desire to return to a normal life after cancer and, on the other hand, some AYAs' need for peer support during their return to a normal life.[31–33] The sustained need for support was further confirmed by 26% of participants in follow-up care, who believed they would continue to be a part of the forum after the follow-up period.

In line with neo-tribe theory, the peer community was temporary and noncommittal.[26] Thus, 97% did not form any close relationships with others, and 71% did not expect to become part of a community privately after deletion of the app. However, also in line with neo-tribe theory, the peer community was strong during the time the app was used, even though the use was sporadic. A total of 94% read others' posts, and 93% experienced that the users helped each other with tips and advice. Only 37% wrote questions or answers in the social forum, which can be explained by the experience of thematic saturation in the threads, as elaborated in the telephone interviews, or the feeling of having to be able to write about certain cancer experiences. Thus, the engagement, experience of safety, and togetherness, as expressed in the telephone interviews, was present, although most of the participants were not active in writing posts themselves. Peoples' experience of connectedness and empathy in online cancer forums is supported by other studies.[34,35]

Compared with 58% of the men, 77% of the women experienced a sense of community with the other AYAs. Additionally, 69% of women and 42% of men experienced a sense of community with the other AYAs, which they did not experience with their own peers, and this difference was even more prominent in women currently receiving treatment, 70%, in contrast to men currently receiving treatment, 27%. There may be several explanations for these major gender differences, for example, general differences in needs and preferences between men and women in cancer care.[36] Also, in the telephone interviews, some men described having a strong network of peers who helped them through the period of cancer. The AYAs' experience of a peer community with other AYAs was described as a mutual understanding of each other's situation—like being in the same boat—which increased the feeling of normality and reduced loneliness.[14,25] In accordance with neo-tribal storytelling, the AYAs exchanged knowledge, medical information, life experiences, and advised each other. Thus, 59% recognized something from other AYAs' stories that had made them more comfortable during their cancer trajectory. A total of 30% more women than men currently receiving treatment felt supported by others' stories.[36]

Of the participants, 26% reported having used cancer communities on Facebook, among them the hospital cancer wards' own closed Facebook groups. Some of the participants experienced the closed Facebook groups to be more personal, vibrant, and dynamic than the app. The reasons were that they often knew the other users from the ward, the interaction in the Facebook groups was more like speaking face to face, and they all received answers to their questions quickly. Other patients have given similar, positive feedback on closed Facebook groups.[37] In our study, the contact with the other users in the app was perceived to be more distant, and one reason for this seemed to be the possibility to create an anonymous profile, which some thought made the contact more superficial. This aspect is supported by another study on AYAs with cancer.[20] Additionally, 81% of the participants in our study believed that they had not been in contact with AYAs from other parts of the country, and several participants explained that they did not know how to find out where others were from, and it did not concern them either. However, many AYAs appreciated the social forum as a broad community because it increased the feeling of being in the same situation as many others, and it constituted a highly valued information source.

Regarding sub-communities in the app, 44% did not know whether it was possible to communicate with AYAs with the same diagnosis. The telephone interviews highlighted that, to most of the participants, specific diagnoses were not relevant to enter a rewarding peer community because, instead, it was fear of death and being put behind in future plans that were shared by most participants.[38] However, some participants with rare diseases felt there was a lack of diagnosis-specific threads. More prominent was the importance of age in the experience of peer communities. In all, 71% ticked that age was important to them, and 20% more women than men experienced age to be essential. Also, age mattered to 21% more men in follow-up care than those currently receiving treatment. The telephone interviews did not ascertain the reasons for these differences. However, in line with other research, many stated that they emphasized the value of being able to communicate with young people of their own age because they experienced completely different challenges than older people with cancer.[8]

It is worth noting that commitment to the Kræftværket app's social forum also differed from neo-tribe theory in one aspect, in that no one had a wish to become part of it. Some of the participants were even so uncomfortable reading the posts that they did not want to engage with the forum at all. Several participants explained that they longed for their normal life. Thus, searching for an identity-forming community as described in neo-tribe theory was not what they were looking for.[26] This is in line with research showing that AYAs with cancer seldom have a wish to identify with their disease.[39]

Limitations

Possible limitations should be considered. The study was conducted during the COVID-19 pandemic, which have may impacted the AYAs' use of mobile technology. We know from the users of the physical room Kræftværket that they were keen on using social media to keep in contact with peers during the first lockdown in Denmark. However, we also know that they began to feel virtual communication strain in maintaining electronic contact during the second and final lockdown. Thus, as this present study was carried out during the second lockdown, it may have affected the AYAs' use of the Kræftværket app during the 6-week test period. Another limitation may be the questionnaire construction. Dichotomous questions limit deep interpretations and often force the participants to decide on an option that does not truly reflect their feelings. To overcome these limitations, follow-up telephone interviews were conducted.

Nursing Implication

The results of this study are highly relevant to health professionals in the planning and development of eHealth cancer apps in collaboration with an AYA target group, and with a view to strengthen peer-to-peer relationships in AYAs with cancer. The app meets AYAs' needs and wishes for age-appropriate cancer support, which can be implemented and provided by nurses.

Conclusion

In this study, we found that the Kræftværket app's social forum functioned as a virtual and temporary peer community for AYAs in a cancer trajectory, and it was meaningful for most of the participants during the time it was used. The peer community helped to reduce loneliness and increased the feeling of togetherness. Being of the same age strengthened the peer community and experience of being in the same boat with like-minded peers. There were no specific communities related to diagnosis or gender, which some experienced to be a disadvantage. In general, the social forum was of great importance to both newly diagnosed AYAs and AYAs in follow-up care; however, there was a disparate picture of how AYAs in follow-up care used the app and how often they used it. The study also showed significant gender differences, in that women were more active and diligent users than men.

Declaration of Competing Interests

None.

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