"I Always Asked a Lot of Questions"– The Information Journey of Young Adults with Cancer in Germany

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Abstract. About 19.3 million people are newly diagnosed with cancer each year, but only a small percentage of all diagnoses refers to young adults (18 - 39 years). Therefore, they are often not focused on within the healthcare infrastructure, although they have age-specific information, care and service needs. This results in difficulties that will be examined in this article concerning the information journey of the target group. Based on fourteen semi-structured qualitative interviews, this article describes the use of information sources during the cancer patient journeys of young adults. Furthermore, it describes problems the target group experiences. The data indicate that young adults, regardless of whether they actively seek information or rarely seek information at all, often have to rely on serendipity to obtain helpful information. Furthermore, problems regarding the reliability of information sources have been identified and information relating to non-medical needs must be sought autonomously, which results in overload and uncertainty. For the circumvention of these difficulties, improvements are needed in the provision of information for young adults. The knowledge about validated information sources would support the information journeys during their cancer patient journeys.

Keywords: Health information behavior · Information journey · Young adults with cancer · Information seeking · Patient journey

1 Introduction

Every year about 19.3 million people are newly diagnosed with cancer and according to latest calculations in 2020, 9.96 million people will die because of this disease [26]. In Germany, 16.500 young adults are newly diagnosed with cancer each year [21, 40]. These are only 3.3% of all new diagnoses. Even though the target group gets more attention during the final years, there are still occurring problems and difficulties that need to be addressed.

The German health infrastructure often pairs young adults together with adolescents or older adults, which have both age-specific characteristics that do not match the characteristics of this target group [13]. Especially young adults are going through a transition phase, which includes social, mental and physical aspects. Therefore, a diagnosis of a

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life-threatening disease as cancer during this phase strongly influences the individual, and results in special information, care and service needs [6, 13, 32, 34, 47]. If those needs are not met, they experience difficulties coping with the disease and its influence on their every-day lives [18, 28]. Further the information seeking behavior of young adults during their cancer patient journey is affected by the lack of available useful information specified for their age-group. This is affecting the accessibility of helpful information during the cancer patient journey [13].

This article is based on the research data of Bressel [12], who conducted 14 semi-structured guided interviews with young cancer patients regarding their information needs. The dataset also contains insights in the information seeking behavior of young adults in Germany during their cancer patient journey, which have not been analyzed before and therefore are part of this article. To understand the information seeking behavior of young adults with cancer during their patient journey and furthermore occurring problems and difficulties, the research questions for this article are the following:

1. Which information sources do young adults with cancer in Germany use during their information journeys at different stages of their cancer patient journey?
2. Which problems and difficulties occur during their information journeys?

Even though the information seeking behavior of young cancer patients is no new research field, this target group is still not treated as a separate patient group in the German health infrastructure. By focusing on used sources and specific stages in which problems regarding information seeking occur, this paper enables insights into specific needed improvements regarding young adults with cancer.

2 Background

2.1 Information Seeking of Young Adults with Cancer

Young adults (YA) are individuals between the age of 18 to 39 [6, 13, 16, 22, 33, 45]. Due to their age, YA are at an unsettled stage of their life, which is dominated by emotional, physical and social changes [5–7, 13, 46].

Especially in this phase, a cancer diagnosis and the subsequent time during treatment and aftercare influences one's identity by taking away crucial elements or changing them through new disease-related circumstances [6, 7, 28]. For YA a cancer diagnosis results in information, service and care needs in ten areas. Those areas include organizational and financial needs, questions regarding the disease itself (diagnosis, prognosis, rehabilitation, and aftercare) and its influence on health practices, fertility, mental health, and the social context [13].

In medical studies, the information seeking of young adults was already researched with focus on specific sources such as the internet, social media and social networking sites [4, 15, 16, 24, 36] or the general preferences of YA and adolescents regarding digital technologies [1]. Boakye et al. [10] moreover compared the health information seeking of adults with and without cancer, where they focused on demographic differences, sources, and topics. Furthermore Germeni et al. [23] identified that research on the information seeking behavior of sick individuals should always include research on information avoidance, because of the correlation of their behaviors in the role of informed patients.

Separate from the target group, research exists about the usage of different channels and sources during a cancer disease [8, 27, 29, 30, 41, 44]. It is known that the use of information sources depends on demographic factors such as age, level of education and income [41].

In addition, individuals with a disease tend to consult interpersonal channels. For medical questions, the first source is family and friends and if the information need is not fulfilled, they consult health professionals [27]. Nevertheless, health professionals, especially doctors, are seen as an authority, depending on the reliability of answers. Regardless, patients tend to seek answers on the internet before consulting health professionals, because it seems to be more credible and able to equalize deficits of doctors in real life [8, 44].

2.2 The Information Journey vs. The Patient Journey Model

In 2005, Adams and Blandford defined the information seeking behavior in the health and academic sector as an information journey. This model consists of three stages: information initiation, information facilitation and information interpretation.

Information initiation is the first stage of the information journey, in which external factors initiate the requirement for information actively throughout a task (e.g., supporting a sick relative) or passively by a person or situation (e.g., receiving a cancer diagnosis). Information facilitation marks the second stage of the information journey, and contains the information retrieval aspects of the information seeking process. The information is sought actively with the help of information systems, or persons relevant to the recognized information need (e.g., consultation by a doctor). The last stage of the original model, the information interpretation, is defined by the process of interpreting the information based on a specific context [2]. Especially in the health context the interpretation process is supported “by someone or some system” to help the following decision-making process (e.g., starting treatment) [3].

Nguyen et al. [39] expanded the information journey in their article about information needs of family carers in collaborative healthcare to another stage of the information journey. Their four-stage journey model consists of three similar stages to the original model (identification, searching, interpretation), and one added stage, the information sharing. This new stage was invented because the sharing process was identified as an important step in a collaborative context, especially if not only the patient but also the carer is involved in the information journey during diseases.

In a non-health-related sector, Du [17] also introduced an information journey. She described the information journey of marketing professionals as determining the work task-generated information need, information seeking, judging, and evaluating the information, sense-making and information use as well as information sharing.

In 2010 a new expanded version of the original information journey by Adams & Blandford [2] was invented. This new version additionally contains the use of the interpreted information as fourth stage (see Fig. 1).

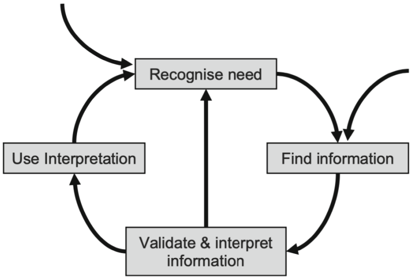


Fig. 1. Extend information journey model by Blandford & Attfield [2]

This fourth stage includes the usage of the previously interpreted information based on the subjective context. Thus, further information journeys can arise if more information is needed or if the information previously interpreted as useful turns out to be unhelpful for the personal context.

Especially papers in the health sector use the term journey as well to describe experiences and processes of individuals affected by a disease. They refer to different stages patients go through during the experience of a disease. Instead of stages related to information processes, which are described in the information journey model, these models describe the behavior of affected individuals during their disease. The concept behind is often referred to as patient journey [11]. In the cancer research field, it was used to analyze unmet information needs of cancer patients of all ages at different stages of their patient journey [25, 31, 35, 37, 43] and information needs of young adults with cancer [13]. It was also used to understand the uncertainty of patients while receiving information during their cancer patient journey [38] and to analyze the information seeking and avoidance behavior of cancer patients [23].

Regarding Bressel [13] the cancer patient journey (CPJ) of YA is divided into two cycles. The main journey, containing the diagnosis stage, treatment stage and aftercare stage and the extended journey containing a longer treatment stage before the aftercare stage is reached (see Fig. 2).

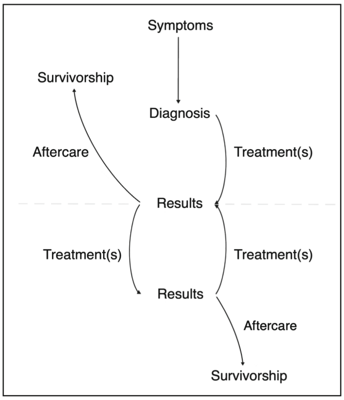


Fig. 2. The cancer patient journey model by Bressel [13]

During each stage of the CPJ, patients go through several information journeys. They have information, service, and care needs in ten different areas [13]. Each of these areas lead to information requirements, which are followed by information journeys. This paper focuses on these information journeys and defines difficulties YA face.

3 Method

3.1 Dataset

The dataset for this study was collected in November and December 2020 for another study to analyze the information needs of YA with cancer in Germany. The dataset contains 14 qualitative semi-structured interview transcripts. The interviewed YA were affected by eight different diagnoses at the end of their treatment, or while already in aftercare (see Table 1). All participants were treated in Germany and the interviews were conducted in German. The transcribed interview data shows clearly that information needs are connected to the information seeking behavior of YA with cancer, and that an analysis of the information seeking behavior based on this dataset would be valuable.

3.2 Analysis

To answer the first research question, the interview transcripts were coded by a deductive approach, based on the identified stages of the CPJ [13] and all infrastructures, sources, and services, named by the participants. For the second research question, the dataset was coded inductively by concentrating on difficulties and problems YA experienced while seeking information at different stages of their CPJ. All quotes were translated from German to English after the analysis.

4 Results

4.1 The Accepting vs. The Active Seeking Behavior

During their CPJ, YA go through numerous, heterogeneous information journeys which correlate with their information needs and result from the subjective context of the YA. Because of the small number of patients affected, available information in sources such as the internet or literature often represents older age groups with different needs. In addition, the information that is available is often general and not adaptable to their situations (P3, P12, P13) or medical jargon and foreign languages complicate the understanding (P4, P5).

> "*I mean, you get your blue books from cancer support. But you can as well put them in the garbage or use them as barbecue lighters. It contains general stories but nothing that would have helped me at the moment.*" (P13)

Table 1. Information about the sample

Age (Diagnosis)	Cancer type	Subtype	Comment
35	Breast cancer	Triple negative mammary carcinomy (genetic)	Pregnant during treatment
34		Specific diagnosis unknown	
28		Specific diagnosis unknown	
22		Specific diagnosis unknown	
35 (1) 38 (2)		Hormone-positive mammary carcinoma (1) Triple negative mammary carcinoma (genetic) (2)	Initial diagnosis (1) Second diagnosis (2)
33		Hormone-positive mammary carcinoma + Liver metastases, Lung metastases	Incurable due to spreading
34	Brain tumor	Glioblastoma	Incurable
40		Anaplastic astrozytoma (sinistral)	
25	Testicular cancer	Testicular carcinoma (unilateral)	
27	Thyroid cancer	Papillary thyroid carcinoma + Metastases + Lymphatic gland	
18	Bone tumor	Ewing's sarcoma (scapula unilateral)	
33	Lymphoma	Hodgkin's lymphoma	
32	Uterus cancer	Endometrium carcinoma	
39	Salivary glands cancer	Mucoepidermoid carcinoma	

Helpful information about YAs information, care or support needs are often hard to discover, which impacts the information interpretation negatively and results in two information behaviors: the accepting behavior vs. the active seeking behavior.

Regarding the data, this distinction especially appears related to diagnosis-, fertility- and prognosis-related questions during the diagnosis stage. While some participants mention that they have no intention to seek information and are satisfied with the information handed to them by health professionals (P1, P2, P3, P6, P8, P9, P14), others seek extensively (P4, P10, P11, P13) as explained by P13:

> *“Maybe someone who is 60 is more likely to say: Yeah okay, I’m going to do what the doctors say. But I think it’s the young people, and I’m one of them, who really have to figure it out for themselves. Looking for something else, like alternatives, right?”* (P13)

> “*Of course, I have asked doctors and nurses a lot, also in the doctor’s meetings and with the gynecologist. I always asked a lot of questions. […] So, I always made sure that I got rid of a lot of questions and actually got lots of answers.*” (P10)

Primarily the active information seeking process leads to the extension of the patient’s state of knowledge, which is needed for meaningful decisions during the interpretation stage. Especially if information needs are answered by different sources and second opinions, the final interpretation remains with the YA, what for some young patients results in overload (P1, P11, P13).

Accepting behavior on the other hand can cause the same result after the initiation stage. Patients don’t know how to answer their information needs (P1, P2, P6, P9, P14), feel left alone by their doctors (P4, P5, P7, P8, P9) or can’t understand or follow fast explanations of complex medical information (P2, P8, P9, P10, P12, P12, P13, P14). This feeling of overload can further result in information avoidance, as P9 explains:

> “*It’s difficult to keep yourself informed about all the things they tell you and what they do to you. You can’t research all of it, and at some point, you just don’t want to research it. Yeah, I think you just don’t want to.*” (P9)

In some cases, the seeking behavior of YA changes during the CPJ. For example, the diagnosis stage is characterized by little knowledge about cancer and associated needs. Reaching aftercare, patients gain knowledge through their experiences. For some YA this leads to a shift from accepting behavior to active seeking behavior, because they are finally able to understand the given information better based on their experiences, which simplifies the information interpretation (P4, P6, P7, P8, P9, P14).

4.2 Use of Sources During Information Journeys

The use of sources during information journeys of YA with cancer is connected to the subjective context of the patients. Differences were recognized regarding the motivation to seek information based on identified information needs within the initiation stage, as well as the choice of sources during the facilitation stage.

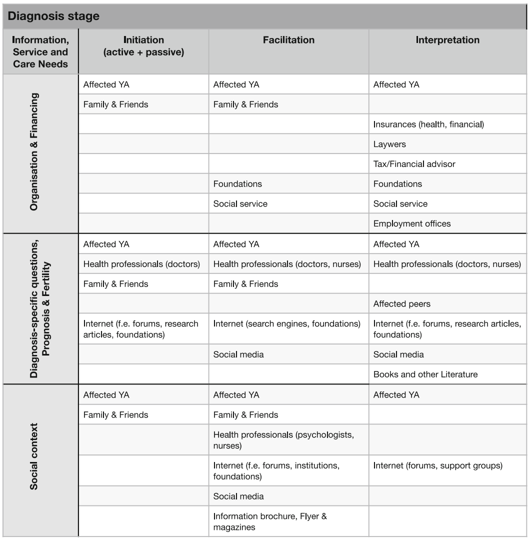
The lack of motivation to start an information journey can have various reasons concerning the personal context and subjective preferences of YA. The choice for sources to seek information during the facilitation stage is often connected to the topic for which information is required, the YA’s state of knowledge, personal preferences, and available resources.

The following tables depict the summary of all sources used by YA with cancer during their cancer patient journeys. The structure inspired by Adams et al. [3] includes three stages: *initiation*, *facilitation,* and *interpretation* (see Tables 2, 3, 4). The fourth stage *use* was omitted because it only includes the affected YA, but no other sources. The sources are assigned to the information needs of YA with cancer identified by Bressel [13].

Adams et al. [3] identified information facilitation as when "someone or some system facilitates required information retrieval" (p. 114). For this reason, the column *facilitation* does not include sources where YA sought and found needed information but sources which supported the seeking process. The last column *interpretation* includes sources, which supported YA interpreting the information.

The dataset includes total answers from 14 participants. This sample indicates sources which are used during the information journey of YA with cancer. Nevertheless, it is not a statistically proven overview of sources and cannot represent indicators of the frequency of use. For those results, another quantitative study could be carried out based on this study.

Table 2. Sources of the information journeys during the diagnosis stage

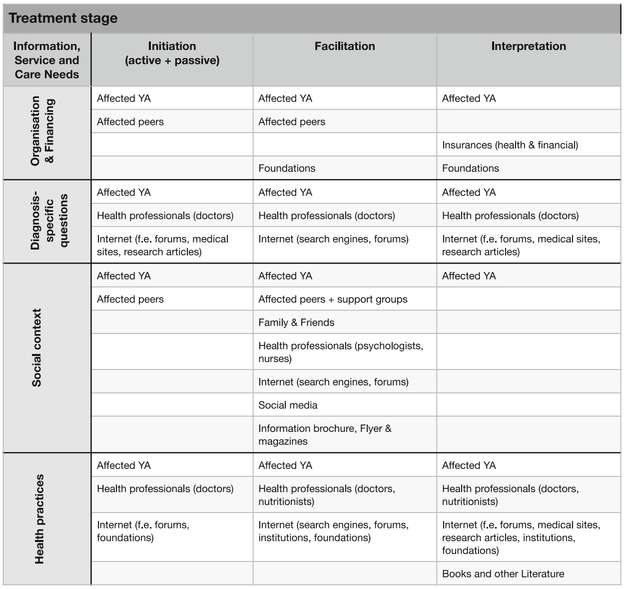


Diagnosis stage			
Information, Service and Care Needs	**Initiation (active + passive)**	**Facilitation**	**Interpretation**
Organisation & Financing	Affected YA	Affected YA	Affected YA
	Family & Friends	Family & Friends	
			Insurances (health, financial)
			Laywers
			Tax/Financial advisor
		Foundations	Foundations
		Social service	Social service
			Employment offices
Diagnosis-specific questions, Prognosis & Fertility	Affected YA	Affected YA	Affected YA
	Health professionals (doctors)	Health professionals (doctors, nurses)	Health professionals (doctors, nurses)
	Family & Friends	Family & Friends	
			Affected peers
	Internet (f.e. forums, research articles, foundations)	Internet (search engines, foundations)	Internet (f.e. forums, research articles, foundations)
		Social media	Social media
			Books and other Literature
Social context	Affected YA	Affected YA	Affected YA
	Family & Friends	Family & Friends	
		Health professionals (psychologists, nurses)	
		Internet (f.e. forums, institutions, foundations)	Internet (forums, support groups)
		Social media	
		Information brochure, Flyer & magazines	

As said earlier, the information journeys of YA with cancer are individual and depend on the subjective context of the patients. The tables represent all sources named by the participants, but not all patients have the same possibilities. The interview data clarified that often, except for diagnosis and prognosis-related questions, young cancer patients must depend on themselves.

As seen in the tables above, the number of sources for the facilitation differs regarding needs. Information on organizational and financing needs is distributed over various sources such as insurances, layers, foundations or social service. These information sources can interpret information regarding the individual case of patients, but the YA first need to find these appropriate sources during the facilitation stage. However, this process is often complicated by the fact that patients do not know who to turn to with these

Table 3. Sources of the information journeys during the treatment stage



Treatment stage			
Information, Service and Care Needs	**Initiation (active + passive)**	**Facilitation**	**Interpretation**
Organisation & Financing	Affected YA	Affected YA	Affected YA
	Affected peers	Affected peers	
			Insurances (health & financial)
		Foundations	Foundations
Diagnosis-specific questions	Affected YA	Affected YA	Affected YA
	Health professionals (doctors)	Health professionals (doctors)	Health professionals (doctors)
	Internet (f.e. forums, medical sites, research articles)	Internet (search engines, forums)	Internet (f.e. forums, medical sites, research articles)
Social context	Affected YA	Affected YA	Affected YA
	Affected peers	Affected peers + support groups	
		Family & Friends	
		Health professionals (psychologists, nurses)	
		Internet (search engines, forums)	
		Social media	
		Information brochure, Flyer & magazines	
Health practices	Affected YA	Affected YA	Affected YA
	Health professionals (doctors)	Health professionals (doctors, nutritionists)	Health professionals (doctors, nutritionists)
	Internet (f.e. forums, foundations)	Internet (search engines, forums, institutions, foundations)	Internet (f.e. forums, medical sites, research articles, institutions, foundations)
			Books and other Literature

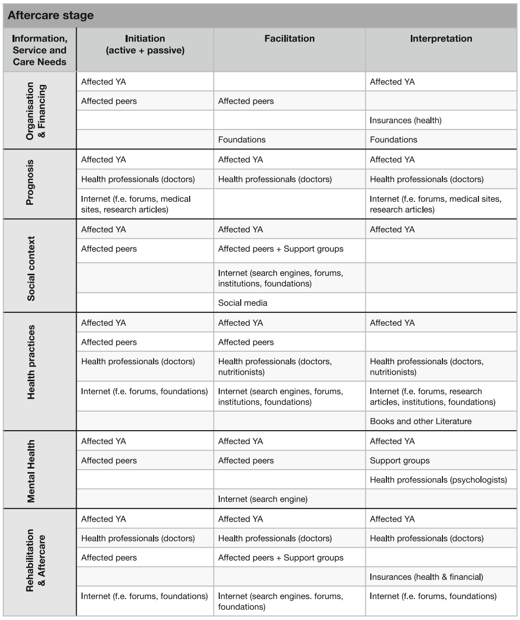
questions. Unhelpful sources delay receiving useful answers, and can lead to reduced motivation to further seek information. Although this stage is supported by some sources, such as family and friends or sometimes from foundations or social service, in general YA have to handle this situation on their own.

Diagnosis-specific information needs are present during the whole cancer patient journey. The main source at all stages of the information journey is health professionals, who initiate the information journey and support the seeking process by providing and searching for helpful information. Afterwards, they interpret the information and adapt it to the individual cases so that YA can use it. Even though some individuals still seek second opinions (P1, P5, P10) or information elsewhere before trusting the interpretation (P4, P9, P11, P12, P13), most participants are satisfied and pleased with the support of health professionals during their information journey.

The situation is different with the use of the Internet. Some respondents frequently consult the Internet to seek information via forums or support groups (P3, P4, P6, P7, P13). Other respondents generally do not trust the Internet or feel that the information is not appropriate to their own situation. For this reason, they avoid or question this source regarding most information needs (P1, P8, P9, P10, P11, P12). Nevertheless, the Internet was mentioned for almost all needs and thus is frequently used.

In conclusion, there are existing sources which can support the facilitation and interpretation stage of the information journeys of YA with cancer. Different contexts affect the use of sources, which leads to heterogeneous facilitation processes. Likewise, the accessibility of sources, which support the interpretation process is affected (see Tables 2, 3, 4).

Table 4. Sources of the information journeys during the aftercare stage



Aftercare stage			
Information, Service and Care Needs	**Initiation (active + passive)**	**Facilitation**	**Interpretation**
Organisation & Financing	Affected YA		Affected YA
	Affected peers	Affected peers	
			Insurances (health)
		Foundations	Foundations
Prognosis	Affected YA	Affected YA	Affected YA
	Health professionals (doctors)	Health professionals (doctors)	Health professionals (doctors)
	Internet (f.e. forums, medical sites, research articles)		Internet (f.e. forums, medical sites, research articles)
Social context	Affected YA	Affected YA	Affected YA
	Affected peers	Affected peers + Support groups	
		Internet (search engines, forums, institutions, foundations)	
		Social media	
Health practices	Affected YA	Affected YA	Affected YA
	Affected peers	Affected peers	
	Health professionals (doctors)	Health professionals (doctors, nutritionists)	Health professionals (doctors, nutritionists)
	Internet (f.e. forums, foundations)	Internet (search engines, forums, institutions, foundations)	Internet (f.e. forums, research articles, institutions, foundations)
			Books and other Literature
Mental Health	Affected YA	Affected YA	Affected YA
	Affected peers	Affected peers	Support groups
			Health professionals (psychologists)
		Internet (search engine)	
Rehabilitation & Aftercare	Affected YA	Affected YA	Affected YA
	Health professionals (doctors)	Health professionals (doctors)	Health professionals (doctors)
	Affected peers	Affected peers + Support groups	
			Insurances (health & financial)
	Internet (f.e. forums, foundations)	Internet (search engines. forums, foundations)	Internet (f.e. forums, foundations)

4.3 Issues During Information Journeys of YA with Cancer

The analysis of the information seeking behavior of YA with cancer regarding the information journey model has shown that there are potentially sources to help YA during the facilitation and interpretation stage. The main problem however is the knowledge about the existence of information for their needs and about helpful and valid sources (P2, P3, P4, P5, P6, P7, P8, P10, P14). In particular, this affects needs regarding organizational and financial needs, health practices and aftercare. Regarding these topics, YA feel left alone during the facilitation stage and are dependent on themselves to find helpful and reliable information (P3, P4, P5, P6, P7, P8, P10, P11, P12, P13, P14).

> "*I did it all myself. […] Unfortunately, you are left alone completely.*" (P14)

Even infrastructures and services that are supposed to support the facilitation (e.g. social services) often do not fulfill this task, which exacerbates the problem (P4, P6, P7, P8, P12, P13). The only exception is the *German Foundation for young adults with cancer* (P8, P10, P12, P13).

> "*I've also had the experience that the social service in the hospital was a joke. First of all, it was never available. […]I researched all that on my own. I tried to call the woman ten times to ask her if she could help me. […] I never spoke to the social worker, because I never reached her.*" (P4)

> "*And what I also disliked at that moment was that you had to check out everything individually. […] I also ask myself how people manage that! Well, I had my husband, who intercepted a lot of these material questions. But others, no idea how they manage that.*" (P11)

The consequence of this is a negative influence or even a discontinuation of the information journeys, as some YA are not able to facilitate helpful sources parallel to side effects of their disease and treatments (P1, P7, P14). This difficulty, combined with contradictory information, which further complicate the interpretation stage, results in overload and insecurities (P1, P5, P6, P7, P8, P9, P14). For some patients, this leads to information avoidance during the diagnosis and treatment stage of their CPJ (P1, P2, P7, P9, P14).

> "*And once you start looking, you get endless information that is also completely contradictory. The doctor tells you that you need nutritional supplements for your body to be in good shape. But a film on the internet about breast cancer patients from a senologist says you should be careful with nutritional supplements: they can be life-shortening under certain circumstances. And then you are there as a cancer patient who wants to do everything to survive, asking: What do I do now?*" (P6)
>
> *"Chemotherapy can also restrict brain abilities, this chemo brain. And then making a selection was sometimes super difficult for me."* (P8)

Information journeys regarding all CPJ-related information needs are influenced by experiences of YA. The increasing state of knowledge leads to the ability to better understand the information regarding the disease and related needs over time (P1, P2, P6, P8, P9, P14). Further, a subjective trust-building process regarding reliable and helpful information sources develops. In retrospect, this can result in the feeling of disappointment, or the wish for more knowledge from the beginning.

> "*If you have questions, you could ask them. But it just goes on for an hour and then he already looks at the clock, because then he has to go to the next appointment. But you can ask questions and they are also more or less answered. But afterwards, you actually have completely different questions. Or partly completely different questions, right? I could always ask only from surgery to chemo to radiation. My knowledge or my attempted knowledge. And now, in retrospect, I would just ask completely different questions, because it's just clear what's happening.*" (P9)
>
> "*The bottom line is that I realized I was getting good therapy. […] But in retrospect, with all the experience I've had, I would have arranged the course of therapy differently.*" (P4)

Another aspect that became apparent from the data was the serendipitous reception of information. This concerns the topics of aftercare, social context or organization and finances (P4, P5, P7, P10, P11, P12, P13). In contrast to the information journey by Adams and Blandford [2], in which the starting point is the initiation, information journeys of YA with cancer often start during the information interpretation. They receive information serendipitously or by seeking information for other needs (P1, P4, P5, P7, P8, P10, P11, P12, P13), often through contact with peers (in person, via the internet or social media) (P4, P5, P7, P10, P11, P12).

By interpreting the information based on their subjective context, they recognize the importance for themselves, and they start the fourth stage of the information journey (P7, P9, P10, P13). If the information is not usable, but they recognize an information need based on the information found, a new information journey starts with the information initiation. One difficulty is that especially YA who have no contact with peers in the same situation and who do not receive this serendipitous information, can only act based on their own experiences, which results in limited sources for the interpretation (P1, P2, P7, P14).

Regarding the last stage of the information journey, the information use, some YA expressed the desire to share their experiences and gained knowledge based on their information journeys to help peers during their CPJ or to process their experiences (P3, P4, P8, P12, P13, P14).

5 Discussion

The analysis of the information seeking behavior of YA with cancer in this study indicates a dependence on sources and topics similar to Boakye et al. [10], as well as on the subjective context of this heterogeneous target group. In contrast to Abrol et al. [1], who said that digital resources potentially improve the experience and engagement of patients, this study identified an ambivalence toward the internet and social media. The difference in both studies is the age of the target group. This affects the success of the seeking behavior of patients. While adults in general can find more information online, unless they are diagnosed with rare cancer types, the needs of YA are more specific. Available information online is often too general or poorly adapted to age-related needs and should be adapted more to the information needs of YA, as already mentioned by Mooney et al. [36]. Additionally, health information literacy is not always present in (young) patients, complicating the selection and finding of needed information online [24].

For the information interpretation of medical, organizational and financial needs, YA tend to consult interpersonal sources first. Similar to Tustin [44], Johnson & Case [27] and Bertelsmann Foundation [8], health professionals are the most important and credible source for medical needs during their whole information journey. In contrast to earlier studies, YA seek information from health professionals during the whole CPJ first, before seeking answers on the internet [8, 44]. This is due to the trust in the competence of health professionals and uncertainty regarding the validity of information from the internet regarding medical needs and health practices.

In the information behavior field, Lambert et al. [29] identified understanding and acceptance concerning the amount of their information seeking behavior, explained as "playing my part and taking care of myself" (p.15). This acceptance was identified regardless of diagnosis, sex, education, or seeking behavior. A distinction regarding age is not further analyzed. In contrast, the YA of this study were overwhelmed by the amount of information-linked responsibility on them. For them, their part is often too much and sometimes not manageable, which affects organizational, financial and social during the beginning and end of their CPJ. Medical needs are excluded, because they are already answered sufficiently by doctors and health professionals. This comparison supports the need to distinguish between YA and older patients in healthcare and research.

Based on the data, validating the information and sources is the first main problem, which results in uncertainty and the feeling of overload in terms of organizational and financial needs, health practices and aftercare. The amount of information, which YA must actively seek from various sources, sometimes results in information avoidance. This was also indicated by Chae et al. [14], Germeni et al. [23] and Serçekus et al. [42]. Accordingly, the concept of the informed patient [23] and its impact on sick individuals, in addition to the effects of their treatments, should be further explored to avoid a negative impact on YA's CPJ.

The second main problem of YA is their lack of knowledge about information and information sources for needs they are not aware of. YA often are dependent on getting information serendipitously, instead of any active seeking behavior. This was also explained by Lambert et al. [29], who identified, that sick individuals start the information exchange with other patients in information grounds as waiting and treatment rooms or support groups [20] whereby serendipitous information is received. In terms of YA, the main difference is the dependency on this information exchange, which is further complicated by little contact to peer in the German health infrastructure.

In particular, this affects needs for aftercare, social context or organization and finances. Sometimes information needs are not recognized by YA until they happen to receive helpful information, such as already explained by Bressel [13]. Regarding the information journey, this causes the lack of two stages of the information journey by Blandford and Attfield [9]. Since the interpretation of serendipitous information starts immediately, the information initiation and facilitation stage fail to occur. However, this implies that not all YA with cancer will receive the same helpful information, which affects the satisfaction and experience during their CPJ. Especially if they have no contact with affected peers or do not actively seek.

To overcome these two problems, YA with cancer in Germany need informative support. Already in 2010, Ferrari et al. discussed the ideal support program for YA with cancer [19]. While Australia, Canada, the United States, the United Kingdom and some Scandinavian countries developed specialized programs for YA and adolescents, Germany barely progressed in this area. Only some sources and infrastructures exist for YA. The *German Foundation for young adults with cancer* and the *University Hospital Cologne* are two examples, which meet some wishes for improvement of YA [13]. The foundation website provides guides for all stages of the CPJ and serves as an information platform. The hospital conducts a survey at the diagnosis stage, to identify mental health, organizational and social service needs. Nonetheless, the data implies that YA, who are not treated at advanced hospitals or get provided with information about the foundation at the diagnosis stage, do not benefit from these offers. To overcome this, information sources such as the foundation website should be actively communicated to the YA by a trusted source at the beginning of their CPJs. Ideally, this would be health professionals, who consult with the YA during their diagnostic phase and who are assessed as trustworthy, based on the data, as well as on Tustin [44], Johnson and Case

[27] and Bertelsmann Foundation [8]. Thus, the information journeys of YA with cancer would be supported by simplifying the information facilitation by one reliable source, substantiating the interpretation with age-related information and in the end simplifying the information use.

5.1 Information Sharing Behavior of YA with Cancer

The data indicates prospects about the information sharing behavior of young adults with cancer. As mentioned before, some patients verbalized the desire to share their experiences and knowledge with affected peers, to help them during their CPJ. This implies an extension to the form of information sharing, for the information journey, similar to Ngyuen et al. [39]. The difference with their paper is the integration of information sharing as the fourth stage of the information journey. This is because sharing behavior is fundamental during the information journey of carers for sick individuals. For YA, the sharing behavior includes the desire to share experiences and acquired knowledge after they have gone through their CPJ, as distinguished from the exchange in support groups during aftercare. Accordingly, it remains to be discussed whether this process should be considered part of the information journey at all, or whether it represents a separate information phenomenon.

More research on reasons behind the information sharing of young adults with cancer or other life-threatening diseases, the positive and negative impact or the motivation to help peers could provide interesting results. Especially since this and previous studies have recognized that YA receive helpful information primarily from peers, since they receive only limited official information relevant to them [f.e. 30].

6 Limitations

Even though the dataset was conducted in November and December 2020, the data still represents current experiences and opinions about the German health infrastructure. Since then, few changes have been initiated to the health care system, with the exception of the project-based informational and service-oriented expansion of the *German Foundation for young adults with cancer*.

7 Conclusion

The goal of this study was the analysis of the information seeking behavior of YA with cancer in Germany based on the information journey model by Blandford and Attfield [9]. Two research questions were addressed. First, which information sources do young adults with cancer in Germany use during their information journeys at different stages of their cancer patient journey? Second, which problems and difficulties occur during their information journeys?

YA go through numerous information journeys during their CPJ, for which they consult various sources. A distinction can thereby be made between the accepting behavior and the active seeking behavior. It is impossible to draw a general conclusion about the sources used by all YA, based on this qualitative study approach. The selection depends on a subjective context and the individual access or the availability of sources. Nevertheless, three tables with all named sources consulted by the participants of this study have been created. From these tables, indications of frequently sought sources can be made. The amount of existing sources and the number of sources used, varies depending on the needs. Affected are the information facilitation and interpretation during an information journey.

Concerning the second research question, two main problems were identified, during the information journey of YA with cancer. The first problem relates to the missing stage of information initiation for some needs during an information journey. This results from an unawareness of YA regarding some of their own needs, which are only identified after serendipitous information discovery. This leads partially to a deviation from the information journey invented by Blandford and Attfield [9]. Depending on the awareness of needs, the start of the information journey varies between the information initiation and the information interpretation. The second problem refers to the difficulty in trusting the reliability of information and sources, which complicates the information facilitation and interpretation for YA.

In conclusion, improvements in information provision for YA with cancer in Germany are still needed. Even though helpful information sources are available, their delivery is lacking. By drawing attention to existing validated information sources at the beginning of the CPJ, negative effects such as uncertainty and overload could be circumvented and the experience of YA during their CPJ could be optimized by better supported information journeys. Further, there should be a functioning social service and additionally a guide about the most important organizational first steps, independent of medical treatment, to reduce the dependency on serendipitous information receiving.

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