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ORIGINAL ARTICLE – CLINICAL ONCOLOGY

Information needs, communication and usage of social media by cancer patients and their relatives

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Abstract

Purpose The aim of this study was to evaluate cancer patients' need for information, their communication and usage of social media.

Methods We developed a standardized questionnaire comprising sections on information needs, communication behavior and usage of social media with respect to cancer and combined this with a validated instrument on eHealth literacy for patients. This questionnaire was provided online and with the help of bloggers and leaders of social media groups, distributed in their networks.

Results The Internet was the most important information source ($n=308$; 77.4%). Yet, most of the participants wanted to get information from their doctor ($n=342$; 85.9%). With respect to trust in a source of information, oncologists were named most often ($n=285$; 71.6%). On the one hand, many participants got in contact with others, especially peers, via social media ($n=319$; 80.3%) with a growing bond to their family members on the other hand ($n=324$; 81.6%). The cancer diagnosis was an impulse for starting with active participation in social media for some participants ($n=196$; 49.2%).

Conclusions With social media gaining importance as source of information for patients, improving the quality of information in these networks is an important task in health care systems.

Keywords Cancer · Patient information · Social media · eHealth service · eHealth literacy

Introduction

Oncology is one of the most important topics in modern health care systems. For Germany, a rise in incidence of oncologic diseases by 20% is predicted for the year 2030, mainly due to demographic change (Robert Koch-Institut 2015). Once diagnosed, patients look for information on a broad range of topics. Most often addressed issues are treatment modalities, side effects, prognosis and living with cancer (Kobayashi and Smith 2016; Rudolph et al. 2015; Keinki et al. 2016).

Physicians are the main and preferred source of information (Hyde et al. 2017). Additionally, the possibilities for individual information seeking are manifold. There are print materials like books, brochures and journals and digital materials like the Internet with websites, blogs and social networks (Keinki et al. 2016). In a Dutch study from 2013, the Internet was the main source of health-related information (Van de Belt et al. 2013). A major advantage of the Internet is, that the patients can share experiences and discuss with other patients keeping their anonymity (Seale et al. 2010).

Blogs are defined as web-based journals with user-generated content. They may be found in social networks or on own websites (Ressler et al. 2012).

The most frequented social network actually is Facebook with 2.1 billion active users worldwide (Rising Media Ltd. 2018). Social media channels are increasingly used for health communication and encouraging users for participation in health topics (Abramson et al. 2015).

In fact, social media may not only provide a place for patients to exchange information but also for recruiting participants for studies and even might be a tool for data collection (Lafferty and Manca 2015).

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Moreover, professional societies as well as profit- and non-profit organizations present an increasing amount of web-based information for different diseases in general and especially for cancer (Liebl et al. 2015).

For cancer patients, the main key to gain control on their disease is by understanding the treatment process (Harkin et al. 2017).

To participate in decision making, it is necessary for the patients to define their own values and preferences with respect to the disease and the treatment options. An appropriate tool for helping patients to understand their prognosis and treatment options are decision aids. Modern versions of these are interactive tools on websites, applications or DVDs (Elmore et al. 2010).

Nevertheless, informing for decision making is not the only goal. Informed patients (e.g., with interactive health communication applications) have better awareness, higher adherence and thus a better clinical outcome (Hong et al. 2012; Murray et al. 2005; Jung et al. 2016; Wuensch et al. 2015).

For most of the patients, getting informed, asking questions and having contact with a medical expert is more important than empathy (Rudolph et al. 2015). While these needs in part may be served by web-based services, empathy is an important competence of physicians. Empathy may raise patients' satisfaction and psychological adjustment.

Due to the historical development of web-based services in medicine, mostly younger patients use them for their decision-making process (Halwas et al. 2017).

Moreover, patients from 18 to 49 years are the largest group of social networkers (Pew Research Center 2018; Lelorain et al. 2012). Communication via the World Wide Web, especially about usage of social networks and their importance is a topic, which is understudied (Koskan et al. 2014).

To learn more on the usage of eHealth offers and participation in social networks, we conducted a survey via Facebook to find out more about information seeking behavior and information needs of younger German cancer patients, acquaintances and their relatives.

Methods

Participants

First, we selected German cancer groups using cancer as the key word in the search bar of Facebook. From these, we identified ten bloggers and leaders of social media groups and addressed them with our project. All bloggers and group leaders consented to participate and distribute the link to our survey.

Inclusion criterion was being part of one of these Facebook cancer groups.

Exclusion criterion was a questionnaire filled in incompletely.

Questionnaire

We developed a standardized questionnaire based on a validated eHealth assessment tool (Halwas et al. 2017). The first draft of the questionnaire was passed to the ten bloggers and leaders of social media groups to get a feedback, whether it comprised all aspects important from their point of view and whether they rated it as understandable for the members of their groups and as suitable for distribution in the groups. Apart from minor revisions concerning wording and spelling, no prominent changes were necessary.

The final version of the questionnaire consisted of six parts:

1. Demographic data (seven questions: age, gender, status (patient before or after treatment, relative, or other), kind of cancer disease, year of initial cancer diagnosis, education level, living environment [bigger town (population > 100,000), smaller town (population < 100,000), village)].
2. Information and patient care (nine questions: e.g., which source of information do you trust?; which kind of doctor listens the most to you?; closed questions and four-point Likert scale).
3. Social changes (three questions: social changes according to friends, family and acquaintances; four-point Likert scale).
4. Internet usage with respect to cancer (seven questions: e.g., do you use the Internet and/or other social networks in relation to your cancer disease?; closed question).
5. Patient care via Internet (seven questions: statements for which the patient should rate his/her approval on a four-point Likert scale; e.g., I would like to get another opinion from an expert via Internet).
6. Validated eHealth questionnaire (15 questions: general Internet usage; closed questions and ten-point Likert scale) (Halwas et al. 2017).

The survey was established and programmed as an online survey. It was anonymous and the participants were informed on the intention of this scientific approach in the introduction of the questionnaire.

The onset was on the 28th of September in 2017 through the social media platform "Facebook" by bloggers and group leaders with a call for participation. The link was open until the 6th of December in 2017.

Ethics

The survey was approved by the ethics committee of the Hospital of the Friedrich-Schiller-University at Jena.

Statistics

We included all completely filled in questionnaires for the analysis of the results.

IBM SPSS Statistics 25 was used for data collection and analysis of frequencies and associations were carried out using Chi square test, $p \leq 0.05$ was considered as significant.

Results

All in all, 538 people took part in the survey. Of those, 398 met the inclusion criteria and were included in the assessment.

Demographic data

Of the 398 participants, 346 (86.9%) were women and 52 (13.1%) were men (for demographic data see also Table 1). Participants were patients after treatment ($n=206$; 51.7%), in treatment ($n=164$; 41.2%) and relatives and others ($n=28$; 7.1%). The most common cancer types were colorectal cancer ($n=97$; 24.4%), breast cancer ($n=90$; 22.6%) and skin cancer ($n=90$; 22.6%). While the category “others” in the table includes all other types of cancer, which were named by the participants, the category “not specified” includes all patients, who did not answer the question. Most of the participants were diagnosed with cancer after the year 2013 ($n=278$; 69.8%).

Information and patient care

Medical care of the participants was provided in hospitals ($n=163$; 41.0%), by general practitioners ($n=150$; 37.7%), resident oncologists ($n=150$; 37.7%), ambulance of a hospital ($n=146$; 36.7%) and other medical specialists ($n=92$; 23.1%).

Correlations showed that medical care of patients with skin or breast cancer was less often provided by resident oncologists compared to patients with colorectal cancer or lymphoma/leukemia ($p<0.001$). In addition, patients with colorectal cancer were significantly more often treated by their general practitioner than other patients ($p<0.001$).

The most often reported sources of information for participants were the Internet ($n=308$; 77.4%), other people affected by cancer ($n=263$; 66.1%), Facebook ($n=256$; 64.3%) and oncologists ($n=247$; 62.1%). In contrast, nursing staff ($n=37$; 9.3%), family and friends ($n=35$; 8.8%), other social networks ($n=22$; 5.5%) and alternative practitioners ($n=21$; 5.3%) were less often named as sources of information. Patients of the age groups under 30 years and 31–50 years used significantly more often nursing staff as information source than older patients ($p=0.018$). In addition, they trusted them more ($p<0.001$). Other social networks as information source were significantly less frequented by all the age groups ($p=0.02$). Facebook ($p=0.245$) and the other information sources did not show any correlations.

Furthermore, females used significantly more often other patients ($p=0.046$) and the Internet ($p<0.001$) as information source than male patients.

Most of the participants ($n=342$; 85.9%) would like their doctor to recommend a source of information to them. The trust in information was very different for the different sources with oncologists being most often trusted ($n=285$; 71.6%) followed by other people affected by cancer ($n=215$; 54.0%) and other medical specialists ($n=175$; 44.0%). Higher educated people used significantly more often books, brochures and newspapers as information materials ($p=0.032$), but trusted them as less as lower educated people ($p=0.029$).

Important topics in information seeking were treatment options ($n=329$; 82.7%), prognosis of a cancer disease ($n=248$; 62.3%) and experiences of other patients ($n=248$; 62.3%) (Fig. 1).

A significant correlation was shown between age and fertility and family planning ($p<0.001$). In addition, age showed another correlation with effects on education ($p<0.001$) and career and long-term consequences of a cancer disease ($p=0.019$). Patients under 30 years showed the greatest interest in these topics. Besides, male patients were more interested in questions of social laws than women ($p=0.037$).

Relatives were significantly more often worried about covering of medical costs than patients ($p<0.001$).

Most patients took advice from oncologists ($n=151$; 37.9%), other medical specialists ($n=77$; 19.3%), family and friends ($n=60$; 15.1%) and other people affected by cancer ($n=46$; 11.6%). Oncologists were the most often consulted doctors in all education levels ($p=0.017$).

Patients reported getting help in coping with their disease from family and friends ($n=302$; 75.9%), other people affected by cancer ($n=237$; 59.5%), oncologists ($n=159$; 39.9%) and general practitioners ($n=135$; 33.9%). General practitioners helped the age groups of 51–70 years and 71–80 years significantly more in dealing with their disease than the groups with younger patients ($p=0.031$).

The best listeners for worries were family and friends ($n=131$; 32.9%), followed by other people affected by cancer ($n=102$; 25.6%). Moreover, quick exchange of information most often takes place with family and friends ($n=139$;

Table 1 Demographic data of the participants ($n = 398$)

Demographic data	Numbers	Percentages
Age (years)		
Under 30	46	11.5
31–50	214	53.8
51–70	134	33.7
71–80	4	1.0
Gender		
Female	346	86.9
Male	52	13.1
Groups		
Patients after treatment	206	51.7
Patients in treatment	164	41.2
Relatives	25	6.3
Others	3	0.8
Education level		
Primary school degree	1	0.3
General certificate of secondary education	191	48.0
Advanced technical college entrance qualification	70	17.6
General qualification for university entrance	55	13.8
University degree	75	18.8
Other graduation	6	1.5
Place of residence		
Village	136	34.3
Smaller town < 100,000 inhabitants	138	34.7
Bigger town > 100,000 inhabitants	123	31.0
Year of cancer diagnosis		
Before 2000	7	1.7
2000–2012	62	15.5
After 2013	278	69.8
Primary tumor		
Colorectal	97	24.4
Breast	90	22.6
Skin	90	22.6
Lymphoma/leukemia	32	8.0
Others	26	6.5
Ovary/endometrium	23	5.8
ENT	9	2.3
Lung	8	2.0
Sarcoma	6	1.5
Gastrointestinal	3	0.8
Not specified	14	3.5

ENT ear, nose, throat

34.9%), other people affected by cancer ($n = 127$; 31.9%), and acquaintances from social networks ($n = 62$; 15.6%).

Changes in social contacts

Since their cancer diagnosis, most participants experienced a stronger bond to family members ($n = 324$; 81.4%) (Fig. 2). Nearly a half also felt a stronger bond to friends ($n = 199$; 50.0%) in contrary to the other half, which felt a weaker bond ($n = 195$; 49.0%). A similar development was reported for the acquaintances ($n = 205$; 51.5% stronger connection). In addition, half of the relatives felt a stronger bond to friends ($n = 12$; 48.0%), while the others reported a weaker bond ($n = 12$; 48.0%). A majority of the relatives ($n = 22$; 88.0%) felt a stronger bond to their family. Only 20.0% of the

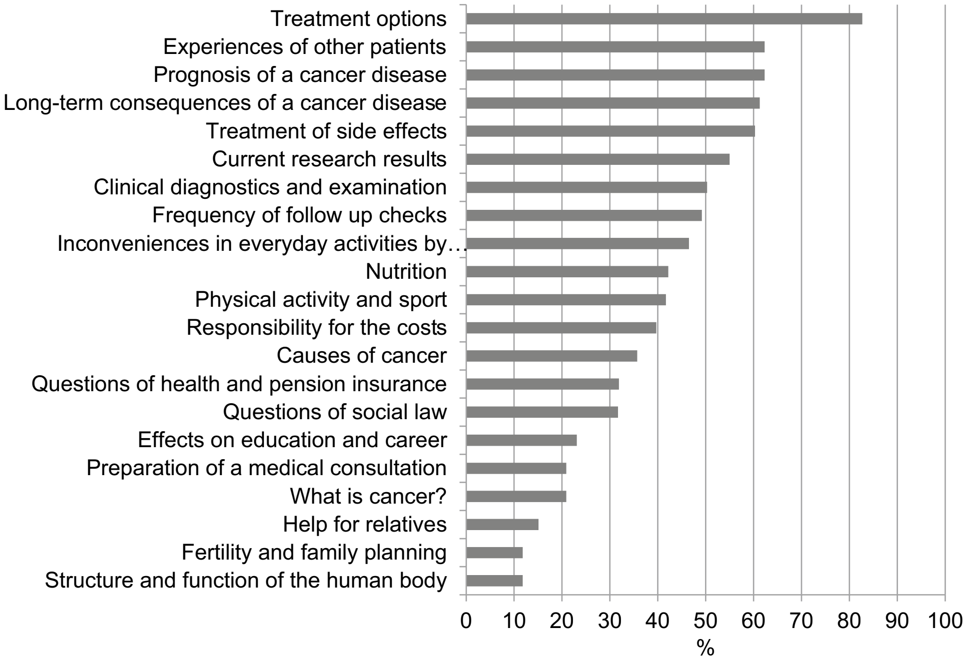

Fig. 1 Topics for information search ($n = 398$)

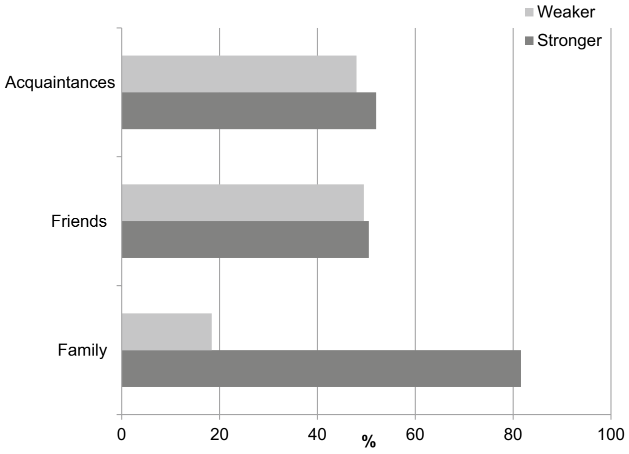

Fig. 2 Changes in social contacts ($n = 398$)

relatives ($n = 5$) mentioned a stronger bond to acquaintances, while 72.0% did not ($n = 18$).

Social media usage in reference to cancer

The majority of the participants reported that they used the Internet for information on cancer ($n = 373$; 93.7%).

Furthermore, a majority of the participants ($n = 319$; 80.2%) got in contact with other people about the topic "cancer" via social media.

From those using social media for information on cancer, most were passive readers ($n = 192$; 48.2%). Nearly a third reported active sharing of foreign articles ($n = 125$; 31.4%) and a fifth active sharing of own written articles ($n = 76$; 19.0%). Patients under the age of 30 years wrote significantly more own articles than older age groups ($p < 0.001$). No significant correlation was shown between gender and the Internet activity ($p = 0.213$). Nearly half of the participants ($n = 196$; 49.2%) reported using social networks since their cancer diagnosis.

Overall, 42.5% of the participants ($n = 169$) got active, because of their first cancer diagnosis. Patients with skin cancer got significantly more often active since their first diagnosis than patients with breast or colorectal cancer ($p < 0.001$). The main reasons for staying passive were privacy ($n = 93$; 23.3%), the abundance of confusing information ($n = 47$; 11.8%) and too much effort for being active ($n = 46$; 11.5%). Active members most often used Facebook groups ($n = 257$; 64.6%). In addition, self-help groups ($n = 118$; 29.6%) and forums ($n = 68$; 17.1%) were also frequented.

Patient care via Internet

Patient care via Internet by advice of a physician is only wanted by a quarter of the participants ($n = 104$; 26.1%) (Fig. 3). Nearly a half rejected this medium ($n = 193$; 48.5%). Web-based mental health support was favored by 23.4% ($n = 93$) and a second opinion via Internet was welcome to 37.4% ($n = 149$). Most accepted services were asking questions to other patients via Internet ($n = 251$; 63.1%), asking questions to an expert after their therapy ($n = 223$; 56.0%) and having a close connection to their attending doctor

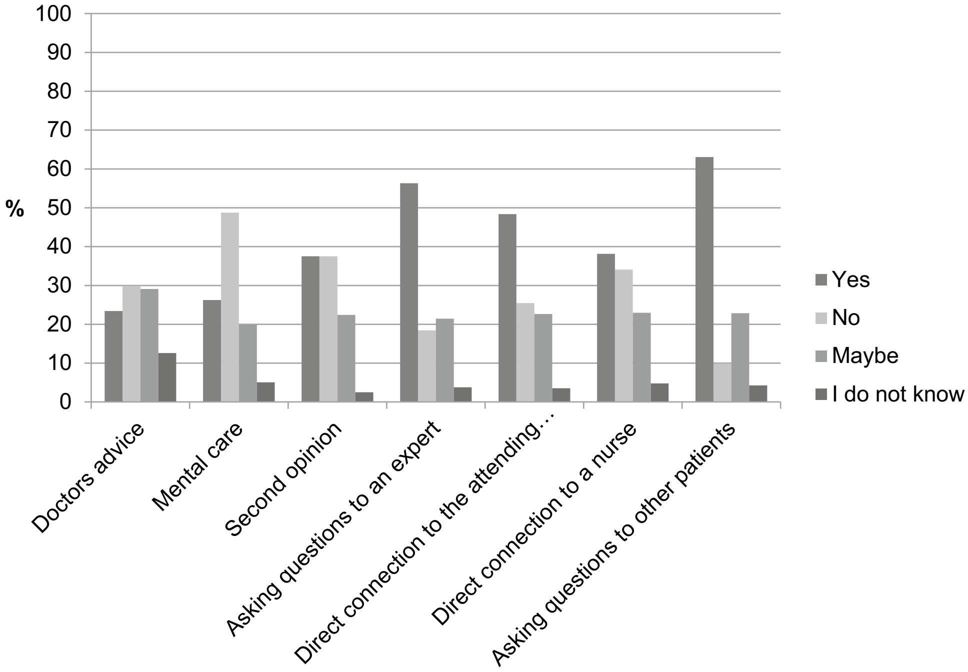

Fig. 3 Acceptance of topics for patient care via Internet ($n = 398$)

($n = 192$; 48.2%). A smaller part wished a close connection to nurses of their hospital ($n = 151$; 37.9%).

eHealth literacy and usage of eHealth services

A vast majority ($n = 373$; 93.7%) reported having used the Internet daily in the last 3 months. Only a smaller part quoted that they used the Internet several times a week ($n = 18$; 4.5%) or several times a month ($n = 2$; 0.5%). Only 1.0% ($n = 4$) reported using the Internet less frequently. Only 0.3% ($n = 1$) did not use the Internet in the last 3 months.

The most often used devices were smartphones and tablets ($n = 379$; 95.2%) or laptops and personal computers at home ($n = 294$; 73.9%). About 26.9% of the participants used the Internet at work ($n = 107$). A smaller part used an Internet access at public places like a cafe, an airport or a shop ($n = 48$; 12.1%). A fast Internet connection was available for most participants ($n = 358$; 89.9%). Nonetheless, 9.3% complained about a too slow Internet connection ($n = 37$). In addition, only one person declared to have no Internet connection ($n = 1$; 0.3%). Electronic health services were used by 76.1% ($n = 303$) (Fig. 4). In contrast, only 23.9% used them regularly ($n = 95$) and 36.9% used them unregularly ($n = 147$). Others did not consider using them ($n = 43$; 10.8%) or used them only once ($n = 61$; 15.3%). All in all, 12.3% did not use electronic health services, but they hypothetically would do so ($n = 49$).

There was no significant correlation between usage of electronic health services and education ($p = 0.122$). Mostly, the participants looked for information about their health on the Internet ($n = 314$; 78.9%), visited forums for patients ($n = 236$; 59.3%) or searched specialists for their own disease via Internet ($n = 195$; 49.0%) (Fig. 5). A similar percentage used medical online encyclopedias ($n = 187$; 47.0%). Web pages from self-help groups ($n = 178$; 44.7%) and download of online brochures were other important avenues. In addition, patients under 30 years significantly more often used websites of self-help groups than older patients ($p < 0.001$). Online brochures were significantly more often downloaded by higher educated people ($p < 0.001$). In contrast, education showed no significant correlation with the use of interactive online courses ($p = 0.742$) or online encyclopedias ($p = 0.168$). Another used format was health videos ($n = 135$; 33.9%), for example, on YouTube and health-related blogs ($n = 114$; 28.6%). A smaller group used emails to arrange a medical

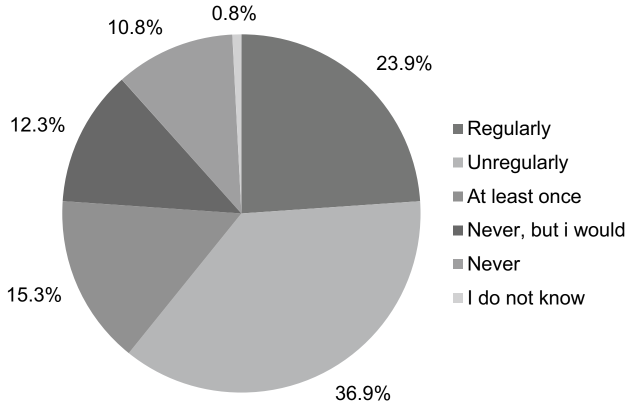

Fig. 4 Usage of electronic health services ($n = 398$)

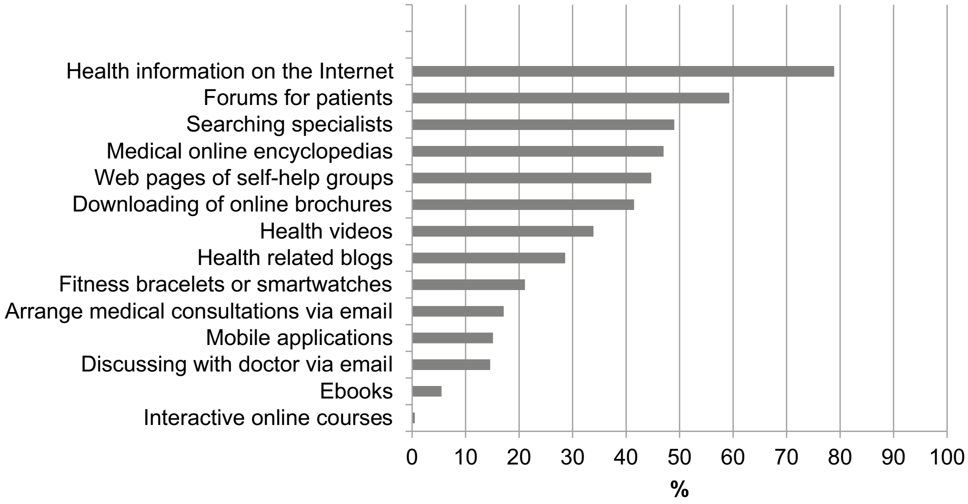

Fig. 5 Used health offers (*n* = 398)

consultation (*n* = 68; 17.1%) or for discussing a health topic with their doctor (*n* = 58; 14.6%).

Mobile applications (*n* = 60; 15.1%) and eBooks about health care (*n* = 22; 5.5%) were utilized less as well as interactive online courses about health (*n* = 2; 0.5%).

Bracelets for fitness and smartwatches were used for health purposes by 21.1% (*n* = 84).

In sum, nearly two-thirds rated their understanding of electronic health services as very good (*n* = 84; 21.6%) and good (*n* = 172; 44.2%) (Fig. 6). The remaining reported that they did not understand the services very well (*n* = 82; 21.1%) or declared them to be bad (*n* = 51; 13.1%). Almost a quarter declared that they knew very well where to find health information (*n* = 88; 22.7% and *n* = 135; 34.8%). The remaining rated their understanding of how to navigate the web as bad (*n* = 101; 26.0%) or slightly worse (*n* = 64; 16.5%). With respect to health care applications in app stores, only 16.6% rated that they knew very well how to find the health care applications (*n* = 65). About half of the participants knew this well (*n* = 113; 28.9%) or not very well (*n* = 86; 22.0%) and the largest group reported that their knowledge about it was weak (*n* = 127; 32.5%). Regarding usage after download, nearly a half thought that they knew very well how to use the app (*n* = 88; 22.7%) or had adequate knowledge about it (*n* = 127; 32.7%). So, about two-fifths were less or badly versed in the usage of applications (*n* = 173; 44.6%).

Gain from usage of the Internet

Overall, 21.7% (*n* = 83) of the participants reported that the Internet greatly improved their medical knowledge. Another 38.4% rated the increase as strong (*n* = 147). A quarter (*n* = 94; 24.5%) reported lower enhancement and a very low enhancement was quoted by 15.4% (*n* = 59).

A small part of the participants reported knowing how to rate the reliability of health information from the Internet very well (*n* = 34; 9.0%). In addition, only 20.9% reported knowing how to do this properly (*n* = 79). Nearly a third (*n* = 102; 27.1%) was less positive about their ability to

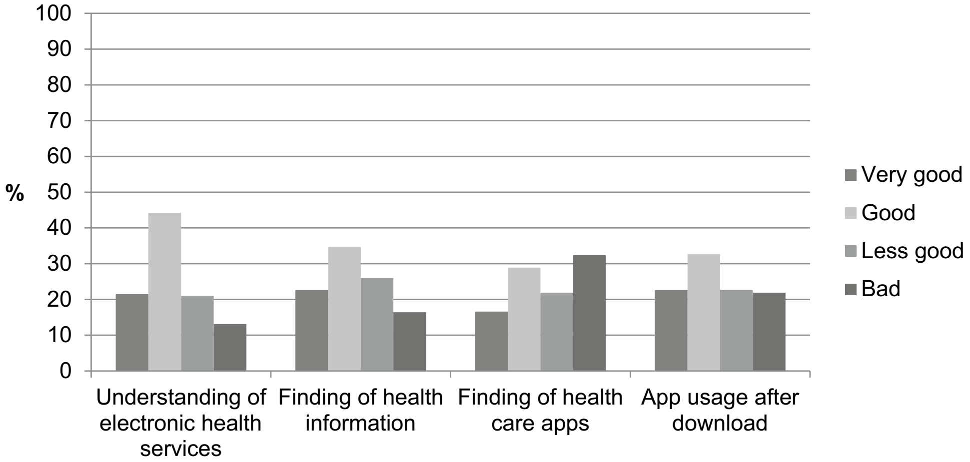

Fig. 6 Self-rating of eHealth literacy by the participants (*n* = 398)

discern reliable from unreliable information. Finally, majority of them did not know how to deal with this task ($n = 162$; 43.0%).

Most participants needed infrequent ($n = 157$; 40.0%) or no ($n = 149$; 38.0%) help with understanding medical information materials (e.g., journals, brochures). Only 17.6% reported needing help sometimes ($n = 69$), 3.6% often ($n = 14$) and 0.8% always ($n = 3$). In case of open health care questions, in the last month, nearly half of the participants asked other people or looked in information portals 1–4 times ($n = 196$; 49.6%). Another 18.7% made use of this 5–9 times ($n = 74$) and 6.1% called for help 10–14 times ($n = 24$). Just 11.1% of the participants looked for help 15 times or more often ($n = 44$). No help was required by 14.4% ($n = 57$).

Only a minority of 5.7% really felt secure in case of decision making with respect to their cancer on the basis of information from the Internet ($n = 22$). The others felt secure ($n = 82$; 21.5%) or less secure ($n = 110$; 28.8%) and about half of the participants did not feel secure about it ($n = 168$; 44.0%). Accordingly, information from the Internet helped patients by making decision making less well ($n = 101$; 26.7) or bad ($n = 141$; 37.3%) for most patients. Usefulness was rated as very good by 40 participants (10.6%) and as well by 96 (25.4%).

Discussion

Our study provides important data on the usage of social media by cancer patients, information seeking and eHealth literacy. In sum, we were able to show that cancer patients have a specific and large demand for information. With smartphones being used more often now, participants search for health information and self-help groups on the Internet. Although the Internet is the most popular source, trust in oncologists as well as family and peer support are necessary to ensure patient-oriented cancer care. In a highly active collective of social media-versed participants, eHealth literacy and usage is high. For many of them, the cancer diagnosis seems to be an impulse for starting active participation in social media.

As already reported by other researchers, young, well-educated females were the most frequent Internet users (Smart and Harrison 2017).

According to current statistics, the most common cancer types are breast, prostate, colorectal and lung cancer. In our collective, a larger group of participants with skin cancer participated which is due to one very active self-help group organized via Internet which distributed the link to our survey.

The Internet is the most frequently reported source of information. Moreover, other people affected by cancer and Facebook were named most often as source followed by oncologists. While the first most probably is due to online survey and the high rate of young cancer patients (65.4% under 50 years), all three sources might point to a change in information culture. While in the last decades, the physician was the most often cited source of information, online sources and communities are gaining importance (Keinki et al. 2016). As these sources are highly different and often of minor quality compared to physicians, this may entail false information and false decisions regarding treatment by the patients resulting in worse treatment results (Liebl et al. 2015).

Patients seem to be aware of the low reliability of online information and trust physicians the most. These data from our study are in accordance with the literature (Finney Rutten et al. 2016). Accordingly, one might speculate, that patients would prefer the oncologist to provide information. If this source is not available as needed, web-based sources are used as a substitute. To gain more security, patients would prefer the physician to recommend web-based information sources which might be a good strategy to develop web-based information as complementary to the information the physician provided. For most physicians, it would be demanding to know, assess and recommend websites, especially, as frequent updates of the assessment would be necessary. In fact, the German Ministry for Health is discussing the establishment of a landing page which will provide links to high-quality websites with health information for the public (IQWiG 2017). Yet, more and more information is provided by social media with a much quicker turn over of content and diverse and continuously changing authors. Accordingly, a landing page should assess the quality of recommended web-based groups and blogs much more often.

To bring health care to the patients' home and allow specialists to care for their patients during times of home stay, care via Internet and telemedicine are developing rapidly. Yet, more than half of the patients favor the presence of a doctor and not the virtual consultation (Basch et al. 2017; Katz et al. 2014).

While other people affected by cancer are trusted strongly by the participants of our study, trust in family and friends was very small. In contrast, they reportedly trusted much more in literature (Shea-Budgell et al. 2014; National Cancer Institute 2010). Furthermore, this trust goes along with strong family support (Najmabadi et al. 2014). Our data may point to an ongoing change in social contacts and behavior, which turns from direct contacts to online communities. Whether and how this will influence social support for cancer patients is to date unclear, but should be watched closely.

Peer groups are good in supporting others with advice in coping and sharing their life experiences (Egestad 2013). Majority of the patients starting with social networking since their diagnosis (49.2%) might demonstrate that contact to peers is a strong desire which is not fulfilled with real-life contacts. In fact, most local or regional self-help groups are only available for frequent types of cancer and/or in bigger towns. In case of rarer cancers or subtypes from frequent types of cancer, patients will have to bridge large distances. In fact, Twitter and other social media most often are used to exchange greetings and daily conversations followed by discussing cancer treatments (Sugawara et al. 2012).

For social media, two modes of participation are described: lurking and posting. While lurking is a more passive process with just reading the messages, posting means to be active and writing own messages visible either for all or for other individuals (Harkin et al. 2017). Lurkers make up the greatest part of Internet and social media users (Nonnecke and Preece 2000). Already before today's social networks were started, lurkers formed the majority of online groups, for example, in email-based discussion lists (Nonnecke and Preece 2000). Reasons for staying passive were mostly keeping privacy and the abundance of confusing information (Nonnecke et al. 2004) as well as too much effort in becoming active. The data from our study are in accordance with that.

While in our former survey, smartphones and tablets were less often used than personal computers (Halwas et al. 2017), now we see a preponderance of mobile devices which allow an easy access to social media at any place and time. Applications on smartphones or tablets are fast and easy to handle. As the first survey was not an online one, but addressed patients attending a lecture on complementary medicine, the higher usage in our collective may in part be explained by the recruitment resulting in a bias but may also point to a real shift in information behavior (Halwas et al. 2017).

With respect to reading abilities for medical topics, 22% of our participants marked limited reading abilities, while Halwas et al. (2017) found a rate of 35.2%. This difference may be due to differences in recruitment. From these data, we do not know how strong eHealth literacy really is in both collectives. Maybe patients using social media are more familiar with the chances and pitfalls of web-based information. This case is supported by a high correlation between reading abilities and the understanding of medical materials and between reading abilities and the education level. However, they may overestimate their abilities, as this was a subjective rating, thus being more in danger to be misled by false information. The most important limitation of our study is the fact that the sample of this study is not representative. It is not even representative for social media users with cancer. To create a large sample, we passed the control of the distribution over to a small group of bloggers and leaders of social media groups. As known from the literature, online recruitment may lead to an incidental snowballing effect in the sampling strategy (Harkin et al. 2017).

Young, well-educated females were the main group of our sample. Furthermore, we had three large cancer groups with colorectal, breast and skin cancer. This is due to the fact that the link to the survey was distributed in different cancer groups on Facebook, probably more in skin cancer groups than in others. Another limitation is the small number of relatives ($n=25$) for whom we may not report reliable results. Another important limitation is missing data on validity and reliability of our questionnaire, which should be measured in a second investigation.

Conclusion

Our data show an increasing impact of social media on patient information seeking. Social media and some websites can help patients learn more about other patients' experiences. Curated patients' narratives may be a modern format of information provision by professional organizations engaged in patient information. Furthermore, coping happens obviously and mostly in families. That is why relatives should get more attention and support from doctors and other professionals. They take over an important task in medical care. It might be useful to develop coping strategies together with them, so they can understand the illness and help better.

The Internet will not replace the empathy, communicative talent and expert know-how of a doctor, but some patients want a close connection to doctors via Internet and they want to ask questions via Internet. Since better outcomes may result from this (Hong et al. 2012), telemedicine via Internet should be considered.

Improving patient information and communication is an important task for medical services. Growing impact of social media in cancer care will become a challenge for both patients and physicians. Improving eHealth literacy on both sides may help to integrate the Internet in a patient-centered care. Yet, while information provision might be solved with better quality assurance, care also comprises direct interaction of human beings. A comprehensive integration of social media may be more challenging.

All in all, further research is needed to understand patients' information and communication needs to develop improved and customized information materials. This could lead to more compliance and better satisfaction with health care on both sides.

As a cancer diagnosis is an incisive change in lives of both, patients and relatives, information channels and communication ways should be defined early. Integrating online services to ordinary medical care will be a prospective task in health care systems.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval The survey was approved by the ethics committee of the Hospital of the Friedrich-Schiller-University at Jena (Reference Number 5281-09/17). All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was not necessary due to the anonymity of the survey. An explanation of the aims of the survey was presented on the first page of the online questionnaire. The participants consented by filling in the questionnaire.

Data availability The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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