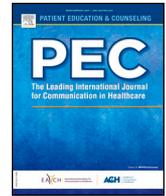




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Patients' challenges, competencies, and perceived support in dealing with information needs – A qualitative analysis in patients with breast and gynecological cancer

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ABSTRACT

Objectives: This study aimed to investigate challenges, competencies, and support in breast and gynecological cancer patients when dealing with information needs and how health literacy as an interplay of these factors might be improved.

Methods: Semi-structured interviews were conducted with patients in acute care (n = 19), undergoing rehabilitation (n = 20) or attending self-help groups (n = 16). Interviews were analyzed using content analysis.

Results: Challenges: gain information according to own needs, internet as information source, information evaluation and decisions, doctor-patient communication, situationally limited information processing, difficult access to information. Competencies: self-regulation of information needs, media and social competencies, communication skills in the doctor-patient conversation, internet competencies, self-directed decisions according to own needs, interest/self-efficacy, previous knowledge, trust in the doctor. Support: by professionals (e.g., patient-centered communication), relatives (e.g., support during consultations), peers (e.g., exchange), facilities (e.g., clinics).

Conclusions: Our findings provide insight into challenges and competencies relevant to patients' health literacy and the influence of support. The individuality of the interplay highlights the relevance of an active patient role and patient-centered care.

Practice implications: Patients' health literacy should be improved in (psycho)oncological work by both reducing challenges (e.g., by communication skills training, involving relatives) and promoting competencies (e.g., by needs- and competence-oriented information offers).

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1. Introduction

After a breast or gynecological cancer diagnosis, most patients need information on various topics related to their disease and its treatment [1,2]. These information needs can change over time [3,4], but often remain high, in general, for months or even years after the end of treatment [1,5–9]. Sufficient information can contribute

positively to different aspects of disease management. Ovarian cancer patients who are satisfied with the information received report less unmet supportive needs in other disease-related domains, like getting access to health care services when required [10]. Furthermore, there seems to be a bidirectional association between information satisfaction in breast cancer patients and their psychological distress one year later [11] and a positive association between appropriate information provision and health-related quality of life in cancer survivors [12]. Moreover, knowledge about illness and treatment is necessary for patients to actively engage in treatment and participate in shared decision-making processes [13].

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Table 1
Interview guide with questions asked by the interviewers about information needs and perceived challenges, competencies, and support.

Topic/domain	Obligatory text/questions	Additional text/questions
Introduction	Patients often wish comprehensive information about their disease and about acute as well as long-term treatment options. Acquiring and using this information might be a challenge.	If necessary, add examples: medication, surgery, side effects, long-term effects, psychosocial support, follow-up treatment
Information needs	How content are you with your current state of information? Which topics would you like more information about? What else would you like to know?	
Acquire information	How did you get relevant information up to now? How could you acquire relevant information yourself?	What difficulties did you encounter?
Understand and evaluate information	How easy or difficult has it been to you to understand and evaluate this information about the disease on your own?	What difficulties did you encounter?
Use information	How can you use this information to deal with your disease?	Were you able to make own treatment decisions based on this information? What difficulties did you encounter?
Perceived support, competencies	What support is helpful to you? What makes it easier for you to acquire and use information?	

Overall, there are compelling reasons to inform cancer patients appropriately according to their needs. Getting the relevant information seems challenging, as breast and gynecological cancer patients have high supportive care needs in dealing with the health care system and satisfying their information needs [2,14,15]. Research identified some important challenges patients might face when gathering information during the diagnostic phase, such as lack of information or information overload [16].

When it comes to cancer patients' information needs, patients' health literacy can play an essential role in addressing challenges in dealing with those needs. Sørensen and colleagues [17] defined *health literacy* as "(...) people's knowledge, motivation, and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course." (p. 3). Studies have shown that low health literacy is associated with less information satisfaction in women with ovarian cancers [18] and higher information needs in those with breast cancer [1,7]. However, health literacy cannot only be understood as a patient's risk but rather as an asset to be built that may support more comprehensive options for self-management [19]. Furthermore, health literacy reflects an interplay of patients' competencies, abilities, and skills and the tasks the health care system is setting them [20].

Therefore, besides asking the question of which competencies make cancer patients more health literate, it is essential to know what kind of support facilitates dealing with information needs. Concerning shared decision-making, patients profited from actively using support services and from helpful patient-physician interactions [21]. Regarding the processes of finding, evaluating, and using cancer-related information, we still need further knowledge about which support is perceived as helpful and how it may contribute to increasing patients' health literacy.

The purpose of the present paper was to investigate the interplay of challenges, competencies, and support and how health literacy might be improved to address the information needs of women with breast and gynecological cancers across the acute disease period and beyond. Thus, this qualitative study explores the following questions:

- 1) What challenges do patients report regarding gathering, appraising, and using disease-related information?
- 2) What competencies do they use to deal with these challenges?
- 3) What support is perceived as helpful to strengthen their competencies?

For a comprehensive view, we examined patients' experiences in the course of the disease, from acute care, across rehabilitation and survivorship.

2. Methods

2.1. Research design

This exploratory multicenter cross-sectional qualitative interview study was conducted as part of the PAKO study (02/2019–01/2022) which was approved by the Ethics Committee of the Faculty of Medicine, University of Würzburg, Germany on 12.03.2019 (reference no.: 254/18-am). All participants provided informed consent.

2.2. Sample and recruitment

We used convenience sampling to recruit participants. Participants were enrolled a) during acute treatment in an oncological clinic, b) while undergoing inpatient treatment in one of three cooperating cancer rehabilitation clinics, and c) among members of cooperating cancer self-help groups (SHGs) in the local area. Inclusion criteria were female gender and a diagnosis of breast, cervical, endometrial, or ovarian cancer. Exclusion criteria were age under 18 years, lack of German language skills, and severe hearing impairment. Staff members (physician, study nurse) evaluated the inclusion and exclusion criteria in the clinical settings and asked for informed consent. A member of the research team informed SHGs about the study and invited to participate through personal visits, telephone, or e-mail correspondence. SHG members contacted the research team to arrange an interview appointment if they were willing to participate. Due to trial design and economic reasons, we aimed to include up to 20 patients in both clinical settings, respectively, and 15 SHG members, even if data saturation was not achieved.

2.3. Data collection

Face-to-face interviews took place between June and September 2019, either at respective clinic premises with acute and rehabilitation patients or at university offices with SHG members. All participants were interviewed once in a one-to-one setting by female psychologists of the research team (KM, Ph.D.; NF, M.Sc.) who both were experienced in conducting qualitative interviews and had undergone informal training beforehand. There were no relationships between interviewers and interviewees prior to the study. Before the interview, participants' sociodemographic and disease-related information was obtained. We used a semi-structured interview guide (Table 1), which was developed by researching literature. After each interview, interviewers took field notes about impressions (atmosphere, nonverbal communication, own thoughts, and feelings) and relevant situational circumstances (e.g., disruptions).

2.4. Data analysis

Interviews were audiotaped, transcribed verbatim, and anonymized. We used the ATLAS.ti 8.2 software to process and analyze data. Two coders (KM; NF) analyzed the transcripts using qualitative content analysis [22]. First, we developed a preliminary coding scheme to determine which aspects of the text material were relevant to the analysis. Therefore, we defined selection criteria, and levels of abstraction derived from research questions and theoretical background for each of the three domains: challenges, competencies, and support. Based on this framework, both coders independently formulated inductive categories based on the interview material, separately for each of the three samples (acute treatment, rehabilitation, SHG). After coding four to seven interviews, coders met to revise and adapt the coding scheme. Afterward, we worked through the interviews again to adjust for relevant changes. Throughout the analytic process, the coders repeatedly reviewed and revised the codings. We compared the codings, discussed, and removed, added, or deleted codes until consensus was reached. Finally, we developed a category system with three levels, paraphrasing and deriving more general subcategories and main categories from final codes. Subsequently, the category systems of the three samples were consolidated to create the final category system.

3. Results

3.1. Sample description

We conducted 57 interviews and excluded two patients afterwards because inclusion criteria were not sufficiently met (diagnosis, language difficulties). The final sample for the analysis consisted of 55 participants. The participation rate was about 50–80% in acute and rehabilitation clinics. Regarding SHGs, approximately 120 members were informed about the study, irrespective of eligibility. Reasons for non-participation were lack of either time or interest in the study, high emotional vulnerability because of cancer disease, or not wishing to talk about cancer anymore. Interview duration ranged from 24 to 113 min, lasting 58 min (SD = 18.8) on average. Table 2 presents the characteristics of the participants.

3.2. Overview

Analysis of the text material resulted in a final category system comprising three levels. We set 496 codings referring to the research questions (domains) that were paraphrased to 67 subcategories which were combined to 22 main categories. The main categories were derived in each setting, but subcategories varied between settings. Fig. 1 summarizes the main categories and integrates the findings into the theoretical framework by displaying the interplay of challenges, patients' competencies, and aspects of perceived helpful support. Supplement Figs. S1–S3 show examples of interplays focusing on selected challenges. The main categories are described below according to the subcategories (Supplement Tables S1–S3). Tables 3–5 contain key examples of patients' quotes.

3.3. Challenges

3.3.1. Gain information according to own needs

Participants reported the challenge of gathering information that meet their information needs, especially during the acute phase of the disease. This means either to get sufficient information or information appropriate in terms of content or to receive it at the right time. Besides, patients who have medical professions may feel it to

Table 2
Sociodemographic and clinical characteristics (N = 55).

	n	%	mean (SD)
Age in years			55.3 (9.9)
Recruitment setting			
Inpatient acute care	19	34.5	
Inpatient rehabilitation	20	36.4	
Members of self-help groups	16	29.1	
Cancer site			
Breast cancer	42	76.4	
Ovarian cancer	4	7.3	
Endometrial cancer	5	9.1	
Cervical cancer	4	7.3	
Time since diagnosis			
1–3 months	16	29.1	
4–6 months	9	16.4	
7–12 months	4	7.3	
1–5 years	17	31.0	
5 + years	9	16.4	
Primary treatment			
Chemotherapy	24	43.6	
Radiotherapy	28	50.9	
Operation	52	94.5	
Marital status			
Single	4	7.3	
Married/with partner	43	78.2	
Divorced/separated	6	10.9	
Widowed	2	3.6	
Parentship	43	78.2	
Children < 18 yrs	9	16.4	
Children ≥ 18 yrs	35	63.6	
Education			
Less than junior (< 10 yrs; basic secondary school)	11	20.0	
Junior (10 yrs; middle-level secondary school)	18	32.7	
Senior (high-school graduate)	8	14.5	
University degree	18	32.7	
Employment before diagnosis	48	87.3	

be hard to satisfy individual information needs, for example, about the cause of the disease or on treatment details.

3.3.2. Barrier: doctor-patient communication

During medical consultations, structural barriers such as short conversation durations because of limited time capacities and frequently changing physicians or other practitioners hindered obtaining information and clarifying concerns. On the other hand, the women experienced internal barriers such as remembering all their questions, inquiring about intimate topics, or asking questions at all because they felt overcharged by the situation.

Furthermore, problems in the communication or relationship (e.g., doctors reject inquiries, changing doctors on rounds, lack of trust) hindered information retrieval or processing. Patients reported on insufficient relationships, e.g., if patients could not build confidence in physicians nor rely on their information supply or openness to their concerns.

3.3.3. Barrier: situationally limited information processing

Participants reported that information intake was hampered immediately after diagnosis disclosure or surgery. Also, gathering and processing information during the early, stressful phase of the disease could be limited when patients had to process the diagnosis disclosed.

3.3.4. Barrier: difficult access to information

Further barriers addressed were structural obstacles, such as lack of information offers in rural areas or during rehabilitation, because of the program's focus on breast cancer. One rehabilitant reported the problem of gathering information while suffering from psychological and physical burdens after treatment.

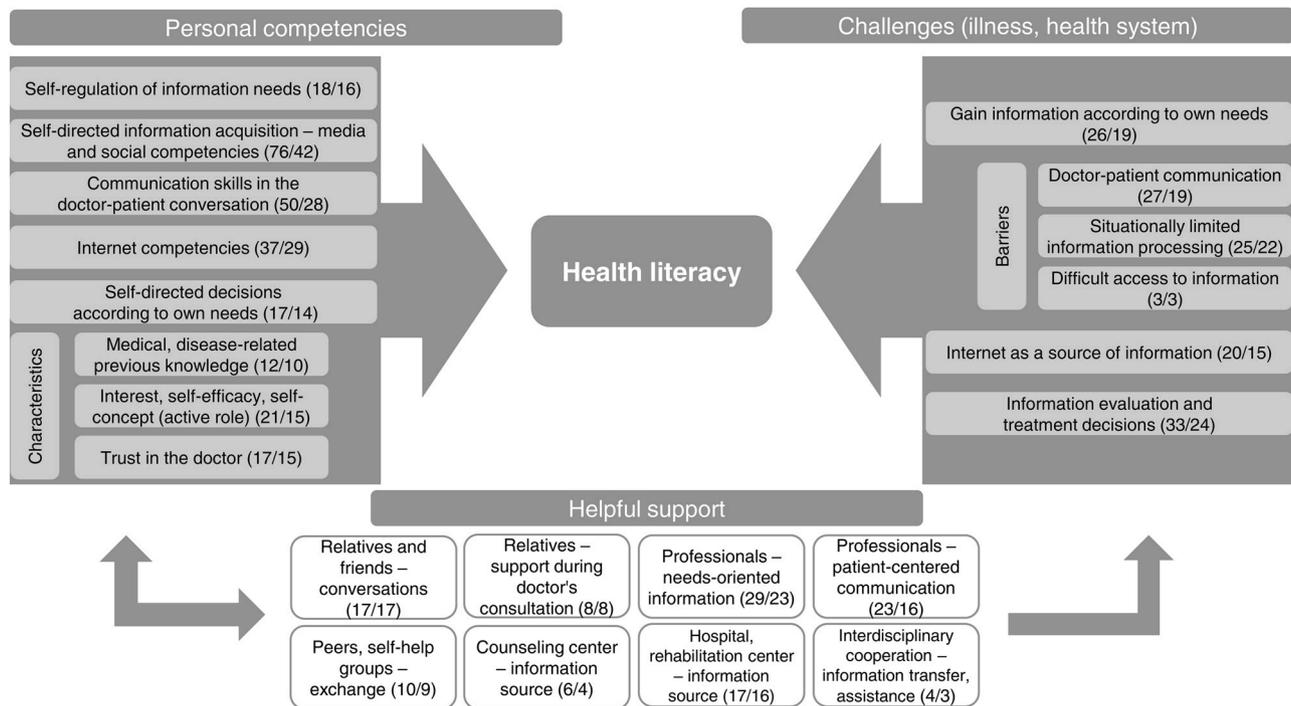


Fig. 1. Health literacy conceived of as an interplay of disease-related challenges, personal competencies, and helpful support. In brackets: The number of codings and persons contributing to this category.

Challenges were defined as disease-related needs, situational demands, and barriers experienced by patients requiring specific competencies to deal with them. *Competencies* were defined as the personal disposition to self-organized and autonomous behavior when dealing with challenges, based on patients' knowledge, personal values, motives, skills, abilities, characteristics, and resources, and realized by patients' motivation and will. *Support* was defined as external factors that were perceived by patients as helpful and promotive when dealing with past, current, or anticipatory challenges.

3.3.5. Internet as a source of information

Participants found it hard to evaluate and cope with threatening information presented on the internet, like negative patient reports or dubious healing offers. Another reported challenge was selecting relevant aspects of the vast amount of information presented on the internet or understanding medical terms on websites. One woman

described the problem of using online data for treatment decisions without being an expert.

3.3.6. Information evaluation and treatment decisions

Participants reported difficulties processing the multitude of information, judge information regarding its reliability and individual

Table 3

Main categories and examples of quotes referring to reported challenges.

Main categories	Quotes/Key examples
Gain information according to own needs	"But concerning these 'female issues' I haven't had access to any information. However, I don't belong to this 'digital generation' who has different channels of communication." (C18)
Barrier: Doctor-patient communication	"Well, you have a strong need to build confidence and that doesn't work if there is a different assistant doctor at my bed each day. And he only knows 50% of my medical record, that really happens and it doesn't work. You need one reference person, a single doctor who is available for the patient. No matter how the clinical routines are." (SH14)
Barrier: Situationally limited information processing	"Or first, after you heard it, to process the information for yourself, in general... 'That's it, here you are.' (...) Then you read something or get told something. And the next moment you forget about it anyway. Or, or it is too much. (...) They tell you this and that. And I think to myself 'oh', back at home, 'what was that again?'" (R15)
Barrier: Difficult access to information	"Then I said, 'You know? I haven't thought about whether I need the wig or not until now.' Because first you are confronted that you have this disease, then everything goes pretty fast, you get your plan where you have to go (...). And then another nurse calls, and she actually bombards you with what's coming after that. You haven't really come to terms with it yet, and you have to think about what's coming after that." (C17)
Internet as a source of information	"It's only about breast cancer in here (...) And then I asked, in the whole group with about 40 women, I said: 'Is there anybody else with a gynecological cancer?'. There was one more, we were only two. Thus, there was no information." (R13)
Information evaluation and treatment decisions	"Especially filtering and deciding on your own, okay, which is really reliable, which is fact. And, well, there are many reports... or many patients write blogs or there are chat forums. In my opinion, you must be aware that someone who gets along with it well, doesn't write there." (C16)
	"How can I make treatment decisions, if I haven't studied this subject? I don't have a clue about what's right or wrong. And even if I learn about it, I would think it's presumptuous. (...) So, to ask someone and say: 'Now decide on your own what you want to do' is hard. Because there is a lot at stake." (C12)
	"(...), because my gynecologist says that's endometrial cancer. Then I came to the professor for pre-op, and he says 'No, no, that's ovarian cancer.' At first, I was confused, and then it took a long time to explain to me exactly what it was." (R07)

Table 4
Main categories and examples of quotes referring to patient competencies.

Main categories	Quotes/Key examples
Self-regulation of information needs	"I didn't even want to know more yet. To me, maybe this will be an issue later, I'm going on step by step and the next step is to come through this hospital stay as well as possible and heal physically. (...) To me sufficient information is most important if relating to my current situation. I don't need to know everything yet." (C14)
Self-directed information acquisition – media and social competencies	"Yes, everything I know, everything I have done, I have worked out myself by word-of-mouth recommendations, by the internet, by inquiries, by researching, by my brother-in-law who suffered from cancer at that time, too." (R18) "But I've also tried to make contact to women, younger women, too. To say (...) who live around the place where I come from and... and just to meet and to exchange experiences and to talk about how things went for them and how they are and how everything was going on. Well, that was..., yes, I met with two women, yes." (SH03)
Communication skills in the doctor-patient conversation	"I brought in my sons to the doctor's consultations. Because I just didn't like to go there alone. Because, I said, 'I am confused, I can't catch on to everything.'" (R07) "When I moved in with my question sheet, he said: 'Oh, Mrs. (...), we only have ten minutes of time today', so I said: 'You will need more time for me today. You have to take more time for me today.' And it works; you just have to demand it (...). You have to know that you are able and allowed to demand it." (SH07)
Internet competencies	"I have registered on, I think, 'Brustkrebs Deutschland e.V.', they have videos on YouTube, a lot. And I attended their meetings, they meet once a year and more. Then they post new videos about new insights and studies and I use to watch them from time to time. (...) I attend groups on facebook that are dedicated to this issue, that is, breast cancer groups or follow up-groups." (SH12)
Self-directed decisions according to own needs	"Well, at least I can speak to the doctors about it, about my preferences. And they tell me their recommendations and then you have to weigh it up. That doesn't mean I have to comply with them, but rather state my opinion, how I would like to have things done." (C06)
Characteristic: Medical, disease-related previous knowledge	"I had to look up a lot of additional information. But I have certain..., I just have certain information sources that are not available to everyone, or also certain... let's say, basic knowledge that perhaps not every person possesses either." (R06) "I have two friends who had suffered from the same problem, thus we've already had a good exchange for years. We talked frankly about it, that's why I've already had a lot of knowledge." (R04)
Characteristic: Interest, self-efficacy, self-concept (active role)	"As to me, I realized that I have to take responsibility for myself. Not have to, but want to. At that moment, I no longer wanted to leave the responsibility to the doctor alone and to the doctors who treated me, but I wanted to have a say in this matter. And it was important for me to inform myself. So, I really wanted to be able to talk with the doctors on equal terms." (SH07) "I am the patient and I have to know what is wrong with me. It doesn't help me if all doctors know what's wrong with me (...) So I'd always try to be able to help myself (...) But I feel, in general, when it comes to health, as a patient you really have to think for yourself." (R07)
Characteristic: Trust in the doctor	"Well, I do have trust in that matter. I also do not need five opinions on that, if that's what's told me in here, it's ok to me then, I'll choose that way." (C03)

relevance, understand medical terms, and consequently appraise information to make a sound treatment decision. Dealing with a large amount of illness- and treatment-related information and making decisions based on the current state of information was

discussed, particularly for the earlier phases of the disease trajectory. Furthermore, dealing with contradictory information or opinions received from doctors and uncertainties because of current knowledge constituted challenges to the women during all stages.

Table 5
Main categories and examples of quotes referring to perceived support.

Main categories	Quotes/Key examples
Relatives and friends – conversations	"Yes, but my partner was also very helpful to me, he really acquired a lot of information himself. And picked out the... the most important sources of information, where you can get informed easily. (...) and that's why I was glad to have my partner who started to organize that." (SH12)
Relatives – support during doctor's consultation	"Well, I think, the support of my family, of course. That there is always someone around. Because during this situation you are somehow..., how to say, distracted (...) So it's always good if there's a second person around who can fully reproduce it to you later." (R10)
Professionals – needs-orientated information	"Well, the doctors were really responsive to me, for example, when the diagnosis and further proceedings of the treatment were disclosed (...) Yes and there was a senior doctor, I approved that it was someone with experience. So that you really got good information and answers to your questions." (SH13)
Professionals – patient-centered communication	"...in the clinic, there is this nurse as a case manager, she's called 'breast care nurse', and she brings all medical information together and imparts them in a way you can understand them, even if you are stressed out and can only retain half of it." (C14)
Peers, self-help groups – exchange	"Because you get a lot of information by the self-help group members, of course. We use a What's App group to exchange and it's a good source of information because you can benefit from other's experiences, yes." (SH15)
Counseling center – information source	"The cancer information service was also very important to me. I called them several times and the kind of consultations were like I would have wished them to be in hospital." (SH14)
Hospital, rehabilitation center – information source	"In regard to the disease, at this place they really do a lot (...). There are presentations, talks about all topics concerning breast cancer. And I think it's great what's done by the rehabilitation clinic (...)" (R05)
Interdisciplinary cooperation – information transfer, assistance	"The flow of information between general practitioner and gynecological experts and acute clinic has been fantastic. (...) Well, I'm always in between, but the communication practice, GP, medical specialist, clinics, psychooncologist... it's a working network. And it's working pretty well." (R01)

3.4. Personal competencies

3.4.1. Self-regulation of information needs

Participants described to close information search deliberately, for example, if the information given was sufficient for a sound decision or they wanted to finish the topic of cancer to concentrate on other aspects of life again. Acute patients reported that they regulated their information search by looking only for information relevant to their present situation and its challenges. Rehabilitants and SHG members decided to reduce or avoid information to gain relief.

3.4.2. Self-directed information acquisition - media and social competencies

The women reported media and social competencies as relevant to successful information seeking. According to their needs, they acquired and read (professional) literature and used multiple media sources (e.g., television, internet, and books). Some acute patients described that they deliberately chose information sources matching their skills and preferences. For example, one woman preferred television or paper-based information because she was not used to internet research.

Furthermore, the women reported to benefit from information exchange on their initiative with experts, peers, relatives, and friends. They contacted suitable persons in their private sphere to gain information or check for knowledge gaps. SHG members visited cancer information events and congresses organized by SHGs. They talked to experts to evaluate information, even after follow-up treatment had already been finished. They also found it essential to actively and self-directedly search for information and information sources.

3.4.3. Communication skills in the doctor-patient conversation

To profit from medical consultations, participants noted questions beforehand or used question prompt sheets and actively, repeatedly inquired about topics of their interest. Some women claimed information and time for the consultation from clinicians. A few participants brought family members with them to support processing or memorizing information and facilitate information transfer. Moreover, acute patients reported that they communicated their individual needs, for example, one woman demanded additional diagnostics because of pre-existing diseases in her family.

3.4.4. Internet competencies

Participants described that they deliberately chose reliable websites and sources to gain or check information, like their acute clinics or independent foundations. Some women avoided distressing sources like patient chat forums. One woman explained: "You really have to beware of attending forums in which, no matter what you are looking for, you only get horror scenarios. (.) Because the information ... either it isn't right, or it's dramatized, at least it isn't balanced. And you never know the source (.) it only leads to confusion." (SH15).

Furthermore, they used the internet purposely and needs-oriented to gain basic and current information and to promote their understanding. Rehabilitants searched online with the necessary persistence to fulfill needs and dealt critically with doubtful contents, as one woman reported that she appraises internet search results carefully and checks new information by talking to peers and experts.

3.4.5. Self-directed decisions according to own needs

Participants described satisfying treatment decisions based on their level of information. They perceived autonomous and participatory decision-making by taking their own needs, experiences, and wishes into consideration. Participants had physicians involved in the decision process to facilitate decisions, even if final treatment

decisions were contrary to the doctors' recommendations. Some SHG members stated that obtaining a second opinion was helpful to be more confident in making their own decisions.

3.4.6. Characteristic: medical, disease-related previous knowledge

Due to occupational or private experiences, some participants possessed previous knowledge about the disease and related aspects. They could better understand and integrate new information and choose beneficial information sources.

3.4.7. Characteristic: interest, self-efficacy, self-concept (active role)

Participants of acute care and SHG settings felt self-efficient regarding information acquisition and processing in current or future situations. Rehabilitants and SHG members described a personal interest in disease-related information and having a self-concept of an active patient role. Thus, they expressed their wish to participate in decision and treatment processes and to inform themselves comprehensively. Furthermore, the women helped themselves by structuring and self-organizing information by collecting materials, sorting them in folders, and facing contents gradually.

3.4.8. Characteristic: trust in the doctor

Another described characteristic was gaining trust in the doctors, their information, and medical approaches. The women were able to reduce uncertainties and confusion, for example, when dealing with contradictory or dubious information, by relying on the information given by their doctors. Furthermore, they reported that having trust in the physicians helped regulate information needs, concentrate on treatment, and cope with their lack of expert knowledge.

3.5. Helpful support

3.5.1. Relatives and peers – conversations, exchange, and support during doctor's consultations

Relatives, friends, peers, and experts in private and SHGs exchanged information and supported the women by sharing their knowledge and experiences – in person or online. Besides, relatives and friends took an active part in the information process, by gathering, structuring, and imparting information or helping to regulate information needs and search if participants were too distressed with it. Relatives had a particular role by attending consultations, as they helped to gain and understand the information given. For example, they asked questions themselves or intervened, like one participant's daughter, who defended her mother's requests against the physician who refused to take time for answering questions.

3.5.2. Professionals – needs-oriented information and patient-centered communication

Participants perceived that professionals, such as physicians, breast care nurses, caregivers, psychologists, delivered information tailored to their needs. Thus, doctors provided sufficient and required information and explained contents comprehensibly and vividly, for example by introducing special programs and showing digital graphics of the surgery. Furthermore, clinicians promoted shared decision-making, by discussing treatment options, risks, and personal recommendations and making (repeated) information offers. Some acute care patients felt relieved by information supply about favorable aspects and positive prognosis of the disease, if applicable. Professionals also provided support by using a patient-centered communication style, when they transferred information factually, asked for information comprehension, and made time for answering questions. Moreover, they created a confidential atmosphere of conversation, stayed empathetic, and admitted the emotional reactions of patients and relatives during the consultation.

3.5.3. Counseling center and hospitals – information sources

SHG members reported cancer counseling services as an auxiliary source of information, by providing helpful contacts or information material and information offers like SHGs and consultation appointments. Additionally, acute and rehabilitation clinics were perceived helpful by providing various information materials and offers, including information folders, lectures, seminars, or patient guides. Acute clinics also informed about contact persons according to specific supportive care needs like psychosocial needs.

3.5.4. Interdisciplinary cooperation – information transfer, assistance

Rehabilitants profited from the interdisciplinary cooperation of the different physicians and institutions, for instance, if there was a sufficient information transfer between practitioners, or acute clinics cooperated with social services or medical supply stores.

2. Discussion and conclusion

2.1. Discussion

This study investigates the health literacy of breast and gynecological cancer patients as an interplay of challenges, personal competencies, and helpful support from the patients' view. With the qualitative interviews, deeper insights could be gained. The women described several challenges in dealing with disease-related information needs and named competencies in fulfilling these needs. Professionals, family, social environment, and different institutions were experienced as helpful support. The individuality of components and complexity of their interplay highlights the relevance of individualized and needs-based care.

Our study particularly illustrates the crucial role of clinicians. The women reported the *doctor-patient communication* as a challenge, since structural, internal, and interpersonal barriers may occur. These might contribute to disagreements between patients and oncologists about the information provided and discussed [23,24]. In line with prior research [21,25], our findings stress the problem of poor physician communication hindering information gathering and shared decision making. On the other hand, the women highlighted *needs-oriented information and patient-centered communication* by clinicians as helpful support. Treatment team members can reduce information needs if the contacts are perceived as helpful [7]. However, communication should match the evolving needs of cancer patients throughout treatment [26]. Thus, it is essential to train the patient-centered communication skills of clinicians as a basis for efficient consultation, which might also contribute to a trusting doctor-patient relationship. So far, there is evidence that communication skills trainings increase empathy and probably other aspects of communication skills, but the evidence is uncertain [27,28]. Having *trust in the doctor* was reported as a positive characteristic when dealing with information needs and uncertainties. Building a good, trusting and, empathetic relationship between professionals and cancer patients has been essential to reduce unmet information needs [29].

Moreover, patients described several patient-related *communication skills in the doctor-patient conversation* that counteract barriers. Feeling *self-efficient* and taking an *active patient role* are characteristics when dealing successfully with information needs. Patients' perceived communication competence, especially when searching for information, is associated with better health-related quality of life [30]. Results highlight the importance of promoting patients' communication skills and engagement, especially at an early disease phase. The use of question prompts during consultations showed positive effects on patients' competence of interaction with the medical team [31], the number of questions asked, and

information recall when discussed and endorsed by doctors. However, studies concerning unmet needs are missing [32].

Situationally limited information processing of patients during consultations or early phase of treatment operates as another barrier. Awareness among doctors and patient-centered communication, that is, active listening, seems essential. Furthermore, relatives were perceived as *helpful support during doctor's consultations*. Prior research shows that partners involved in oncology consultations can provide emotional and informational support [33]. Patients should be aware of that and empowered to use family support. Exploring patient's information processing capacities can help caregivers to provide a needs-oriented information supply, for example, by making further consultation offers in the early disease trajectory or introducing constant contact persons during treatment.

Further challenges were *gaining information according to own needs*, the barrier of *difficult access to information*, different aspects regarding the *internet as a source of information*. Findings are in line with prior research on information challenges during the diagnostic phase of breast cancer [16] but show that rehabilitants and SHG members still report similar experiences, implicating that those problems last throughout treatment. Women reported a wide array of competencies they used to overcome those challenges. Regarding information gathering and access, they *self-regulated their information needs or acquired information self-directedly*. They actively got involved by using various information sources and contacted others including *relatives, friends, peers, counseling centers, and hospitals* who, vice versa, offered helpful support by exchange, information, or interdisciplinary cooperation and assistance.

Contrary, the *internet* was perceived as a *challenging source of information*. A significant proportion of cancer patients could not search health-related information online successfully [34]. Therefore, the progressing digitalization of disease-related information poses a growing problem [35]. On the other hand, participants reported different *internet competencies* to deal with dubious or overwhelming online information. Therefore, assistance, reliable recommendations, suitable aids like guidelines or medically verified websites for cancer patients, and training to perform successful online research might foster health literacy. With corresponding competencies, internet portals and health-related social networks like online health communities can then, in turn, be helpful. Online communities, for example, could provide emotional and informational support and thus contribute to cancer survivors' health literacy when using electronic sources [36].

Prior research stated that cancer patients more often prefer a passive role in treatment decision-making [37], or their participation preferences are unmet [38]. This might be due to experienced problems in *evaluating information and making sound treatment decisions*. Patients' uncertainties and poor physician communication can be barriers, but, in turn, physician consideration of cancer patient preferences can facilitate shared decisions [21]. Some women highlighted *self-directed decisions according to their needs* either on their own or together with their doctors. By reducing uncertainties and taking patients' experiences and wishes into account, clinicians can provide individual and patient-oriented support to medical decisions.

2.1.1. Strengths and limitations

A strength of our study is the integration of information needs in the theoretical background of health literacy and patient competencies. The categories derived from the interviews of our study can similarly be found in other concepts of cancer patient competences regarding information needs [39]. Another strength is that we interviewed patients in different phases of the disease trajectory to get a comprehensive insight into the patients' experiences and perspectives on dealing with cancer-related information needs.

However, limitations need to be considered. We have little information about the reasons for non-participation. Possibly women with lower health literacy did not participate. Sample characteristics show a high educational level. On the one hand, this must not be a disadvantage for our aim to capture as many health competencies as possible. On the other hand, lower educational groups may have different or additional challenges. Another limitation is the pre-defined sample size and the monocentric recruitment in the acute setting due to organizational reasons. However, we think we reached data saturation as no further themes emerged after most of the interviews were analyzed for each setting. Nevertheless, we did not interview experts, clinicians, or family members. Different perspectives could help to gain an even better understanding of the interplay model presented. Furthermore, results cannot neither be generalized to other types of cancer nor be interpreted as unique to breast and gynecological cancer patients. Therefore, further research should focus on that.

2.2. Conclusion

Women with breast and gynecological cancers face multiple challenges to successful information access, evaluation and use across and beyond the course of treatment that need to be addressed in (psycho-)oncological work. Individual information needs can be met primarily through an active patient role. There are many personal competencies, which can support patients' health literacy. However, patient-centered communication and care appear to be critical to reducing patient challenges. The reported challenges and competencies could be implemented into a theoretical model of health literacy as an interplay of both components [20]. Our study provides examples of challenges and competencies relevant to cancer patients' health literacy and integrates the influence of perceived support. can help patients overcome challenges and facilitate patients' efforts to apply and improve their competencies when dealing with information needs. On the other hand, it can directly reduce challenges. Thus, our results contribute to finding ways of promoting cancer patients' self-management of the disease.

2.3. Practice implications

According to our theoretical model, there are two possible ways for clinicians and caregivers to improve patients' health literacy and consequently address their information needs. Firstly, it is essential to know about the challenges patients face and develop strategies and supporting offers to reduce them. According to our results, training in patient-centered communication skills may be a fundamental approach and making information easier to access and evaluate. Secondly, we found several patient competencies that should be assessed through screenings or exploration before providing information. In this way, existing competencies can be deployed, and consultations can be adapted individually, for instance, by referring to prior knowledge, promoting an active patient role and self-management, and offering needs-oriented information material, sources and aids. Finally, our findings show that actively involving relatives, peers, SHGs or counseling services in the information and treatment process can also positively affect both components of health literacy. Clinicians should aim to improve cancer patients' health literacy according to their needs and thus, contribute to patients' information satisfaction, self-management, and quality of life.

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CRedit authorship contribution statement

Natascha Fahmer: Formal analysis, Investigation, Writing – original draft. **Hermann Faller:** Conceptualization, Funding acquisition, Methodology, Validation, Supervision, Writing – review & editing. **Dirk Engehausen:** Resources. **Holger G. Hass:** Resources. **Monika Reuss-Borst:** Resources. **Kristin Duelli:** Resources. **Achim Wöckel:** Conceptualization, Funding acquisition, Project administration, Resources. **Peter U. Heuschmann:** Conceptualization, Funding acquisition, Project administration. **Karin Meng:** Conceptualization, Formal analysis, Investigation, Methodology, Validation, Writing – review & editing, Project administration.

Declaration of Competing Interest

All authors confirm that there are no conflicts of interest.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2021.12.006](https://doi.org/10.1016/j.pec.2021.12.006).

References

- [1] Halbach SM, Ernstmann N, Kowalski C, Pfaff H, Pfortner TK, Wesselmann S, et al. Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. *Patient Educ Couns* 2016;99:1511–8. <https://doi.org/10.1016/j.pec.2016.06.028>
- [2] Maguire R, Kotronoulas G, Simpson M, Paterson C. A systematic review of the supportive care needs of women living with and beyond cervical cancer. *Gynecol Oncol* 2015;136:478–90. <https://doi.org/10.1016/j.ygyno.2014.10.030>
- [3] Fletcher C, Flight I, Chapman J, Fennell K, Wilson C. The information needs of adult cancer survivors across the cancer continuum: a scoping review. *Patient Educ Couns* 2017;100:383–410. <https://doi.org/10.1016/j.pec.2016.10.008>
- [4] Lu H, Xie J, Gerido LH, Cheng Y, Chen Y, Sun L. Information needs of breast cancer patients: theory-generating meta-synthesis. *J Med Internet Res* 2020;22:e17907 <https://doi.org/10.2196/17907>
- [5] Pauwels EEJ, Charlier C, De Bourdeaudhuij I, Lechner L, Van Hoof E. Care needs after primary breast cancer treatment. Survivors' associated sociodemographic and medical characteristics. *Psycho-Oncology* 2013;22:125–32. <https://doi.org/10.1002/pon.2069>
- [6] Burg MA, Adorno G, Lopez ED, Loerzel V, Stein K, Wallace C, et al. Current unmet needs of cancer survivors: analysis of open-ended responses to the American Cancer Society Study of Cancer Survivors II. *Cancer* 2015;121:623–30. <https://doi.org/10.1002/cncr.28951>
- [7] Schmidt A, Ernstmann N, Wesselmann S, Pfaff H, Wirtz M, Kowalski C. After initial treatment for primary breast cancer: information needs, health literacy, and the role of health care workers. *Support Care Cancer* 2016;24:563–71. <https://doi.org/10.1007/s00520-015-2814-6>
- [8] Faller H, Hass HG, Engehausen D, Reuss-Borst M, Wöckel A. Supportive care needs and quality of life in patients with breast and gynecological cancer attending inpatient rehabilitation. A prospective study. *Acta Oncol* 2019;58:417–24. <https://doi.org/10.1080/0284186X.2018.1543947>
- [9] Lehmann-Laue A, Ernst J, Mehnert A, Taubenheim S, Lordick F, Gotze H. Supportive care and information needs of cancer survivors: a comparison of two cohorts of longterm cancer survivors 5 and 10 years after primary cancer diagnosis. *Psychother Psychosom Med Psychol* 2020;70:130–7. <https://doi.org/10.1055/a-0959-5834>
- [10] Rietveld MJA, Husson O, Vos MCC, van de Poll-Franse LV, Ottavanger PBN, Ezendam NPM. Association between information provision and supportive care needs among ovarian cancer survivors: a cross-sectional study from the PROFILES registry. *Psycho-Oncology* 2018;27:1922–9. <https://doi.org/10.1002/pon.4742>
- [11] Faller H, Strahl A, Richard M, Niehues C, Meng K. The prospective relationship between satisfaction with information and symptoms of depression and anxiety in breast cancer: a structural equation modeling analysis. *Psycho-Oncology* 2017;26:1741–8. <https://doi.org/10.1002/pon.4358>

- [12] Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol* 2011;22:761–72. <https://doi.org/10.1093/annonc/mdq413>
- [13] Keij SM, van Duijn-Bakker N, Stiggelbout AM, Pieterse AH. What makes a patient ready for shared decision making? A qualitative study. *Patient Educ Couns* 2021;104:571–7. <https://doi.org/10.1016/j.pec.2020.08.031>
- [14] Fiszer C, Dolbeault S, Sultan S, Bredart A. Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review. *Psycho-Oncology* 2014;23:361–74. <https://doi.org/10.1002/pon.3432>
- [15] Nicolaije KAH, Husson O, Ezendam NPM, Vos MC, Kruitwagen RFFPM, Lybeert MLM, et al. Endometrial cancer survivors are unsatisfied with received information about diagnosis, treatment and follow-up: a study from the population-based PROFILES registry. *Patient Educ Couns* 2012;88:427–35. <https://doi.org/10.1016/j.pec.2012.05.002>
- [16] Ormel I, Magalhaes M, Josephson D, Tracey L, Law S. How to know what to know: information challenges for women in the diagnostic phase of breast cancer. *Patient Educ Couns* 2021;104:179–85. <https://doi.org/10.1016/j.pec.2020.06.030>
- [17] Sorensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* 2012;12:1–13. <https://doi.org/10.1186/1471-2458-12-80>
- [18] Verkissen MN, Ezendam NPM, Franssen MP, Essink-Bot ML, Aarts MJ, Nicolaije KAH, et al. The role of health literacy in perceived information provision and satisfaction among women with ovarian tumors: a study from the population-based PROFILES registry. *Patient Educ Couns* 2014;95:421–8. <https://doi.org/10.1016/j.pec.2014.03.008>
- [19] Nutbeam D. The evolving concept of health literacy. *Soc Sci Med* 2008;67:2072–8. <https://doi.org/10.1016/j.socscimed.2008.09.050>
- [20] Parker R, Ratzan SC. Health literacy: a second decade of distinction for Americans. *J Health Commun* 2010;15:20–33. <https://doi.org/10.1080/10810730.2010.501094>
- [21] Covvey JR, Kamal KM, Gorse EE, Mehta Z, Dhumal T, Heidari E, et al. Barriers and facilitators to shared decision-making in oncology: a systematic review of the literature. *Support Care Cancer* 2019;27:1613–37. <https://doi.org/10.1007/s00520-019-04675-7>
- [22] Mayring P. *Qualitative Inhaltsanalyse: Grundlagen und Techniken. [Qualitative content analysis: basics and techniques.]* 12th ed. Weinheim: Beltz; 2015.
- [23] Eggly S, Penner LA, Hagiwara N, Gonzalez R, Harper FW, Heath EI, et al. Patient, companion, and oncologist agreement regarding information discussed during triadic oncology clinical interactions. *Psycho-Oncology* 2013;22:637–45. <https://doi.org/10.1002/pon.3045>
- [24] Sakai H, Umeda M, Okuyama H, Nakamura S. Differences in perception of breast cancer treatment between patients, physicians, and nurses and unmet information needs in Japan. *Support Care Cancer* 2020;28:2331–8. <https://doi.org/10.1007/s00520-019-05029-z>
- [25] Koay K, Schofield P, Jefford M. Importance of health literacy in oncology. *Asia-Pac J Clin Oncol* 2012;8:14–23. <https://doi.org/10.1111/j.1743-7563.2012.01522.x>
- [26] Shim EJ, Park JE, Yi M, Jung D, Lee KM, Hahm BJ. Tailoring communications to the evolving needs of patients throughout the cancer care trajectory: a qualitative exploration with breast cancer patients. *BMC Women's Health* 2016;16:1–8. <https://doi.org/10.1186/s12905-016-0347-x>
- [27] Bos-van den Hoek DW, Visser LNC, Brown RF, Smets EMA, Henselmans I. Communication skills training for healthcare professionals in oncology over the past decade. *Curr Opin Support Palliat* 2019;13:33–45. <https://doi.org/10.1097/SPC.0000000000000409>
- [28] Moore PM, Rivera Mercado S, Grez Artigues M, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database Syst Rev* 2018;3. <https://doi.org/10.1002/14651858.CD003751.pub4>
- [29] Neumann M, Wirtz M, Ernstmann N, Ommen O, Langler A, Edelhauser F, et al. Identifying and predicting subgroups of information needs among cancer patients: an initial study using latent class analysis. *Support Care Cancer* 2011;19:1197–209. <https://doi.org/10.1007/s00520-010-0939-1>
- [30] Trudel JG, Leduc N, Dumont S. Perceived communication between physicians and breast cancer patients as a predicting factor of patients' health-related quality of life: a longitudinal analysis. *Psycho-Oncology* 2014;23:531–8. <https://doi.org/10.1002/pon.3442>
- [31] Zetzl T, Mann D, Gruner S, Schuler M, Jentschke E, Neudert S, et al. Question prompts to empower cancer patients: results of a randomized controlled trial. *Support Care Cancer* 2020;28:2571–9. <https://doi.org/10.1007/s00520-019-05036-0>
- [32] Licqurish SM, Cook OY, Pattuwaage LP, Saunders C, Jefford M, Koczwara B, et al. Tools to facilitate communication during physician-patient consultations in cancer care: an overview of systematic reviews. *CA Cancer J Clin* 2019;69:497–520. <https://doi.org/10.3322/caac.21573>
- [33] Stewart SJ, Roberts L, Brindle L. Romantic partner involvement during oncology consultations: a narrative review of qualitative and quantitative studies. *Patient Educ Couns* 2021;104:64–74. <https://doi.org/10.1016/j.pec.2020.08.018>
- [34] Heiman H, Keinki C, Huebner J. EHealth literacy in patients with cancer and their usage of web-based information. *J Cancer Res Clin Oncol* 2018;44:1843–50. <https://doi.org/10.1007/s00432-018-2703-8>
- [35] Ector G, Hermens R, Blijlevens NMA. Filling the gaps of patient information and comprehension. *Curr Opin Oncol* 2020;32:262–8. <https://doi.org/10.1097/CCO.0000000000000633>
- [36] Zhou J, Wang C. Improving cancer survivors' e-health literacy via online health communities (OHCs): a social support perspective. *J Cancer Surviv* 2020;14:244–52. <https://doi.org/10.1007/s11764-019-00833-2>
- [37] Brom L, Hopmans W, Pasma HR, Timmermans DR, Widdershoven GA, Onwuteaka-Philipsen BD. Congruence between patients' preferred and perceived participation in medical decision-making: a review of the literature. *BMC Med Inf Decis Mak* 2014;14:1–16. <https://doi.org/10.1186/1472-6947-14-25>
- [38] Mansfield E, Bryant J, Carey M, Turon H, Henskens F, Grady A. Getting the right fit: convergence between preferred and perceived involvement in treatment decision making among medical oncology outpatients. *Health Sci Rep* 2019;2:e101 <https://doi.org/10.1002/hsr2.101>
- [39] Weis J, Giesler JM. Subjective dimensions of patient competence: relationships with selected healthcare usage behaviors and general features of self-rated competence. *Patient Educ Couns* 2008;73:511–8. <https://doi.org/10.1016/j.pec.2008.07.010>