From Gaps to Solutions: Semi-Structured Interviews to Identify Care Gaps in Breast Cancer Care and How to Solve Them with Digital Solutions

Von Lücken zu Lösungen: halbstrukturierte Interviews zur Ermittlung von Versorgungslücken in der Brustkrebsversorgung und wie diese mit digitalen Lösungen behoben werden können

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ABSTRACT

Background
Standardized treatment pathways should make it easier for medical staff and patients to achieve the best possible individual treatment outcome by making sure all relevant information are taken into consideration. The aim of this paper is to identify gaps in care along the treatment pathway through semi-structured patient interviews. Subsequently, it will be discussed if mobile health applications can close these identified gaps in care.

Material and Methods
Nine semi-structured interviews of patients with invasive lobular breast cancer were conducted in March 2023 in German at the breast cancer center at Charité Universitätsmedizin Berlin, which were subsequently transcribed word for word and processed using a thematic analysis approach.

Results
Eight recurring themes are identified in the patient interviews: 1. Limited capacity to absorb information, 2. Discrepancy between information needs and information provision, 3. Need for individual initiative, 4. Uncertainty, 5. not being seen and heard, 6. Patient's desires and suggestions for improvement, 7. Use of mobile health apps, 8. Support through an app for patients.

Conclusions
The identified gaps in care of breast cancer patients can be largely addressed through the use of digital health solutions after the establishment of regulatory frameworks, thus improving care for patients with early breast cancer.

Trial Registration
The interviews were done within a registry for which ethical approval was obtained by the Ethics Committee of Charité Universitätsmedizin Berlin EA4/180/17.

ZUSAMMENFASSUNG

Hintergrund

Standardisierte Behandlungspfade sollten es dem medizinischen Personal und den Patienten erleichtern, das bestmögliche individuelle Behandlungsergebnis zu erzielen, indem sichergestellt wird, dass alle relevanten Informationen berücksichtigt werden. Ziel dieses Beitrags ist es, durch halbstrukturierte Patienteninterviews Versorgungslücken entlang des Versorgungspfads zu identifizieren. Anschließend wird erörtert, wie mobile Gesundheitsanwendungen diese identifizierten Versorgungslücken schließen können.

Material und Methoden

Im März 2023 wurden im Brustkrebszentrum der Charité Universitätsmedizin Berlin 9 halbstrukturierte Interviews mit Patientinnen mit invasivem lobulären Brustkrebs in deutscher Sprache geführt, die anschließend wortwörtlich transkribiert und mithilfe eines thematischen Analyseansatzes verarbeitet wurden.

Ergebnisse

In den Patienteninterviews wurden 8 wiederkehrende Themen identifiziert: 1. Begrenzte Fähigkeit, Informationen aufzunehmen, 2. Diskrepanz zwischen Informationsbedarf und Informationsangebot, 3. Notwendigkeit von Eigeninitiative, 4. Unsicherheit, 5. nicht gesehen und gehört zu werden, 6. Wünsche und Verbesserungsvorschläge der Patienten, 7. Nutzung von mobilen Gesundheits-Apps, 8. Unterstützung durch eine App für Patienten.

Zusammenfassung

Die identifizierten Versorgungslücken können nach der Schaffung von rechtlichen Rahmenbedingungen durch die Nutzung von mobilen Gesundheitsanwendungen zum großen Teil geschlossen werden und somit die Versorgung von Patientinnen mit frühem Brustkrebs verbessern.

Registrierung der Studie

Die Interviews wurden im Rahmen eines Registers durchgeführt, für das die Ethikkommission der Charité Universitätsmedizin Berlin EA4/180/17 ein positives Votum vergeben hat.

Background

Breast cancer is the most common cancer among women worldwide, affecting approximately 71 000 women per year in Germany alone [1]. One in eight women will be diagnosed with breast cancer in her lifetime. The global incidence is increasing due to effective screening programs, an aging population, and lifestyle changes [2]. Breast cancer in men is rare, accounting for about 1% of cases [3]. Diagnosis is based on clinical examination and imaging techniques like ultrasound, mammography, and MRI, confirmed by tissue sampling and pathological examination. Treatment includes surgery, systemic therapies (chemotherapy, targeted therapy, immunotherapy, and anti-hormone therapies), and radiation therapy, tailored by a multidisciplinary team based on factors like tumor characteristics, patient health, genetics, and preferences to optimize therapeutic benefit while minimizing risks and side effects.

Advances in diagnostics and therapies have reduced the mortality rate from 14.4% (1990s) to 1–5% (2019) [4]. Survival is achieved through personalized therapies, extending up to 10 years post-surgery, depending on tumor type. However, these treatments bring short, medium, and long-term side effects impacting patients' quality of life, work capacity, and social life [5]. Rising breast cancer rates, expanded treatment options, and longer care duration have increased complexity and workload for medical professionals. To manage this complexity and achieve the best treatment outcomes, evidence-based guidelines have been regularly published since 2004, resulting in standardized treatment pathways [6]. A clinical pathway is a structured approach to treating a specific patient group over a set period, simplifying communication, coordination, and activity sequencing for the treatment team and patients based on scientific knowledge. It helps monitor deviations and patient flows. The goal is to enhance care quality, reduce risks, boost patient satisfaction, and optimize resource use [7]. However, traditional pathways often end with therapy completion, omitting the post-treatment phase. According to Deery et al., the transition to survivorship is a time of uncertainty, as active treatment is seen as a coping strategy [8]. While disease significance, treatment options, side effects, and legal issues matter during diagnosis and treatment, the post-treatment phase focuses on lifestyle, nutrition, physical activity, promoting health, and minimizing cancer recurrence risk [9].

Critics argue health care lacks patient-centeredness [10]. Transitioning from disease-centered pathways to patient-centered ones, often termed "Patient Journey," aligns healthcare with business's "customer journey." It focuses on healthcare touchpoints and decision-making from the patient's perspective [11]. The Patient Journey broadens interactions, encompassing information gathering, treatment options, side effects, daily life impacts, and patient decisions. It offers rich data on goals, emotions, findings, and more [5, 12]. However, the combination of medical complexity, societal factors, patient preferences and unpredictable change in routine is making a standardize patient journey very challenging [11]. Implementing cancer patient pathways therefore requires a context-aware approach and breaking down hospital silos and outpatient-inpatient divisions.

Patient-centered care means considering each patient's preferences, needs, and values in decision-making and guiding clinical choices with these values [10, 13]. It fosters patient-provider rela-

tionships, communication, health education, and patient participation [2, 14]. It is a core principle in healthcare quality according to the Institute of Medicine [15]. Germany's Hospital Structure Act of 2015 emphasizes patient centeredness. However, achieving patient-centered care often requires infrastructure changes. While electronic health records and online appointment scheduling might impact patient satisfaction [16], they do not make the care itself more patient centered. To promote patient-centered care, organizations define eight principles [17]:

1. Trustworthy healthcare professionals for effective treatment
2. Continuity of care with structured handovers
3. Patient involvement and respect for preferences in decision-making
4. A clean, safe environment for physical well-being
5. Emotional support, empathy, and respect
6. Involvement of family and friends
7. Clear, understandable information and self-care support
8. Prompt access to reliable healthcare

Scientific evidence supports that patient-centered care is reducing costs with shorter hospital stays, fewer adverse events, and lower healthcare service utilization [18, 19, 20]. It enhances healthcare professional job satisfaction, as well as treatment adherence [18] and improves quality of life and physical health outcomes [21]. Despite these benefits, patient-centered care is still not fully implemented [14, 22]

Digital technologies gain interest in cancer patient and survivor care [23]. eHealth is defined by the Federal Ministry of Health in Germany as the use of modern technology for patient support. mHealth, including mobile health apps, integrates prevention and healthcare into daily life. Advancements like wearable sensors, smart device connectivity, and cloud computing are now affordable and widespread. A cultural shift is evident in social media use, self-tracking, and improved health literacy [24]. In 2018, Bertelsmann Stiftung compared international digital health progress [25]. German hospitals' digitalization levels range from below average [26] to average [27]. Barriers include legal frameworks, data protection, and poor fiber optic infrastructure [28]. COVID-19 revealed the consequences of limited digitalization. Scarce telemedicine options worsened access to care. Fragmentation hindered contact tracing and coordinated responses [29]. Inadequate digitalization complicated pandemic data collection and research collaboration.

The Digital Healthcare Act (DVG) was passed by the German Bundestag in November 2019, before the COVID-19 pandemic. It promotes telemedicine, improves health data usability for research, and grants statutory health insured individuals access to specific digital health apps called DiGAs. In general, digital health applications are health apps on smartphones or browsers, divided into three groups [30]:

1. Lifestyle Apps help you streamline daily tasks; in addition to that, they enable to set goals and track data about progress toward those goals. Fitness, diet, mindfulness, time management, quitting smoking are examples.
2. Service Apps are a type of mobile application that provides a specific service or function to its users. Food delivery, transport, online-booking, pill reminder are examples.
3. Medical Apps are used for diagnosing or treating diseases.

After DVG implementation, medical apps in the third category can be prescribed by physicians or psychotherapists and covered by health insurance after approval by the Federal Institute for Drugs and Medical Devices [31]. Specific approval criteria apply, such as risk classification and achieving a medical purpose through digital core functions [32]. Three DiGAs for breast cancer patients are listed in the directory (as of March 19th, 2024) [33]: "Optimune" offers cognitive behavioral therapy methods, while "PINK! Coach" enhances health-related quality of life and literacy, addressing breast cancer's psychological, psychosomatic, and somatic effects. "Untire" is designed to reduce fatigue in breast cancer patients and survivors.

Most mobile health apps are not DiGAs; they mainly focus on psychoeducation for health understanding [34, 35, 36] or improving quality of life through patient-reported outcomes [37, 38], for some the use is limited to studies [39]. Previous analyses identified apps related to cancer prevention and therapy information [40, 41], but few cater to the follow-up phase [42]. Knöppler et al. categorized health apps into seven types [43]:

1. Health literacy
2. Analysis and insight
3. Indirect intervention: self-efficacy, adherence, and safety promotion
4. Direct intervention: skills, behavior, and condition change
5. Health and medical history documentation
6. Organization and administration
7. Shopping and supply

Given the matured guidelines of evidence-based medicine with clear guidelines for the development and evaluation of the effectiveness of biomedical or behavior-related health measures, there are still only a few guidelines for the systematic development and evaluation of digital health interventions [44, 45] or relevant evaluation criteria suitable for long-term implementation.

To achieve patient-centered care and thus provide high-quality care to all women affected by breast cancer, gaps from the perspective of patients along their treatment journey can be identified in semi-structured interviews. The long-term goal is to close these care gaps. Therefore, it will also be discussed within the scope of this work which of the identified needs can be addressed by using mobile health applications.

Methods

Recruitment

The recruitment of patients was conducted through the e-mail distribution list of a self-help group affiliated with Charité university hospital. Fourteen patients, who were interested and already part of the invasive lobular breast cancer registry, were contacted via a letter of invitation via personal e-mail and asked to sign consent for a semi-structured interview about gaps in care along their treatment path and potentials for the use of mobile health applications by the author of this paper. Nine of them replied to confirm their interest via e-mail and signed the consent form for recording, transcription, and use as part of this project.

Interview guide

The interview guide was prepared using a two-way feedback loop involving the Karsten-Speiser working group (two clinician-physicians, two research-only physicians, one study nurse), and two patient representatives. A statistician of the Institute of Biometry and Clinical Epidemiology was involved for case planning [46, 47].

Interviews focused on the following information:

- Relevant topics regarding the disease and therapy from the patient's perspective
- Difference between information provision and information need
- Current use of mobile health applications
- Problems/gaps in care from the patient's point of view
- Ideas/wishes/suggestions for closing gaps in care

Interview

The patient interviews were conducted as part of the invasive lobular breast carcinoma registry under ethics vote EA4/180/17 of the ethics committee of Charité Universitätsmedizin Berlin. All initially interested patients participated in an interview. Outside of the clinical experience gained by the author over the last seven years while working as a physician, no further training in conducting qualitative interviews took place. None of the nine patients was treated by the author of the study prior to conducting the interviews. An introduction of the person and function (TP, medical doctor, specialist in gynecology with additional qualification in drug-based tumor therapy, employed at the Breast Center of Charité Universitätsmedizin Berlin) and motivation (research project for the development of a digital companion within the Digital Health Accelerator Program of the Berlin Institute of Health at Charité) took place at the beginning of the interview.

Patients were allowed to choose between conducting the interview in person at the premises of the Breast Center of Charité Universitätsmedizin Berlin or via digital videoconference through Microsoft Teams. Four of the Interviews were conducted in person on the premises of the Breast Center and five were conducted digitally via Microsoft Teams. None of the patients brought a companion to the interview.

Transcription and analysis

The interview transcripts were transcribed word for word in German by the author of the paper. None of the patients requested a hard copy of the transcript. The transcripts were processed using a thematic analysis approach as a mixed deductive-inductive thematic analysis according to Mayring [48]. This analysis approach is becoming increasingly important in the field of medical care research [49].

Results

Nine German female patients between 45 and 67 years (mean 56 years; SD 7.9 years) were interviewed between 13 and 35 minutes (mean 26.3; SD 6.8 min). All interviewed patients were in the post-treatment phase of early breast cancer (year of diagnosis: 2015, 2016, 2017, 2018, 2019, 2019, 2019, 2021, 2021).

Of the interviews, four were conducted in person at the premises of the Breast Center of Charité Universitätsmedizin Berlin and five digitally via Microsoft Teams.

The following recurring themes were identified during the content analysis, which are presented below:

- Limited capacity to absorb information
- Discrepancy between the need for information and the provision of information
- Need for personal initiative
- Uncertainty
- Not being seen and heard
- Desires
- Use of mobile health applications
- Support through an app

Limited capacity to absorb information

All patients report that a great deal of new information has to be processed in the course of the diagnosis and therapy phase. At certain points along the treatment pathway, absorption, processing and recall are particularly difficult.

"Of course, especially with the diagnosis, there are always moments when you are first in shock and then you can ask three times, but the information just doesn't stick in your brain and I find that totally difficult." (Patient 2)

"Then I am told, I might need chemotherapy after all, then the head already blacks out the first time, you can't really listen anymore and when the wig prescription is handed over, I black out completely. At that moment, you can no longer ask any questions or think clearly." (Patient 7)

"I have had moments when I thought: no one has told me anything. But when I looked it up in my notes, it was part of the conversation." (Patient 8)

Discrepancy between need for information and provision of information

A large proportion of female patients state that information about the process of diagnostics and therapy falls significantly short of their needs.

"What does this mean for me now? I lacked the outline and overview." (Patient 2)

"So from the doctor I just got the facts, the tumor characteristics, but I didn't know what that meant in detail then or where that could lead or whatever, I explained all that to myself." (Patient 5)

The explanation of therapy options and their side effects as well as alternatives also appears inadequate.

"For example, I then learned afterwards at lectures what the options are for surgery. And I don't even know who decides about it, whether the health insurance company decides about it or the surgeon, so I was a bit surprised that there are different options at all. It was never brought up, neither before nor after in the clinic. It's not in any protocol either." (Patient 3)

"I found that difficult, I also found it difficult that so this topic of side effects played a subordinate role in the education." (Patient 8)

"Well, of course, I would wish that if I got worse, that I would then also get some advice on what I could do." (Patient 4)

"Well, I think so, in the conversations, so what I needed in terms of information, absolutely needed, I certainly got, but my need for information, of course, somehow went beyond that." … "So there was someone in my hospital room, put the things on the table for me and otherwise it was said: you are welcome to call. So there were no personal conversations." (Patient 5)

Need for personal initiative

All patients interviewed reported that they Googled information about their disease and therapy and sought out individual sources of information. In doing so, they were often unsure which sources to trust. Respondents report that more than half of the information they had obtained regarding your condition by the end of treatment was through independent research. For some, this is estimated to be as much as 80 % of their knowledge about their condition and the treatment pathway.

"At the time of diagnosis, I didn't feel well informed at all, and then I switched to self-research relatively quickly." (Patient 8)

"…whereas I looked for a lot of things myself, so my attending physician I would say was rather sober about it." (Patient 6)

"Well, I took care of it myself." (Patient 4)

"Well, I have to say that I come from a bit of a medical background, I am a veterinarian. In this respect, I may not have had quite as many questions as other patients, who are not so medically educated, but nevertheless a big hole opened up at that time" (Patient 9).

"I found the medical terminology hard, it took me hours to familiarize myself with it." (Patient 8)

"I would say 20 % of information came from the doctor and 80 % I learned myself." (Patient 5)

The patients describe it as beneficial to go into the discussions with their treatment team prepared and to work through lists of questions.

"so I asked the doctors and then they told me." (Patient 2)

"I've always read everything myself, so that I can go into the discussions quite professionally or better prepared." (Patient 7)

"I made a list of questions beforehand." (Patient 9)

Uncertainty

In the course of the interviews, the interviewees also repeatedly reported moments of uncertainty in which they did not know what to do, what their task was and where to get support.

"So just shortly after the diagnosis, before the operation, I was somehow in quite a bit of turmoil and then just: how do I now get these examinations that still have to be done for this? It is unbelievable what you have to take care of within a period of time when you are not well." (Patient 2)

"I didn't think of many questions either, I wasn't allowed to bring anyone with me to any of the talks. A lot of things fell under the table for me, i.e. a lot of things that I didn't take away from the conversations. Maybe I also misunderstood because there was no second pair of ears listening in." (Patient 5)

"But honestly, at first I didn't know what I was looking for, what to know in the first place." (Patient 6)

"When the diagnosis came and I needed to inform relatives or friends, colleagues, the instructions always came: don't look up in the Internet at all, you'll only get confused and you'll only be dragged down and, Yes, then I had thought about how best to deal with it. And I didn't ask my doctor any further, because he had a very sober way of dealing with the whole thing and considered a lot of things superficial. So where should I look?" (Patient 6)

"So I don't know at all in the end what happened to me, I find that very unfortunate. And of course I would like to have some influence on what happening." (Patient 8)

Not being seen and heard

The interviewees reported several situations in which both their physical and mental well-being did not resonate with the treatment team.

"I also felt really bad on the first day back then and I thought yes, I have the emergency number, tried there for hours to reach someone, then someone was on the line and then he told me yes, we have other emergencies here now, call back later." (Patient 9)

"I didn't know at all if this is the way for me and through this literature I had got a bit of the impression, there are other possibilities, a spectrum and also room for negotiation, which I need for myself." (Patient 8)

"Topic libido, physical closeness, these are things that play a subordinate role in the educational talks. Where I also feel like you have to address that very clearly as a patient, that you have an issue with that now." (Patient 8)

Patient's desires and suggestions for improvement

During the interviews, the patients expressed numerous wishes for the improvement of care along the treatment pathway, which are exemplified with some quotes.

"A cancer guide or therapy guide, however you want to name it, whether you want it in general or only for the time of acute therapy, but someone who stands by your side a little bit and just knows what's important and also knows what things you often forget." (Patient 5)

"An extra application for relatives, friends and acquaintances, because they are not in your skin and you always have the feeling that actually only patients, who are also affected understand you, the others don't understand you at all. For them, you speak a different language" (Patient 6).

In summary, the most frequently mentioned wishes and suggestions for improvement can be grouped as follows:

- Discussions in the presence of accompanying person, involve relatives
- written material from verified sources for reference
- Overview of treatment pathway
- pointing out treatment alternatives and consequences
- place more emphasis on patient preferences
- Integration of complementary medicine from the beginning of treatment
- Improved management of side effects
- Contact person, 24/7 contact during chemotherapy
- Enable care by cancer specialists in the aftercare phase

Use of mobile health applications

Patients have so far been very reluctant to use mobile health applications, but have consistently used the Internet to find out more about the disease and therapy of breast cancer. Here, however, they complain that it is very difficult and only possible to a limited extent for laypersons to filter literature with medical evidence and to distinguish it from unqualified contributions.

A patient explains to use an app for weight monitoring and reduction. She finds reminders, setting individual goals and visual weight progress particularly motivating and helpful.

"No one pushes me, it's a totally voluntary thing, but I have someone watching me […] Noom, so I think it's really good and you can set your goals. There are also curves, you can see how you're doing and yes, and the curve always calms me down somehow." (Patient 1).

One patient said she had downloaded an app for gymnastic exercises, but never used it because she found it impractical to do sports with her cell phone in her hand. Another patient reported a meditation app, that she had already learned about from breast cancer and then used it a lot again during chemotherapy, financed by the statutory health insurance. In addition, the patient used a diary app.

"Just to see how I'm doing and really document that and next day also just to be able to objectively assess, so to speak, as far as possible, whether it's better or worse or the same." (Patient 3)

Patient 5 states that she has downloaded an app for breast cancer patients, but that she does not see any added value in it.

"Well, there's an app, in retrospect I ask myself why I have it at all, because it can't do anything, so apart from the fact that I entered my data there at some point, it doesn't actually do anything for me." (Patient 5)

One patient was critical of the idea of mobile health apps, expressing that human interactions are most important to her and therefore she has not used mobile health apps to date.

"I still read all that in a book. I still do all that in analog or in a group, and that's important to me anyway, people, people are always important to me." (Patient 4)

Patient 6 has used two health applications. She has found the input and monitoring of symptoms during chemotherapy very helpful. Another one was prescribed for her by the rehabilitation clinic for continuing exercise therapy at home after discharge.

"… the Mika App, which the Berlin Cancer Society had presented at an event, […] this checklist and then I answered every day how I feel […]", "and it was called the Casper App […] simple sports exercises on the floor, so that you train the abdominal muscles. And there were also fantasy journeys and I found them quite good, quite relaxing." (Patient 6)

One patient downloaded the PINK Coach app and reported especially appreciating the reminder function.

"Which I find very helpful because it reminds you of everything like drinking, exercise, appointments and things like that, and then there is also support in my opinion where you can enter complaints and then you get a slight orientation there as well." (Patient 7)

One of the patients raised privacy concerns.

"I always get a problem when I have the feeling that I am sending my health data to an American or Russian server." (Patient 8)

Patient 9 stated that she had so far only used the pedometer on her cell phone, but had not otherwise dealt with the issue of digital support, in particular because she was concerned that it did not represent any medical evidence.

"I haven't thought about it hard enough yet […] I would always like to have medical evidence somehow, where I then say OK, I can explain that to myself, I can rely on that or do I want to rely on that?" (Patient 9)

Support through an app for patients

Several patients state that they would like digital support for mapping their treatment pathway, ideally this should be linked to further information about the therapy.

"If this path is included, for example, as I said, it was problematic for me after the diagnosis before the operation, where do I get all this? Yes, that's the thing that's pending, who does something like that at all, so that I don't have to start googling all over again" (patient 2).

"Well, I would definitely like to see a section in the digital application: Where can I get more information? And then with different links to guidelines uh, experience reports, maybe also consultation structures?" (Patient 8)

The translation of the tumor formula and of technical terms is requested, as well as an explanation of the relevance of laboratory values. The desire for an explanation of the drugs and their mechanism of action as well as for a keyword search also appears several times. Documenting and managing short- and long-term side effects under therapy, here especially chemotherapy, but also anti-hormone therapy, has a high priority.

"The women can express themselves via an app and it is received on the other side, so this information and the computer makes something out of it, so develops a score now here is somehow yet danger imminent and we must perhaps react and the doctor should perhaps contact there." (Patient 7)

"So it would have been good to have an app like this, I enter this, yesterday I had chemotherapy with this and this drug and today I have these and these complaints. What could that be?" (Patient 9)

Socio-legal aspects along the therapy path, such as entitlement to transportation and counseling structures, but also concerns around re-entry into working life are also very important to the women interviewed.

"… and to see that just in an application, that I have right to transport to chemotherapy and can go there by cab. That you have an overview, who can you turn to, where can you make which appointments." (Patient 2)

"So I would still wish for legal things, do I have a right to rehab again? How does it look work-wise?" (Patient 6)

One of the respondents suggests using mobile health applications also for information around quality and standards of therapy locations.

"What distinguishes a breast center? There are more than private and statutory, more important is that they have experience with surgery and that they operate well." (Patient 2).

Reminders of aspects of individual health management such as exercise and nutrition also run through numerous portions of the interviews and play a relevant role in the long-term use of a mobile health app.

"Yes, so such an app honestly helps me to always remember that I should move, that I should also do smaller exercises in everyday life so I also have at my workplace." (Patient 6)

However, Patient 6 explains that she considers exercise goals adapted to the course of therapy to be extremely important in order to maintain motivation, as the state of health can fluctuate on a daily basis, especially during chemotherapy.

"Yes, during treatment is difficult, because if I think of my chemo time, it was so that it went so wavelike, directly after, after I got the chemo, one day after [...] I went jogging and it also did me relatively good and then there was of course such a drop in performance." (Patient 6)

The same applies to the topic complex of aftercare, in which not only the reminder of appointments, the management of long-term side effects of surgery and chemotherapy as well as anti-hormone therapy converge, but also topics such as re-entry into professional life. Bringing attention to new treatment options or findings is also perceived as relevant in this section.

"Hints about no idea, new therapy options, new research results so what interests a hold around the own disease." (Patient 5)

Discussion

In this interview study, the immense contrast between information needs and provision stands out. Those findings are consistent with the results published to date.

Summary of principal findings
Patients express a strong need to take initiative in gathering information about their diagnosis and treatment. They would prefer to receive an overview of treatment phases at diagnosis, followed by detailed information in small segments throughout their journey. Additionally, they seek insights into treatment alternatives including their short and long-term consequences. This empowers patients to make informed decisions aligned with their preferences and quality of life. Due to insufficient discussion of treatment options and their preferences, patients often feel overlooked.

Critical moments, where patients struggle to absorb information, include diagnosis, chemotherapy recommendation, and provision of a wig prescription. They emphasize the importance of discussions in the presence of a companion and involving family members, especially in psycho-oncological counseling.

Patients struggle to find evidence-based literature and seek reliable written materials from their treatment team, both in print and online. They also find education about side effects lacking, particularly in managing mild side effects, leading to significant uncertainty and anxiety throughout their journey, including post-treatment phase. Patients also request a designated point of contact for organizational matters and access to cancer experts for discussing side effects during and after chemotherapy. Furthermore, complementary medicine is underutilized and patients therefore, seek more support.

Comparison to literature
Mobile health applications show promise in addressing gaps in early-stage breast cancer care, as identified through literature review and patient interviews. They provide the opportunity to deliver targeted information to patients that can aid in their understanding of their diagnosis and treatment [50], especially when there is limited time for personal discussions with the healthcare team [51]. As Brual et al. suggest the use of predefined filter questions or relevant clinical information enables tailored and personalized information for each individual patient [52]. Mobile health apps improve treatment appointment readiness and follow-up. They enable pre-appointment and therapy-accompanying completion of digital questionnaires for patient's personal health, medical history, their preferences as well as risk factor screening, facilitating early treatment initiation [53]. Amongst others Ponder et al. showed that, based on this data, the valuable and limited time in the discussion with the informed patient can be better utilized to address outstanding questions and make decisions together [54, 55]. Mann and Lawrence affirm that through the use of mobile health applications, the time for information dissemination by the healthcare team is no longer limited to the time spent in the examination room, but can be continuous along the patient's journey [56]. As Ciria-Suarez et al. also explain, during the brief personal conversation when the cancer diagnosis is communicated, it can be challenging to fully process the many potentially life-changing pieces of information, especially as this conversation is often characterized by excitement, concern, and sometimes fear of mortality [57].

Mobile health applications can provide evidence-based literature for reference and digital decision aids to help patients. By delivering information in smaller, treatment pathway-aligned segments, comprehension is facilitated.

Scientific evidence supports the use of mobile health apps especially for managing side effects [58, 59, 60]. Lu et al. could show that a symptom diary allows patients to reflect on their symptoms [61], aiding treatment discussions. Employing a chatbot to assist with mild side effects offers guidance without burdening medical staff was shown by Tawfik et al. [62]. Several randomized controlled trials have shown that regular collection of patient-reported outcomes (PRO) can be combined with an alarm system to manage data efficiently [63, 64]. Communication of patient condition and alarms to both the healthcare team and patients is crucial [65]. As Lagendijk et al. also conclude symptom screening before treatment appointments can shift the focus from problem identification to problem-solving and address overlooked topics like sexuality [66]. Integrating evidence-based recommendations for managing side effects is highly desired by patients and can alleviate pressure on medical staff [54].

Patients desire evidence-based information beyond disease specifics, covering topics like nutrition, physical activity, mental health, social rights, and counseling [52]. Legal and social counseling should extend into post-treatment, aiding in workforce reinte-

gration [67]. Keyword search in a digital knowledge portal enables quick access to diverse materials. A feedback function allows users to rate articles and request new content, ensuring relevance. Digital support can enhance the post-treatment phase [68] by providing reminders for follow-up examinations, information on long-term treatment consequences, and updates on treatment recommendations. Mobile applications can also facilitate community engagement through chat functions and online events, as well as in-person meetings and support groups within the digital platform [69].

Limitations

The recruitment of patients for interviews was conducted through the e-mail distribution list of a self-help group affiliated with a university hospital. It is important to note that this may introduce a bias and select for engaged patients who potentially engage more with their illness and related topics than the average patient. All interviewed patients were in the post-treatment phase. For a comprehensive assessment of information needs along the patient journey, patients from all stages of treatment should be interviewed. Although no significant differences were observed between video and in-person interviews either during the interview period or in terms of content focus, this should be examined more closely in future analyses. With a small sample selection, the generalizability is limited, even if the interview results align with those in the literature.

Conclusion

Collaboration between medical professionals, patients, and technology partners is crucial for maximizing the potential of mHealth apps. This collaboration should start early in the conception and development phase, aiming for user-friendliness based on feedback from patients and healthcare providers. Participatory design and co-creation are increasingly recognized as vital in developing innovative digital health services. Smooth data flow across departments and sectors is essential, enabling quick access to necessary data and reducing documentation efforts. Interoperability between different digital applications is key, requiring standardized language based on international standards. Flexible privacy regulations are necessary to protect patients' rights while ensuring efficient data handling. Expanding telemedical and digital infrastructure is vital for successful mHealth app implementation.

Overcoming these challenges will help close care gaps for early-stage breast cancer patients, leading to improved healthcare.

Other Declarations

Ethics approval and consent to participate

The patient interviews were conducted as part of the invasive lobular breast carcinoma study of AG Karsten-Speiser, study director PD Dr. med. Maria Magarete Karsten, under ethics vote EA4/180/17 of the ethics committee of Charité Universitätsmedizin Berlin.

Availability of data and materials: Transcripts of interviews are available in German at corresponding author.

List of Abbreviations

DiGAs   Digitale Gesundheitsanwendung, Digital health care application
DVG   Digitale Versorgungsgesetz, Digital Healthcare Act
mHealth mobile Health
PRO   patient-reported outcomes

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