An interface between ehealth, health literacy and health-related behavior: Qualitative interview study on laypersons experiences with a mobile symptom checker app

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Abstract

Background: Symptom checkers are designed to support their users in recognizing medical symptoms and recommending courses of action. The applications are not yet reliable for self-triage and diagnostics. Users (e-)health literacy plays a role in how symptom checkers are used, but it is unclear how the process from symptom via application input to consulting health care works.

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Methods: As part of the CHECK.APP project, 15 medical laypersons were interviewed about their experiences with a specific symptom checker using an interview guideline. The transcripts of the interviews were analyzed using the integrative basic procedure. It combined an analysis of social positioning and agency with Achtziger and Gollwitzer's Rubicon model as concrete heuristics.

Results: App use corresponds to a cyclic process. Its initiation depends on biographical, social and contextual factors. Users employed symptom checkers for three purposes: Information gathering, action recommendation and communication. They integrate various social, personal and digital resources in their health-related behavior. Their evaluation of the use process depends on context factors, app output and the result of their health-related behavior.

Conclusions: Health literacy and e-health literacy are expressed at each step of the process, showing that symptom checkers rely heavily on users’ health literacy. To be more effective, symptom checkers should be more transparently integrated in health care.
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Original Paper

An interface between ehealth, health literacy and health-related behavior: Qualitative interview study on laypersons experiences with a mobile symptom checker app

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Trial Registration: German Clinical Trials Register (DRKS) DRKS00022465; https://tinyurl.com/yx53er67.

Keywords: Symptom checker applications; Health literacy; eHealth literacy; Qualitative research; Interview study

Introduction

This qualitative study focuses on investigating relationships between the three concepts eHealth literacy (eHL), health literacy (HL), health related behavior (HRB) and the use of a specific symptom checker application (SCA) by medical laypersons.

SCA are readily available digital applications on mobile devices that support medical laypersons in the assessment of symptoms and/or self-triage[1, 2]. In Germany, SCA play a role in layperson's health information-seeking behavior (HISB) alongside books, other internet resources and consulting friends or family [3]. Despite continuous efforts to improve them, SCA algorithms remain mainly risk-averse at the cost of diagnostic accuracy, especially in non-acute situations [4-7]

Several studies associate SCA use by laypersons with the concepts of eHL, HL and HRB [1, 8-10]. Aboueid identified HL as both an enabler of and a barrier to SCA use in young adults [8]. The author also found that technology-affine users have a higher odds of using SCA in the future than technology-rejectors [11]. Hypochondria and worries about one's health status are associated with SCA use [8, 12]. In order to better understand the meaning of the three concepts (eHL, HL, HRB) for laypersons using SCA, definitions are given below:

The concept of eHL defines a skillset specifically required to navigate electronic, digital and mobile health information resources [13, 14]. According to Norman and Skinner, the skillset encompasses six domains [13]: Traditional literacy (Reading/writing skills), computer literacy (to use computers), media literacy (to know how knowledge is distributed across information channels in society), scientific literacy (to be able to assess how knowledge is generated) and information literacy (to have strategies for searching and structuring knowledge). It also includes the complex concept HL.

HL is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions [15-17]". According to Nutbeam, three levels of HL can be distinguished: functional, interactive, and critical HL [18]: Each domain refers to a different skillset. Functional HL refers to the basic skillset that is needed to process health information and access services. Interactive HL adds cognitive and literacy skills which, together with social skills, enable individuals to participate in activities and derive meaning from communicating with others in a dynamic environment. Lastly, critical HL enables individuals to critically appraise health information and consider social determinants of health. The context and situational demands of the health care system and an individual's situation determine if the skills applied by an individual meet the current demands of the health-related issue and its social circumstances [15-17, 19].

HRB is the result of a motivational process in which both HL and eHL play a role [20, 21]. Von Wagner proposed a model in which individual factors (knowledge, cognition) and external influences (social, educational environment and experiential learning) dynamically shape HL. Both literacy concepts are linked via HRB to health outcomes in three health care domains: Self-care, patient-provider interaction, and health system navigation [21, 22]. Self-care especially encompasses both patients' skills and knowledge to navigate health care problems and support technologies that empower patients to assess and document their complaints. HL is also linked to the related model self-efficacy, especially in persons with chronic diseases[23, 24]. In eHL research, the relationship to health-related outcomes is less conclusive, but suggests that health-promoting behavior and eHL are related [21]. Both HL and health-related outcomes such as HLB consistently follow a social gradient [25, 26]. A significant proportion of the European population has low HL, which is correlated with negative health outcomes[27, 28]. HL and health outcomes are distributed through social networks and family [29].

How the occurrence of a symptom leads medical laypersons to engage in SCA use and consecutively act on the SCA output has not yet been described as a process [1, 30]. There are several challenges to researching SCA, such as different user profiles, context-dependency of app use and the rapid rate of development in the field [1, 11, 31]. The following is known about laypersons' use of SCA:

When a motivator for app use occurs (e.g. a health symptom), laypersons enter health-related information into the SCA. Curiosity about one's health status or the desire to rule out possibly dangerous conditions, the availability of health care services, trust in SCA as well as certain symptoms are known factors associated with SCA use [2, 8, 10, 32-36]. Further engaging with SCA warrants distinct user experiences that are shaped by the confidence in one's ability for self-assessment [8-10, 34], personal illness experiences [2, 8, 9], proficiency in navigating informational sources [8, 9], age [32, 37] and the ability to process and understand health-related information [1, 8-10, 37], all of which are part of the abovementioned concepts.

Based on user input, the applications then present a ranked list of plausible causes together with feedback on how urgent the matter is and a recommendation (e.g. “go see a doctor”). This output can make some users feel more or less anxious to seek medical help [1, 8, 38, 39]. Users prefer following the SCA’s recommendation if it is “wait and see” [2, 39]. Satisfaction with app use is not necessarily linked to compliance in regard to following its advice [40], e.g. users can be dissatisfied with the app but follow its advice, nonetheless[36]. Researchers voice concerns that this range of health-related outcomes together with the diagnostic inaccuracy of the applications might lead laypersons to unnecessarily consume HC services [4-6, 41]. However, there still is a substantial lack of evidence if SCA use actually “triggers” health-care seeking behavior (as in a cause-and-effect relationship) in that user group [1, 3, 12, 35, 36, 39].

The aim of this study is to describe the process of how medical laypersons use a specific SCA from their perspective and taking eHL and HRB into account. Three main research questions are posed: 1) How do users describe the process of using SCA for health-related complaints? 2) What are the entry points and possible outcomes of SCA use? 3) How are eHL and HL expressed during the use of SCA?

Methods

Study design and sampling strategy

This study is embedded in the larger context of the joint project “Ethical, Legal, and Social Implications of Symptom Checker Apps in Primary Health Care” (Acronym CHECK.APP) [42]. The CHECK.APP project is based on a mixed-methods design and has four foci (1: Ethical, legal, and social issues, 2: Epidemiology of SCA use and predictors of use, 3: Patterns of SCA use and impact on individuals, 4: Impact of SCA use on the health care system and health care workers). The present study was part of Focus 3 and followed a six-week self-monitoring diary study that aimed to generate quantitative data on SCA usage patterns. The present study’s contribution to the project is to gain deeper insights into SCA use and its impact from the user's perspective. Study design and method of the present study are presented adhering to the SRQR statement [43].

Study participants were recruited from n=48 active SCA users after they had completed the six-week self-observation diary study. All users used Ada (Ada Health GmbH, Munich, Germany). The diary study participants were addressed and asked if they were interested in performing additional in-depth interviews based on their respective diary experience. Participants signaling interest were selected for the interviews based on their age, gender and frequency of SCA use (sparse: less than 10 times in the six weeks, frequent: more than 10 times in the six weeks). Based on the 5D model of information power by Malterud et al [44], a sample of n=15 interviews was estimated to be sufficient.

Research paradigm, qualitative approach

This qualitative interview study follows a constructivist research paradigm: Users construct their reality by integrating experiences, self-image and bodily perceptions into their biography [45]. They learn from experience[46]. These integrated factors are expressed through the social act of narration during the interviews. Kruse’s integrative basis procedure is used as a qualitative approach to reveal latent meanings and the way users “make sense” of the app and their experience with it [47].

The CHECK.APP research team consists of persons with a professional training and research experience in medicine, family medicine, psychology, sociology, law, medical ethics and philosophy. The project is conducted in the context of the German health care system with a focus on primary health care.

Ethical issues pertaining to human subjects

The study received a positive vote from the Ethics Committee of the University of Tübingen

(Number 464/2020BO) and was conducted following the Declaration of Helsinki. All participants gave their informed consent before the interview began. The participants received a monetary compensation for their participation in the interviews. All data is stored on encrypted servers.

Data collection methods

The interviews were performed by a pair of interviewers (I) using an interview guideline (see supplement 1). The interview guideline was created by the research team for the study and piloted with n=2 interview partners (IP) that were not included in the analysis. The test interviews were used to review the guidelines and interview styles in a group feedback discussion between the interviewers and their supervisors. One interviewer was from the Institute of General Practice and Interprofessional Care (IGPIC) and the other either from the Institute of Ethics and History of Medicine (IfEHM) or the Institute of Applied Social Science (IFAS). The interviewers were JW, RK, MTS (IGPIC), RM (IfEHM) and MK (IFAS). After consent was obtained, the interviews were performed using the ZOOM video client and audio-recorded on local, secure computers at Tübingen University hospital (UKT).

The interviews took place from 18th January 2022 until 15th March 2022. Analysis was started during data collection.

Sample

Of the 48 persons participating in the journal diary, n=28 (56%) expressed interest in an interview. A chronic condition was reported by n=10 potential interview partners. 17 persons used the SCA infrequently (less than 1x/week). Mean age was 28.1 years. 14 persons identified as female and the rest as male. No person identified as non-binary. Racial characteristics were not asked in the diary study. Most potential participants (n=22) had a school education qualifying for university studies (“Abitur”). All interview partners were caucasian. No interview partner had a migration background.

The average interview duration was 46 minutes (min. 35 minutes, max. 76 minutes). Initial reading of the transcripts showed a decline of new topics and a saturation of the thematic foci of the study after 12 interviews. No further recruitment was undertaken after 15 interview partners.

The relevant characteristics of the interview participants can be seen in table 1 below.

Table 1. Relevant characteristics of the 15 interview participants.

Category	Item	N=
Age		
	<45	12
	45-55	2
	>55	1
Gender		
	Female	9
	Male	6
	Diverse/non-binary	0
SCA use frequency		
	Sparse (<1/week)	6
	Frequent (>1/week)	9
School education		
	Abitur[a]	12
	Realschule[b]	2
	Hauptschule[c]	1
Place of residence		
	Urban	13

	Rural	2
Chronic condition		
	Present	5
	Not present	10

[a] For above-average abilities and motivation. Leading to the exam required for studies at university/college

[b] For the practical-minded, preparing for vocational training. Leading to 2-3 year apprenticeship, to secondary vocational, general schools or attaining a highschool diploma

[c] For the practical-minded, preparing for vocational training. Leading to 3-year apprenticeship or to secondary vocational schools

Data processing

Interviews were transcribed pseudonymously by a third party (Amanu, Germany). Transcripts were stored on protected servers at Tübingen University Hospital. For analysis, Microsoft Excel and Microsoft Word were used.

Data analysis

The integrative basis procedure uses a three-step process to allow an in-depth analysis of self-perception, biographic relations, self-image and perception of social roles in interview material [47]. The analysis was performed by RK and MTS cooperatively using strategies to enhance trustworthiness and rigor (see below).

The analysis first step in the integrative basis procedure was a “detailed micro-language analysis”, a linguistic approach in which the transcripts were deconstructed. The idea behind the first step is that different verbal expressions represent different levels of the speakers’ attention: Pragmatic/interaction (interaction and relationship between interviewer and participant), Syntactics (specific grammar as expression of cognitive structures) and semantics (specific choice of words, metaphors). Micro-analysis also slows down the process of getting to know the transcripts and thus helps researchers to shift their focus on different meanings in the same text unit to be able to get deeper into the analysis.

Next, the transcripts were interpretatively analyzed using methodological and thematic heuristics. In our case, the methodological heuristics used were an analysis of social positioning and agency [48, 49]. In terms of thematic heuristics, we employed Achtziger and Gollwitzer’s Rubikon-model as a framework for motivational processes and intention building [50]. The accepted model was deliberately chosen to help structure intra-personal motivational processes.

Finally, the findings from these first two steps were integrated in the third step: It begins with the formulation of questions for each interview transcript that represent central interpretation of the interview (German: “Lesarten”). For each interview, the questions to the text were condensed into interview-specific motifs and patterns. These were then integrated between the interviews, summarized, categorized and finally compiled into a coherent result text that represents the central motives and patterns of the interview study. The latter is the results text in this manuscript.

Techniques to enhance trustworthiness

First, RK and MTS performed each of the above three analysis steps independently on the same transcript. Then, they compared their results after each step. Differences were discussed and if possible, a mutual understanding of the texts and the method was established. When disagreements arose, they were discussed in monthly multidisciplinary methodological workshops within the CHECK.APP project research team.

Relying on the method of peer-checking, the interim results were presented and discussed several times in a multidisciplinary research workshop on qualitative research methods. In a member-check with the majority of the interview partners, the interim results were discussed and validated during a three-hour session. Furthermore, in a multidisciplinary validation workshop, intermediate states of the analysis as well as open questions were discussed and illuminated under consideration of the perspectives from law, ethics, social medicine and general medicine.

Results

Visualization of the process

Based on the four stages of the Rubikon model, a cyclic model of the SCA use process according to the IP was developed. It is presented in figure 1 below.

<insert figure 1 here>

Caption Figure 1 SCA app use process with eHL and HL domains marked out
The figure describes the path from an entry point (such as noticing a health-related complaint) via intention formation (influenced by motivational and volitional determinants) and volition to health-related behavior as an outcome. The latter can take place in different contexts. The behavior, in turn, leads to new experiences that are evaluated by the individual and integrated into the biography.

1) Motivation, pre-decisional

Motivational stage

Users assessed the severity of the issue by comparing it to their own pre-existing experiences. IP did not reflect on the relevance or validity of their perceived symptoms and experiences – they took for granted that both were real and valid. If the symptoms were perceived as less severe and comparable experiences were available in the user's biography, the sensation was described as manageable.

> *Yes. I have that once in a while. I don't even know where that comes from. I also think that it's possibly one of those things that kind of comes from stress, I definitely feel like that. And because I just never knew what it was, but I also knew that it would go away again, so because I had it before, as I said, I just looked it up in the app once. (NT45,120).*

At times, when individuals couldn't find relatable experiences from their own health history or perceived the issue as more severe, they expressed negative emotions like fear or shock.

> *[…] In the end, it was a migraine attack. But I didn't think about it at that moment, I was shocked at first. (NT39, 28)*

Trust in the app also played a role in the decision to use it, as the following excerpt illustrates. The same IP continued to elaborate how trust in the app competed with trust in health care professionals:

> *But, yes, because I couldn't describe my problem in detail - I didn't trust the app so much at that moment- , it was important for me to go to the doctor quickly, because I knew, okay, there are important things that I couldn't tell the app, and then that would explain the diagnosis, so to speak. (NT41, 265-269)*

Context of app use

IPs reported on different contexts in which they considered to use the app. The most commonly reported context was the occurrence of a health-related complaint. They first reflected on whether the symptom was even 'real' – meaning if they just imagined them or if the perceptions really represented an issue worth dealing with. They compared the symptom with their health-related experiences and biography and tried to make sense of what was happening to them:

> *Yes, I also clearly had chest pains. I mean, at that point I was already asking myself: Okay, to what extent is this happening now? But I mean, then I lay there and I had the feeling and thought: Yes, come on - so it was already real for me at that moment. (NT47,19)*

Users also reported being motivated to use the app by health-related complaints of others. One user reported that she uses the app for her family. She said she was more resistant to possible anxiety than her family, who she described as prone to hypochondria.

> *I: And what made you decide to [use the app] for [your daughter] and not with her?*
>
> *Interviewee: That I wanted to check it out first ... My husband is a bit of a hypochondriac and so is my child. So when I sort of poke them, or it could be something dramatic, then I always don't know what will come of it. That's why I did a pre-check for myself first. (NT21; 201-206)*

Health system accessibility or formal requirements because of their work further influenced users' motivation to take health-related actions:

> *IP:[…] It […] is also one of the reasons why you don't like going to the doctor so much, is that it is hard to get an appointment with such specific doctors somehow. Especially a dermatologist or something like that, you have to wait two or three months and then you usually let it drop.*
>
> *I: So access to a doctor or to care plays a role for you?*
>
> *IP: Yes. Yes. I think if I knew, okay, I'm going to get an appointment in one, two, three weeks, then I'd be more likely to have something like that checked out. (NT41, 257-264)*

2) Volition, Intention formation (Pre-actional)

Purposefully initiating SCA interaction

The motivational process described above led to a planning stage for health-related behavior. Users enumerated three distinct motifs when planning to use the app: 1) To understand and validate one's condition, 2) to receive recommendation for further actions and 3) to communicate and document health-related issues.

Understanding and validating one's condition

Users were interested in understanding their condition. The app provided an opportunity to find more information. Information seeking was described as one way to deal with the complaints.

> *[...] I see [the app] as a first aid, first source of information, where you can think about [...]: What do I do now? Then I can take a look or maybe I think again: What do I do now? [...] so as [...] again to update the normal knowledge that you have as a non-medical person. (NT37, 62)*

Finding a clear cause also drove the users and induced HRB.

> *I woke up with 39 and something degrees. And of course I opened the app again and entered my symptoms, just to see [...] what it was saying now. [...] Yes, then I knew ... Okay, these are clearly the symptoms. Which of these is now Corona,*

> *which is maybe something else. Yes, I can still remember, [...] that I was lying in bed suffering and had the app open. (NT05, 31)*

Sometimes users described that an element of surprise was needed to find an explanation of their complaints. They admitted that they were not aware of all possible causes of their condition. The ability to surprise was attributed to both doctors and the app as external information sources.

> *Maybe it's (what is needed to accept a diagnosis) a "click" moment that you didn't realize before. As an example, maybe a doctor or a diagnosis app asks a question [like: Does it get worse when it's cold] and then you think to yourself: Ah, yes, when I think about it, it does get worse when it's cold, or whatever. (NT24, 73)*

At other times, users already had a suspicion of their own, which could be verified by the HRB.

> *[…] I also have migraines and sometimes I can't quite identify whether it's a migraine or a headache. And the app often helps me and then I can practically distinguish: OK, do I treat it like a headache now or do I treat it like a migraine now. (NT41, 94)*

In summary, the purpose of gathering information was to add to one's own knowledge about the condition and to actively seek out validation of one's subjective impression.

Receive recommendation for further actions

Besides collecting more information about one's condition, users stated wanting to receive options for further health-related actions to improve their condition.

> *What were the first experiences? […] I used the feature best or most, simply these suggestions about which therapies you can take for which symptoms. And so I always looked here again to see what the app actually recommends. (NT44, 7)*

Even if the app was primarily used for information gathering, the recommendations were perceived and considered.

> *[…] I looked to see what information was available if I somehow ... well, with children there's always something. And then I just thought the app was so good, because sometimes they had a few other tips. And then I just looked to see what one says, what the other says. [...] It was always a push in the direction: 'I should go to the doctor' (NT21, 35)*

Users also typed in symptom combinations several times to see if anything changed in the app's output.

> *Well, of course I also had accompanying symptoms during the heart rhythm disturbances. So sometimes trembling or high blood pressure, but some of it was only temporary. I then sort of started to play with that. I added the symptom once and indicated it and left it out once to see what it recommended. Because the option of selecting that a symptom only occurs temporarily or is concomitant, only temporarily, is not available in the app. And then I wanted to play around with what would come out in the end if I indicated this and didn't indicate it. But apart from that, the reason was ... I gave everything I had and always answered the questions truthfully. (NT19, 278-287).*

If the sense of medical urgency was very high or life-threatening, app use was explicitly excluded.

One participant described such a hypothetical scenario:

> *If I somehow had symptoms of a heart attack or something like that, then I would probably call the ambulance service directly and not look on the app to see if I really had a heart attack or if I was bleeding to death or something like that. (NT49, 112)*

Communicate and document health-related issues

Users documented their own symptoms in the app.

> *It was recommended to me a long time ago to track symptoms, just to keep a diary of symptoms […]. (NT31, 13-19)*

The app was also used to prepare for a visit to health care professionals. In that context, the documentation contained in the app was primarily used for the orderly and rapid presentation of complaints.

> *So I can already describe my state of health more specifically than if I hadn't inquired beforehand. (NT06, 97)*

3) Volition, Intention implementation

Integrating personal, social and digital resources in SCA interaction

To implement the purpose of the initiated action, users integrated different resources into their behavior. One example leading to a health care visit is given by IP NT41 below:

> *My doctor didn't tell me that [oral iron supplement pills] could have side effects. And then I had discolored feces and abdominal pain and all sorts of things for a week or two. […] So I used the app and then I googled it and then I think I also talked to a friend about it. (00:04:27) She was like: Hey, maybe it's from the iron tablets. And then I realized that it was the iron tablets. And then I stopped taking them and then I talked to my internal medicine physician and she was like: Yes ... And prescribed me other iron tablets. (NT41, 34)*

Personal resources

Personal resources were provided by biographical reference points, such as previous experiences, special knowledge from one's own professional activity or skills. As soon as the purpose of the action was determined in the pre-actional phase, personal resources were factored into the user's action. Users described certain skills that they used in the process, but also a sense of self-efficacy. If enough personal resources were available, users could actively decide against the app’s recommendation, as the following example shows:

> *And then I entered that [the symptoms]. The app said it could be a torn ligament or a fracture and that I should go to the emergency room. And then I thought: [...] I don't know how I could have broken any bone in the way I was walking. For me, the ligaments were more plausible. [...] I've had it before, so I already had a bit of experience of what it's like. And then I thought: OK, the app says one thing, but I'll just look at it again in two or three days and see how it develops. (NT42, 58)*

Social Resources

Users also intentionally and purposefully sought out social resources. Friends and family were attributed a role in understanding and responding to complaints.

> *[…] I once suspected a stroke and then I was at home and had a reduced field of vision and thought: What is this? But that was before I knew about these apps. And of course I immediately called a friend and said: What could this be? What is that? And she said: Make sure you have it checked out the next day. (NT21, 309-313)*

Health care professionals such as physicians were attributed a special role: A visit to a health care professional was seen as mandatory to obtain a final validated diagnosis or to obtain health care services such as a sick leave or a prescription. The interactions with physicians were mostly intentionally made by the users if other resources were depleted or did not improve their situation.

> *And I had then already contacted my family doctor anyway, just from the fact that I also need a sick note […] Of course, if this [the symptoms] were to last longer, the app would be of no use to me in the end, then I would have to go back to the neurologist or […] the family doctor. (NT39, 14)*

The only social resource with physical access to the users' body were physicians, as they could perform physical examination.

> *And then I went there [to the General Practitioner], described it again and showed it. Then [...] [she] turned the [painful arm] in different directions and said that no part, neither the forearm nor the upper arm muscle, is affected in any way. That comes in any case, exactly, so from the tendons […] And then I just said: yes, [the complaint comes] from climbing [...] And then she said: how much do you climb? So if you don't climb four hours a day, it's very unlikely that it comes from that. (NT31, 175-176)*

Reviewing the input and results together with health care professionals, e.g. a GP, was mostly described hypothetically. The prospect of discussing app results with their GP, however, was seen as beneficial by the users.

> *[…] what I would like is when you come to the doctor and say: I assume that I have this because I googled it or found out on an app. That he then says: Yes, what symptoms did you enter? Or: How did you then come up with this result? […]So that he then, I don't know, doesn't have to start again with Adam and Eve, but that he can already inquire more intensively. (NT06, 49)*

Mostly, users made a conscious decision to leave the app out of the social context of health care. They expected a negative impact on patient-doctor relationships.

> *I: Did you also mention there (at the GP) that you used the app?*
>
> *IP: No, because I have the impression that doctors tend to react badly to this. Because then, they always like to say Dr. Google […] and the topic has a bit of a bad reputation. (NT07, 112)*

Digital and technological resources

The app and search engines were seen as competitors in the same category with distinct advantages and challenges. Search engines were mainly used as a supplement to obtain information that was missing in the app.

> *[…] when you're constantly googling, sometimes very worrying answers come up and you can also enter a lot of specific things in the app and it's just more practical and you somehow feel, how should I put it, the diagnosis somehow feels*

> *more trustworthy than through Google (NT-41, 6-13)*

> *[…] I missed in the symptom checkers, that you somehow get such a tip, such old home recipes, […] belly compress or something, and then such a guide to it. […] I then thought: […] now I'm googling, what can one do, yes, perhaps with a homeopathic approach. Because that's what I was missing (NT21, 118)*

In contrast to app use, users found search engines overwhelming when they tried to check their symptoms there.

> *[Referring to searching complaints with internet search engines] In principle I never really figured it out, because there were 10, 15, 20 possibilities, and I couldn't really assess it at all. Really. (NT19, 53-57)*

Other technological resources and devices, such as users' wearable devices or imaging procedures in the hospital exist alongside the app. Devices able to monitor and measure bodily functions were described as decisive and important factors that can contribute to a decision.

> *I […] always measured the blood pressure. And even my [smartwatch], which is so clever, then recognized that there is a heart rhythm disturbance, at times. That time, it showed a rhythm disturbance. […] Then I thought: Okay, now I have to go to the doctor. (NT19, 138)*

User experience and usability features of the app were discussed. For example, the chatbot-based approach with questions asked to be answered by the user was both perceived as helpful and as limited. Users missed the opportunities to clarify their input, ask questions or to address their own uncertainty and ambiguity.

> *[…] I would have put it (a surprising app-result) down to the fact that the app didn't really understand me, […] because I somehow couldn't really convey exactly what I wanted to say on the basis of the questions and the selection options. [...], I would have said: OK, it just misunderstood me. (NT37, 68)*

According to the users, affinity to technologies played a role in the use of the app.

> *Yes, for my mum, for example, I use it (the app) quite often, because she's not that into the internet and apps and stuff. (NT41, 73)*

4) Evaluation

Transforming results of the interaction into health-related experiences

Once the health-related behavior had been executed, a comparison was made as to whether the intention of the action had been fulfilled. Whether the app's results represent an actual diagnosis was negotiated individually by each user. Users described having difficulties accepting the app results depending on the topic and their own interpretation of the results. If the two diverged too drastically, they were at a loss and saw potential problems in understanding or misinterpreting the given recommendations.

> *I think the app always told me: stress and mild depression or something like that. I didn't feel that stressed, but yes, I think that was the thing. [...] I read through it, but then I thought: Well, I still don't know exactly what's going on. (NT37, 20-24)*

Concerning recommendations especially, users critically evaluated the app's output. How they reacted to it depended on the intended purpose of the action, the user and the context in which the assessment took place.

> *I was a bit shocked that [the app] now sends someone directly to the emergency room (with the app result tonsillitis). Because I work for a health insurance company […] and I find it a bit exaggerated that patients are sent so quickly to the emergency room. They are so overloaded at the moment. (NT39, 12)*

Users reported that they were reassured by validated external information about their condition. The app sometimes could provide such reassurance.

> *It's a bit like this: Is it true now? Of course, we are aware, especially with this vaccination, that the side effects come from the vaccination. But somehow it's still like that: Yes, you feel safer and somehow more confirmed, even if you only have it in an app, but, yes, you are somehow more reassured. (NT41, 82)*

On the other hand, users also found the app results unsettling and misleading.

> *So it could really only be overstretched ligaments (user's suspicion), this fracture (app result) made me a bit ... A bit scared at that moment. (NT42, 63)*

Users acknowledged that having received information contributed to a learning process that affected how they reacted to future symptoms:

> *I still have it on my mobile phone, I still like to look at it once in a while, even if it's just to advance my knowledge a bit. And, yes, it has become ... I have found that I look at it a little less, but also because I find that when things repeat themselves in some way, you already know how you could react. (NT44, 37)*

Discussion

Principal Results

The study's findings indicate that the use of SCA by medical laypersons is a multifaceted and iterative learning process that involves individual motivational factors, contextual elements, and interaction with digital, social, and personal resources. Both EHL and HL play a significant role in this process. The subsequent discussion section addresses the three research questions.

1) How do users describe the process of using SCA for health-related complaints?

The process of SCA can be described in four distinct steps (motivation, intention formation, intention implementation, evaluation) [50]. These stages can be viewed as an iterative learning cycle that generates health-related experiences, according to the constructivist paradigm [46]: During the motivational stage, users negotiate app use depending on the context. If users choose to use the app, they do so intentionally for three distinct purposes: Obtaining information and HISB, receiving recommendations, and documenting and communicating health-related issues. The purpose determines the strategy the user employs and the resources utilized to achieve it, including personal, social and digital/technological resources. User's experiences with SCA can influence their motivation to use it in the future and how they incorporate it into their health-related behavior. Making meaning plays a crucial role in this, as users try to understand their bodily perceptions and symptoms[45]. This process aligns with the model proposed by Von Wagner which links HL and HRB and emphasizes the role of learning in HL [20]. The study highlights that the use and evaluation of SCA in line with the dynamic concept of HL, varies over time and is dependent on the context and purpose of use[16-19]. This poses a challenge when researching SCA [2, 8, 31].

2) What are the entry points and possible outcomes of SCA use?

Entry points

Entry points were identified during the motivational / pre-decisional phase. They were influenced by the context in which SCA use was considered [20]: In addition to the user's own health needs, situations involving the health needs of others were also relevant. Motivational determinants included attentiveness towards symptoms, past experiences (biographic factors), confidence in one's health, trust in the app and one's ability to respond to symptoms. Some of these factors for app use were also identified by Aboueid and Meyer [2, 8, 10]. Accessibility of health care and availability of social networks were described as external factors. Aboueid identified the lack of accessibility of health care as an enabler of app use, while social influences were identified as a barrier [8]. In a longitudinal journal study from the CHECK.APP, Wetzel et al found that the first occurrence of a symptom and certain symptoms such as heart, skin or eye-related complaints increased the likelihood of SCA use [35]. In the sample, IPs considered the abovementioned factors in their decision to use the app, but did not specify whether they were facilitators or enablers. Although many of the listed factors have been identified in previous research, their role in SCA use is ambiguous since they can act as both barriers and enablers[1, 7, 34]. As both situational and individual factors shape when and to what purpose SCA are used, the term 'context factors' seems much more appropriate than 'barriers and enablers'[1, 16, 17, 34].

Outcomes

Meaningful learning experiences

The most common outcome of using SCA as a digital information source and HISB is the act of learning, which is difficult to measure[13]. This outcome is expressed through the *purpose of understanding one's condition*, based on users' need for more information. Users already have predefined concepts about their condition in mind when planning their course of action. Therefore, they also want to validate these concepts by gathering information. In a substudy of the CHECK.APP project by Wetzel et al it was found that SCA were the least important for HISB in the general population. The subsample of active SCA users reported that internet use and consulting a physician were more important for HISB than SCA[3]. In the study by Meyer et al, the majority of SCA users stated that they used SCA to understand the cause of their condition and found the information they received useful[2]. During the evaluation stage, users consider the extent to which the information is meaningful and influenced HSB is considered in the evaluation stage. They base their evaluation on their experiences with SCA use and the health-related actions, and determine whether the intended purpose was fulfilled and whether meaningful learning experiences were generated[40, 46].

Health-related behavior

Another type of outcome is health-related behavior, which is planned in the intention formation stage and implemented in the following stage. The actions described in the intention implementation stage relate to measurable HRB, such as visiting a health care professional or seeking advice from friends or family [20]. Depending on the purpose of app use, two types of behavior can be distinguished in this category:

As a result of using SCA for the purpose of *receiving recommendations for further action* (b), such recommendations are generated. This occurs frequently: In Meyers sample, the purpose ranked second among SCA users [2].

Our IPs then considered whether to follow app recommendations or not thoroughly. If the recommendations do not align with user's concepts and expectations, they are sometimes discarded as unrealistic. However, this mismatch between concept and recommendation can also cause anxiety and create the need for more information or confirmation by healthcare professionals [33-35]. Turner also observed the rejection of app recommendations, especially if they were given in a context where the action could not be implemented (eg out-of-hours) [51]. Verzantvoort et al found that users intended to follow app advice if the advice was to contact their GP during the daytime (75%) and practice self-care (67%) [40]. If the concept and recommendation align or if users are very anxious or surprised about the result, a visit to healthcare professionals is a possible outcome.

In order to better understand this behavior, a dialogue option could be implemented in SCA: “Have you followed my recommendation?” and whether or not further resources such as health care professionals were contacted. That way, not only symptoms could be traced but also user behavior and impact of SCA in health care utilization.

Communicating and documenting health-related information (c) serves users’ need to structure their experiences and to prepare for contacts to healthcare services. This sets up SCA as a possible interface between the user and health care services. This purpose and possible use in health care has not been described yet, apart from the CHECK.APP project[34]. SCA can increase patient autonomy, as other research has postulated [39]. However, users specifically exclude telling their doctors about the SCA usage.

According to our sample, direct communication with HC professionals over app results and app does not happen. Aboueid found that attitudes towards physicians and the health care system may impact app usage [8]. Meyer reported that only about 50% of patients using SCA consider informing their physicians about their SCA usage [2]. The present study indicates that users may share the output of the app including given recommendations or probable diagnoses. However, they are less likely to inform their physician that they used a SCA to generate these results.

Further research is needed to explore ways to facilitate open communication between health care professionals and SCA users. The quality of the communication and its contents are suggested as measures for this outcome.

Satisfaction with app use

Finally, satisfaction with the use of the app is an outcome expressed in the evaluation stage. It is related to the intended purpose and the two aforementioned outcomes: health-related behavior and learning. Therefore, satisfaction with SCA is a complex outcome that includes the user experience with the app, health-related behavior and learning[36, 40].

Satisfaction resulting from app use depends on how well the users perceive the SCA’s alignment with their needs, expectations and intended purpose. Users become insecure and sometimes dissatisfied with the app when their concept does not match the output. This association with user satisfaction indicates that users’ expectations also play a role in how they validate the app [40]. In a substudy of the CHECK.APP project, Müller distinguished between user expectations and motivations for app use and found that these factors play a role in SCA use [34]. In fact, according to Kopka’s sample, 33% of SCA users reported that SCA’s usefulness varied [52]. Turner et al conducted a study on an online SCA and found that users were dissatisfied with SCA, because too little information on about what to do themselves was given [51]. From their point of view, the outcome did not fit their intended purpose. This should be critical in first-time users, but can also influence how users validate the app over time[52].

This indicates that simply measuring a single outcome of app use may be a shortcoming of previous research as it ignores the context of use and the intended purpose. SCA apps provide a wide range of potential services that are integrated into a complex network of resources [2, 4, 6, 8, 9, 36]. Therefore, researchers and developers must consider to address the intended purpose of use, expectations, and specify the desired outcome.

3) How are eHL and HL expressed during the use of SCA?

he main finding of this study is that both eHL and HL are present throughout every stage of the complex process of SCA use. However, different aspects of these concepts are relevant for different stages. Therefore, we will discuss the expression of eHL and HL in relation to the stages of the SCA use process below.

Motivational stage

During the motivational stage, users are primarily motivated by the presence of a health-related issue and the context in which it arises. The user’s abilities, as defined in the concept HL, are available as personal resources, but their application is shaped by the context[16, 17]. The descriptions of these skills by the IP’s can also be conceptualized as self-efficacy and self-care, which are interlinked with HL[24]. In a substudy of the CHECK.APP project, Wetzel et al found that, unlike eHL, self-efficacy could be a determinant of app use – however, a sensitivity analysis revealed that the initial correlation was not viable. Kopka et al found that individuals who perceived SCA as useful had higher self-efficacy [12, 52]. This ambiguity can be resolved by considering the context of use as an additional factor. Some symptoms may be more alarming than others and may exceed the available skills of even those with high HL [35].

Trust in apps, or the lack thereof, plays a role at the motivational stage. Regarding eHL, the IP in our sample positioned themselves as having high technical knowledge and the ability to critically appraise app output (eHL). They trust the app, but also their HL skills. This is consistent with the observation made by Kopka et al [33]: Users with high eHL are more likely to trust SCA, possibly because they have higher confidence in their ability to critically evaluate app output. Conversely, lack of trust has been identified as a factor in intentional non-use [3]. Neither technology affinity nor eHL are predictors that differentiate SCA users from non-users [12]. Aboueid identified different technology affinity profiles as a predictor of future app usage for self-triage[11]. Both technology affinity and trust represent attitudes rather than skills. They shape expectations and motivation to use apps but are not predictors[34].

In summary, the skillsets defined in HL and eHL, as well as context factors influence how the motivational stage unfolds [16, 17].

Intention formation

SCA can serve as both an information source and a tool for shaping one's HRB. Navigating digital tools for information gathering and evaluating this information is related to eHL. Applying the information to one's behavior and learning from it is more closely related to HL [20, 21, 40]. Therefore, planning to use SCA relates to both eHL and HL [13, 18].

Users with high HL may anticipate the app’s output and choose not to use it or only use it for information gathering and HISB. Additionally, users may experiment with different inputs to observe changes in the output. This demonstrates the interconnection between HL and eHL during the intention formation stage. Users understand the inner workings of the app (eHL) and plan to use it to satisfy their information needs, but do not intend to actually follow its advice (HL) [13, 53]. According to Kopka et al, users are more easily be persuaded to follow app recommendations when they are ambiguous or unsure about their own decision. This aligns with IP’s self-reports that they are less inclined to follow the app’s recommendation if they feel their condition is critical or if the recommendation significantly differs from their own concept (e.g., recommending to seek emergency help when users feel perfectly healthy). Additionally, using apps to communicate about symptoms connects the concepts of eHL and HL to a social context in healthcare[14, 15].

Intention implementation

Users apply various resources related to eHL and HL to achieve their intended goals.

Personal resources, such as the ability to assess one's health and navigate the healthcare system (HL), critically evaluate information across different platforms, or use and comprehend digital applications (eHL), are essential for SCA use [13, 17-19]. In our sample, users expressed confidence in their eHL skills, including media literacy, information literacy, and computer literacy. However, the extent to which they utilized these skills depended on their purpose and the availability of other resources.

The demand for applying interactive health literacy is not met by SCA because it does not allow for direct communication with others in a social context. This is particularly evident when users seek to validate their own ideas about their condition or receive recommendations for actions. In such cases, users may seek out social resources and discuss their condition with friends and family. Alternatively, they may present the app results to a healthcare professional without disclosing their use of the app. This demonstrates that users extend the app’s use to other contexts, integrating those contexts into their overall user experience [20, 50]. This study demonstrates that HRB can transition from digital interaction to social interaction in the context of SCA use. This finding aligns with Edwards’ concept of distributed health literacy [29], highlighting the importance of social networks in realizing the benefits of SCA. Real-life interaction can provide what the app interaction lacks. The ability to actively listen, notice and respond to emotional nuances, provide support, and express understanding for the person's situation is also important. According to Wetzels observation, SCA users still refer to friends, family and physicians for HISB, albeit to a lesser extent than non-users[3]. Future research in ethics and social sciences will reveal the impact of large language models that mimic empathic responses and conversations on the use of SCA. Preliminary data suggests that such models may enhance the SCA experience [54].

IPs consider SCA as one of the many available digital resources available today. According to users, the app asks dichotomous questions, leaving them with a feeling of not being able to tell their whole story, address ambiguity, or ask questions themselves [40]. However, SCA offer a more personalized experience than internet searches[8], which remains a core component in HISB, even in SCA users[3]. The personal resources that enable users to utilize the app and apply its results also impact the integration of other digital resources into their HRB [13]. Therefore, there is potential in enhancing interoperability between different technologies such as wearables and apps.

Evaluation

The app's results, whether they provide information or recommendations, may challenge users' pre-existing concepts regarding health-related issues. The extent to which users follow these recommendations depends on their preconceived notions about their condition, their expectations for its resolution, and their ability to cope with uncertainty, which is related to HL [18, 34].

Users evaluate whether the app results align with the severity of their condition, their expectations of the appropriate course of action, and past experiences. This evaluation requires critical health literacy [18]. If users feel uncertain due to app use, they may need to contact others, such as healthcare professionals or their social network, for additional validation outside the app. Individuals with high levels of hypochondria [12] or anxiety [52] may be considered vulnerable groups in this context, particularly if they have low self-efficacy and health literacy and lack access to social or healthcare resources.

For the IP, SCA serve as an interface between information gathering [3, 8], learning and sense-making [2, 45] and interaction with the healthcare system [3, 41]. In summary, the skillset necessary for meaningful interaction with SCA in the context of healthcare services is best described using eHL and HL. Together with contextual factors, both models can provide a deeper understanding of the dynamic mechanisms underlying SCA use.

Implications for health care and research in regard to SCA use

Overreliance on user’s HL and eHL results in wasted potential[10]. The findings of this study support the idea that for the implementation of SCA in healthcare, transparency is crucial [2, 32]. The lack of transparency and reliance on user’s HL and eHL are a design flaws in SCA, which, from a legal standpoint, only present information to be interpreted by the user who provided the input. In a worst-case scenario, users may feel isolated and insecure [1, 7]. If the app was designed as a communication tool between physicians and users, such as in teleconsultations, their potential as symptom trackers and decision aids for both user groups could be realized in a safe setting. Users’ insecurities could be discussed with a health professional and possible harm, such as health anxiety, could be reduced.

The skillset provided by eHL and HL might be the reason why users are able to use SCA to their health benefit at all despite SCA's questionable diagnostic accuracy [4, 31, 55]. A pure cause-and-effect relationship, as suggested by its user interface principle (input - algorithm/AI - output), is prevented by users' HL, self-efficacy, and self-care. Satisfaction with app use is influenced by users' HL, context, and experiences[20, 34, 36, 40]. SCA development and research should take into account user expectations, context of use, and the need for social interaction.

Our study has uncovered phenomena that require further investigation in the future. These include SCA use in various social settings [40]. Our results demonstrate that users apply SCA much more frequently for family and friends than previously assumed. Different technological resources, such as wearables, other applications and internet searches were perceived as possible contributors to the three purposes by the IP. Thus, research on the topic should consider the entire landscape of digital resources and their interoperability.

Limitations

Experience-based research is limited to the information that interview participants are willing to share about themselves. It is not possible to directly observe the psychological processes that occur in someone's mind. However, by collecting and synthesizing users' stories and perspectives, we were able to describe a general process. The Rubikon model helped us to organize the stories coherently and with a focus on motivation.

It is important to critically evaluate the method and sample used. It should be noted that even in our sample of predominantly Caucasian, well-educated female users, each individual had their own perspective on how the app fulfilled its purpose in the described contexts. While a general process could be derived, the outcomes were highly dependent on the user. Additionally, the results are primarily applicable to the context of the German healthcare system and can therefore only be transferred to similar healthcare systems, which is a common challenge in SCA research[31].

Our sample consists of predominantly very reflective individuals with presumably high health literacy. This may limit the applicability our results to individuals with less health literacy. We can neither make assumptions about or extend our findings to marginalized groups excluded from app use [37, 56]. The IP's reflectivity level provided insight into how health literacy relates to HRB in SCA users. The sample represents the most common characteristics of SCA users. [1, 3].

The integrative basic procedure method is not yet widely used and, like all qualitative procedures, requires attentiveness to quality. We applied the principle of member-check, presenting our findings to our interview partners, who supported us in the description presented above. Additionally, we used a variety of validated techniques to enhance trustworthiness in qualitative research. It is important to note that this study has limitations, including a focus on just one app. While we believe to have extrapolated generalizable information, it is possible that other apps may have different user experiences and human-app interactions. Additionally, due to the pandemic, the interviews were conducted online via videoconferencing software. It is possible that conducting in-person interviews could have attracted different interviewees and revealed additional information due to the different setting.

Conclusions

In our qualitative interview study, we could demonstrate that from SCA users’ perspective, a simple cause-and effect relationship between symptoms and SCA use is unlikely, at least in individuals with high (e-)health literacy. Rather, SCA use is described as a complex cyclic process. Context-dependent and biographical factors, as well as the dynamic concepts eHealth and Health Literacy are expressed in users’ description.

According to our limited sample, SCA are used for three distinct purposes (understanding one’s condition, getting recommendations for action, communicating on and documenting health-related information). Each purpose warrants its own planning, implementation and evaluation in HRB. Each

purpose may be implemented using different personal, social and technological resources.
SCA have shortcomings in needs relating to interactive health literacy. Users seek external validation of app findings in their social networks and professional health care services. However, they have the potential to become an interface between user and health care services. This potential is not realized, which should be a design goal for their continued development.

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Conflicts of Interest

none declared.

Abbreviations

CHECK.APP: “Ethical, Legal, and Social Implications of Symptom Checker Apps in Primary Health Care”
eHL: eHealth Literacy
HISB: Health Information-seeking Behavior
HL: Health Literacy
HRB: Health-related Behavior
IFAS: Institute of Applied Social Science
IfEHM: Institute of Ethics and History of Medicine
IGPIC: Institute of General Practice and Interprofessional Care
IP: Interview Partner
SCA: Symptom Checker Application
UKT: Tübingen University Hospital

Multimedia Appendix 1

Interview guideline.

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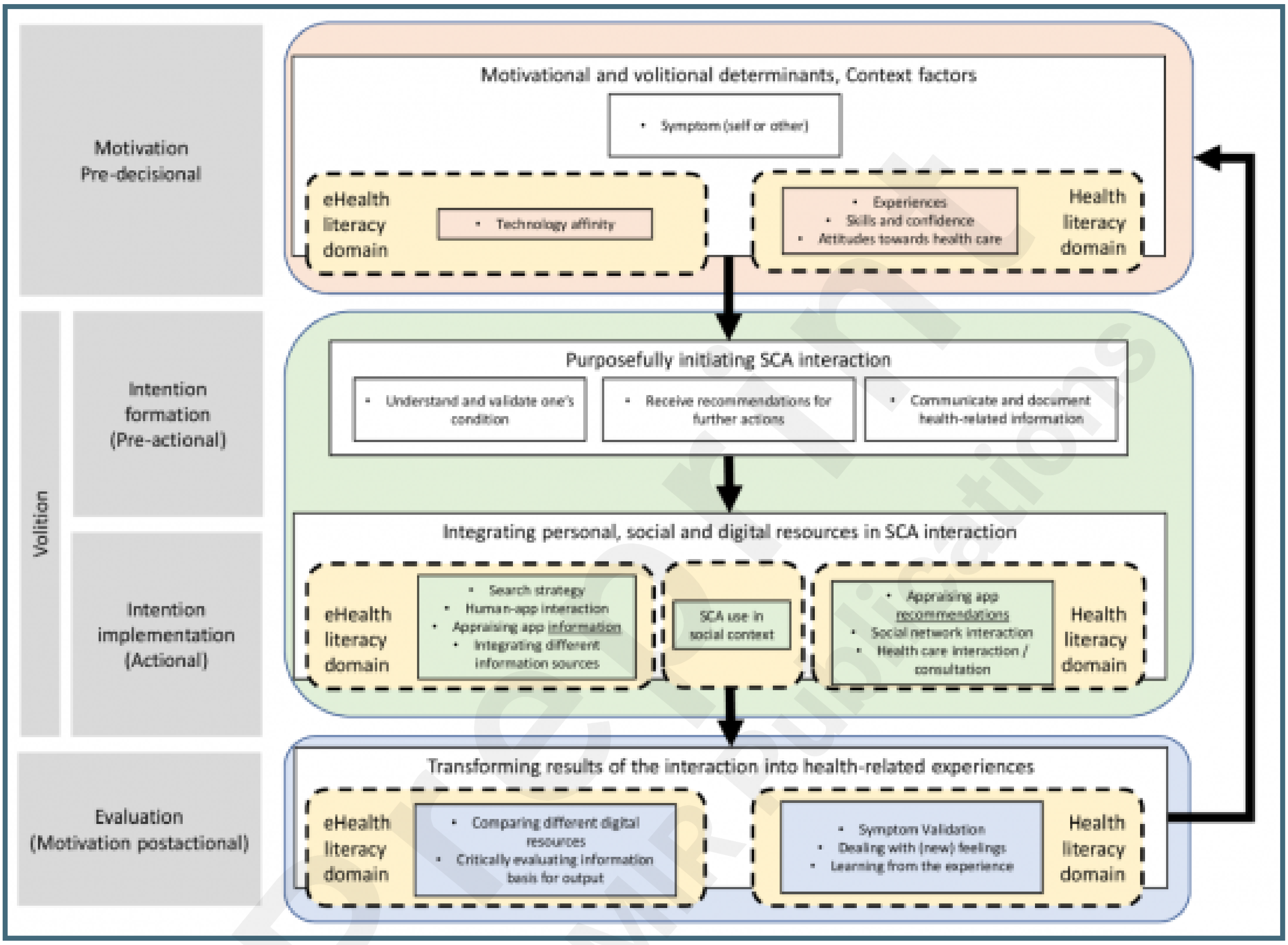
Supplementary Files

Figures

SCA app use process with eHL and HL domains marked out. The figure describes the path from an entry point (such as noticing a health-related complaint) via intention formation (influenced by motivational and volitional determinants) and volition to health-related behavior as an outcome. The latter can take place in different contexts. The behavior, in turn, leads to new experiences that are evaluated by the individual and integrated into the biography.



Multimedia Appendixes

Translated interview guideline used in the interviews.
URL: http://asset.jmir.pub/assets/39c57a8035ecd36d2aad53b3695a9b9e.docx