



Exploring supportive care and information needs through a proposed eHealth application among melanoma patients undergoing systemic therapy: a qualitative study

Itske Fraterman¹ · Savannah L. C. Glaser^{1,2} · Sofie Wilgenhof³ · Stephanie K. Medlock² · Henk A. Mallo³ · Ronald Cornet² · Lonneke V. van de Poll-Franse^{1,4,5} · Annelies H. Boekhout¹

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Abstract

Background During and after systemic therapy, patients with high risk and advanced melanoma experience challenges regarding cancer-related symptoms, treatment-related adverse events, and an impact of these symptoms on their physical and psychosocial well-being. Few studies have investigated the specific needs of these patients and the potential role of eHealth applications in meeting those needs.

Objective To explore the supportive care and information needs of high risk and advanced melanoma patients, and how these needs can be supported by eHealth applications.

Methods In this qualitative study, semi-structured interviews with high risk and advanced melanoma patients during or after systemic treatment were conducted to understand their needs and requirements as possible end-users of mobile eHealth applications. Interview transcripts were independently coded and thematically analyzed.

Results Thirteen participants consented to be interviewed, aged 31 to 71 years. Nearly all patients ($n = 12$, 92%) experienced unmet information and supportive care needs during and after active treatment. Patients expected to value eHealth applications that facilitate information gathering, wellbeing interventions, and symptom management. The majority of patients ($n = 10$, 77%) anticipated various advantages from using an eHealth application, including increased autonomy, higher quality of life, and improved disease self-management.

Discussion High risk and advanced melanoma patients have unmet supportive care and information needs during and after systemic treatment. The use of eHealth applications might be an effective way to meet these unmet needs. Patients anticipate a variety of advantages from using these applications, including deriving various benefits from the use of these applications, such as enhanced autonomy.

Keywords eHealth · Qualitative methods · Melanoma · Immunotherapy · Intervention development · Self-management · Patient education

Itske Fraterman and Savannah L. C. Glaser contributed equally.

✉ Annelies H. Boekhout
a.boekhout@nki.nl

¹ Department of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, The Netherlands

² Department of Medical Informatics, Amsterdam University Medical Centers, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

³ Department of Medical Oncology, Antoni Van Leeuwenhoek, Amsterdam, The Netherlands

⁴ Department of Research and Development, Netherlands Comprehensive Cancer Organization, Utrecht, The Netherlands

⁵ Department of Medical and Clinical Psychology, Center of Research On Psychological and Somatic Disorders (CoRPS), Tilburg University, Tilburg, the Netherlands

Introduction

Incidence rates for melanoma are increasing worldwide [1]. In the past years, the introduction of immunotherapy with immune checkpoint inhibitors (ICIs) and targeted therapies such as BRAF/MEK inhibitors (when BRAF-mutated) have significantly improved the prognosis of patients with high risk and advanced melanoma [2–4]. Systemic treatment can lead to long-lasting remissions. However, during and after treatment, melanoma patients experience challenges regarding cancer-related symptoms, treatment-related adverse events (inflammations that can occur in any organ or body part) and the impact of these symptoms on their physical and psychosocial well-being [5–7].

EHealth applications may support cancer patients in tackling these problems from different angles. First, web-based monitoring systems facilitate the collection of patient-reported outcome measures and symptom monitoring. The collection of patient-reported outcome measures supports and improves patients' self-care, symptom control, and communication with healthcare professionals. Web-based monitoring systems have also been shown to increase patient satisfaction and health-related quality of life (HRQoL) [8–11]. Second, web-based monitoring systems can provide personalized advice and inform the patient of tailored supportive care options [9]. Therefore, eHealth applications may also contribute to address the care and information needs of patients and their caregivers. The need for information on a range of domains (e.g., physical activity, healthy lifestyle and social/psychological care) is frequently reported in cancer patients and survivors [12, 13]. Additionally, advanced cancer patients in general often encounter unmet care, support, and information needs [14–16]. Good information provision is an essential aspect of cancer care [12] and is associated with better treatment responses and better quality of life [17]. EHealth applications have been shown to facilitate information provision, with observed positive effects on knowledge levels and perceived support of cancer patients [18].

Previous studies have investigated the supportive care and information needs of melanoma patients [16, 19, 20]. In these studies, information and supportive care needs in the psychological, social and physical domain were uncovered. However, in the new era of systemic therapy, these needs have not been explored by using qualitative study designs. Qualitative study methods are useful to get detailed insight into patients' subjective needs and to define a coherent model for the development of an eHealth application [21]. In addition, the patient perspective on how these needs can be supported by eHealth applications remains unknown. Therefore, we conducted a qualitative

study in high risk and advanced melanoma patients treated with systemic therapies to investigate the supportive care and information needs and how these needs can be supported by eHealth applications. Furthermore, we investigated the additional requirements, facilitators, and barriers for such tools. This qualitative study provides a deeper understanding of advanced melanoma patients' needs, relevant for the successful development and implementation of eHealth applications.

Methods

The methods and results are reported according to best practices for qualitative research. The Standards for Reporting Qualitative Research (SRQR) were followed to provide data transparency and quality [22].

Recruiting and inclusion

The primary outcome of this study was the perspective of patients with high risk and advanced melanoma treated with systemic therapy on unmet supportive care and information needs, as well as the potential role of eHealth applications in meeting those needs. The Institutional Review Board of the Netherlands Cancer Institute (NKI) approved this study.

Patients diagnosed with high-risk (resectable stage III) or advanced (stage IV and unresectable stage III) melanoma during or after systemic treatment (immune checkpoint inhibitors with or without targeted therapy) with ICIs were eligible to participate. Furthermore, patients were ≥ 18 years of age and had sufficient understanding of the Dutch language. Patients were not selected based on internet and/or (mobile) application use. A purposive sampling strategy was used to obtain a sample of participants that varied in sex, age, treatment characteristics, and stage of treatment [23]. Eligible participants were identified and informed by their treating healthcare professional. Patient characteristics, such as age, gender, and treatment details were obtained from the electronic health record. Written informed consent was obtained from all participants.

Interviews

A general inductive approach was used for data collection. Semi-structured interviews were performed. An interview guide was developed to help the patients think about concrete experienced situations in order to get more precise information [23, 24]. The interviews were based on an inductive research design and interview guides were structured based on existing literature [23]. The interview guide started with collecting data on the current (clinical) situation of the patient. The proposed features of the intended

mobile application [25] were then explained. Open-ended questions regarding the content of this mobile application were categorized in two domains, namely (1) experienced supportive care and information needs during and after diagnosis and treatment and (2) acceptability and preferences towards the mobile app. To elicit (unmet) supportive care and information needs, questions were steered (if not identified by patients themselves) towards previously identified domains of information needs (e.g., physical, sexual, social, financial, and psychological aspects, autonomy and patient care and support) [14]. The Technology Acceptance Model was used to elicit requirements of eHealth applications, perceived usefulness, and user acceptance of the proposed technology [26]. The interview guide is presented in Appendix 1. Different steering sub-questions were used to reach data saturation within interviews. Data saturation was defined as the point at which no new information was identified in the interviews [23]. Interviews were conducted by the research coordinator (I.F.), who had no clinical relationship with, and did not know the participants. Interviews were done in person, by videoconferencing or by telephone. The planned duration of the interviews was 45 min. Two test interviews were done

to assess the length of the interview, to check the flow and to validate whether the content correctly answered the research questions.

Data analysis

Interviews were recorded by audio recorders and transcribed verbatim by I.F. and S.G. Transcripts were anonymized by key-codes, and audio files were stored on a secured driver accessible by the research team only. Patients who expressed interest in receiving their transcripts were sent their interview transcript. Data was collected from August 2020 until April 2021. Figure 1 describes our inductive coding and thematic analysis, performed by the methods of Braun and Clarke [27].

A first codebook was made from the first four interviews and used for independent coding of the remaining interviews. We added new codes that arose to the codebook. Patient inclusion was halted when data saturation was reached, meaning that no new codes arose from the interviews. No special software was used for coding and thematic analysis.

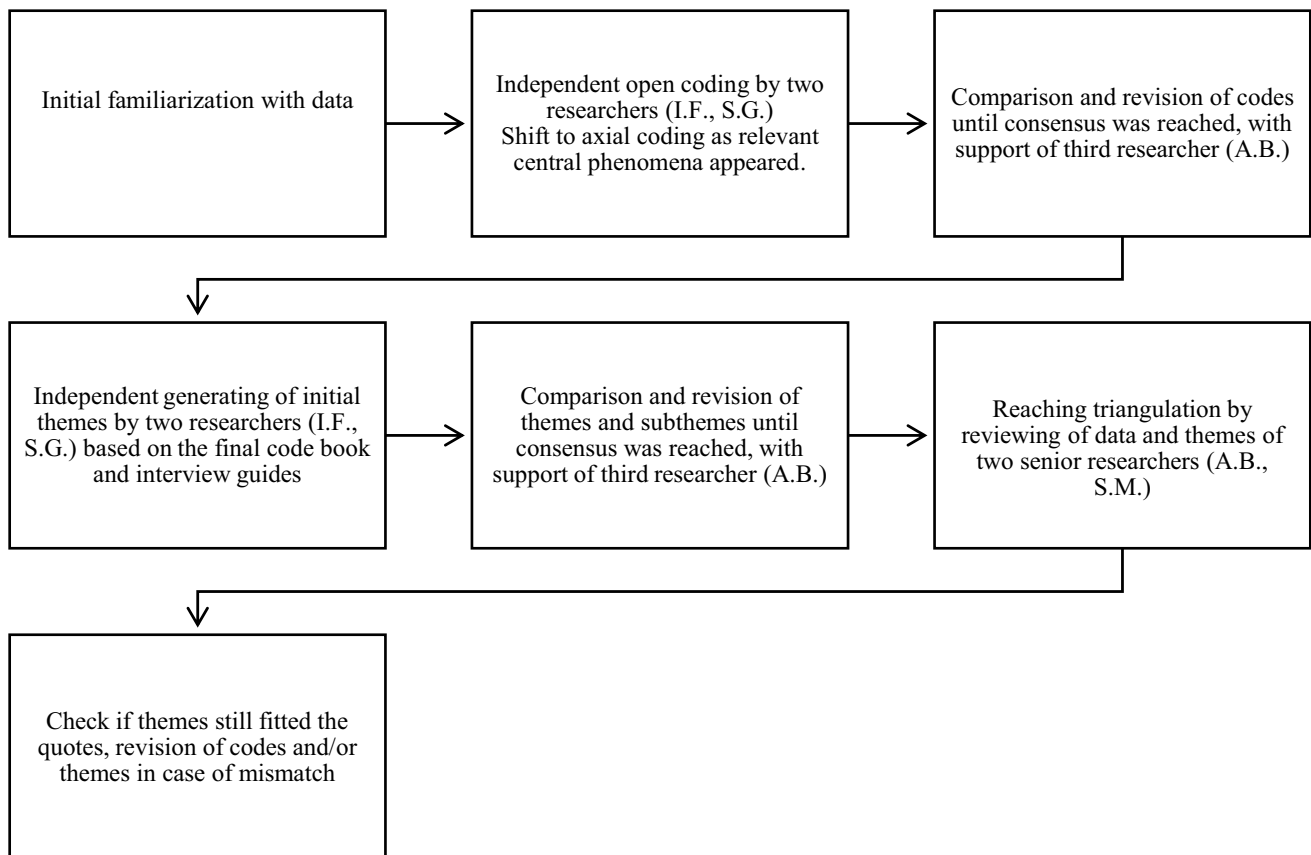


Fig. 1 Inductive coding and thematic analysis process

Results

Study population

Of the fifteen eligible participants who were diagnosed with stage III/IV melanoma and invited to participate, thirteen consented to be interviewed. Two patients declined to participate due to their disease burden. Two participants were interviewed in person in the hospital. Because of the coronavirus disease of 2019 (COVID-19) pandemic restrictions, two participants were interviewed through teleconferencing and nine through phone, all in their home environment. Interviews lasted between 30 and 75 min. Saturation in the codebook was reached once 13 participants were interviewed, where after recruiting stopped. The participants consisted of 6 men and 7 women, ranging from 31 to 71 years of age. All frequently used the internet and/or mobile applications, of which the older participants tended to use the internet only. Type of immunotherapies and treatment line differed in patients, as well as the occurrence and type of adverse events (AEs). Treatment characteristics are presented in Table 1.

Themes

Seven broad themes emerged from the thematic analysis: “patient experience and cancer journey,” “quality of life,”

“use of internet, mobile applications and eHealth,” “information needs,” “needs for remote patient monitoring,” “app requirements of patients,” and “facilitators and barriers of an eHealth application.” These themes are described in the following text and presented in Table 2. Supporting quotes for the thematic analysis are presented in Table 3.

Theme 1: Patient experience and cancer journey

In addition to immunotherapy treatment, eight out of thirteen patients underwent surgery and/or received targeted therapy. All patients mentioned having experienced at least one cancer or treatment-related side effect, ranging from having chills or experiencing fatigue to hospitalization due to side effects. Patients did not explicitly distinguish between adverse events related to immunotherapy or targeted therapy. Seven patients experienced fatigue, both during treatment and in follow-up.

Eight patients expressed they either had feelings of anxiety regarding their diagnosis and treatment and/or experienced their entire cancer journey as an emotional rollercoaster. Social-emotional support was in the majority of patients provided by their partner, children, other family members or friends. A few patients (5/13) also consulted a social worker.

Due to the purely clinical focus of the treatment plan, four patients felt that their feelings and experiences as human beings with cancer were disregarded during treatment.

Table 1 Treatment characteristics of included participants

Stage of disease	Advanced melanoma (stage IV)	N = 11
	High-risk melanoma (resectable stage III)	N = 2
Type of systemic therapy#	Anti-PD1 monotherapy (nivolumab or pembrolizumab)	N = 7
	Anti-CTLA4 monotherapy (ipilimumab)	N = 1
	Anti-PD1 + anti-CTLA4 combination therapy (nivolumab + ipilimumab)	N = 5
	BRAF/MEK inhibitors (dabrafenib + trametinib)	
Patient status	Currently on treatment (2 months to 1 year on treatment)	N = 6
	Post treatment	N = 7
	Complete response (3 months to 5 years follow-up)	N = 4
	Progressive disease	N = 2
Experienced AEs*	Immunotherapy stopped due to irAEs*	N = 1
	None	N = 4
	Hepatitis	N = 3
	Colitis	N = 3
	Gastritis	N = 1
	Hypophysitis	N = 2
	Thyroiditis	N = 2
	Adrenal insufficiency	N = 1

Anti-PD-1 programmed death-1 antibody, *anti-CTLA-4* cytotoxic T lymphocyte-antigen-4 antibody, *T-VEC* talimogene laherparepvec, *AEs* adverse events

#Patient could have received multiple/different lines of immunotherapy

*Patient-reported

Table 2 Themes and subthemes

Theme	Subthemes
Patient experience and cancer journey	Treatment Response Side effects Psychosocial state Interpersonal relationships Social support system Relationship with HCP Patient autonomy and empowerment
Quality of life	Positive impact Negative impact Impact COVID-19
Use of internet, mobile applications, and eHealth	General use of internet and mobile applications Current use of eHealth Motivation for using eHealth applications
Information needs	Educational topics Interventions Fellow patients/peer support
Needs for remote patient monitoring	Feedback Input Use of sensors
Requirements for eHealth applications	Availability Ease of use Evidence-based information Functionalities Information architecture Information presentation Integration with current applications Notifications Privacy (compliance to privacy laws)
Facilitators and barriers for eHealth	Information needs Perceived user needs of an app Use of sensors Remote patient monitoring Frequency of app use

HCP healthcare professional, *COVID-19* coronavirus SARS-CoV-2

Furthermore, some patients stated that they did not receive adequate education from their healthcare providers about their own abilities to self-manage their disease and daily life throughout treatment. They believed that if they had been better informed about the effects of disease and treatment on their daily lives, they could have mentally prepared themselves more effectively.

Theme 2: Quality of life

Nine patients mentioned the importance of having tools to self-manage their disease and daily life for their quality of life. These patients defined self-management

as being informed about things they can do to maintain or improve their physical and mental well-being, aside from adhering to clinical treatment. Patients indicated activities of self-management to contribute to feeling autonomous during their treatment.

More than half the patients experienced feelings of anxiety, uncertainty and negative thoughts both during treatment and in the post-treatment phase. Patients mentioned causes such as uncertainty about treatment response and survival and fear for cancer recurrence in patients without active disease. Patients frequently struggled with accepting the changes in their daily lives, caused by the disease, particularly the inability to work.

Table 3 Themes with supporting quotes

Theme	Quote
Patient experience and cancer journey	<p>“And then you also have to think, no more energy, gosh, I was happy when I could get from the couch to the toilet and back again. And then I could “puff, puff, puff”, I could make coffee again, uhm, and then again back, uhm. And it wasn't that I could do all kinds of things in house, one after the other. So your world became really small and it really is a form of survival.”(R6)</p> <p>“Yes you know. In the end, it comes down to the fact that you just want a bit of security (in the cancer journey) and that no one is actually giving you that security. I'm realistic enough to see how that works of course.” (R10)</p> <p>“Yes, but it's taken very lightly as well. Y'know, it is not nothing that happens and I missed something, like, it seems like some sort of rational agreement that you make, like, ‘we will prolong your life. And there can be some consequences but you just have to accept them in your story.’ And of course you do that, at least, I do that, but that does not mean that it isn't a huge blow psychologically now and then” (R11)</p>
Quality of Life	<p>“Good quality of life? That I just, yes, that I have as much fun as possible and that I can mean something for someone else. So that I can also make others happy And that I do not have to sit passively behind the geraniums like a greenhouse plant.”(R7)</p> <p>“Uhm, well, bad days, yes, you always have sad days and frustrating days, that you cannot do everything you did before. And hey, yes, there are a lot of uncertainties in the entire process ...” (R4)</p> <p>“It is of course also a bit more difficult with corona. Because now, I am sitting, we are sitting on the terrace, but I do have troubles, uhm, to sit inside somewhere. And now winter is coming, so I find that quite difficult.” (R2)</p>
Information needs—educational topics and interventions	<p>“Everything is in the forms, you read them in five minutes, you sign them. I think there could be more attention towards that [information provision]. And of course it's not positive to mention to the patient everything that can happen [adverse events], you know, as much more can happen. This was enough for me but much more can happen.” (R11)</p> <p>“Well, I guess moving is, so keep moving and stay somewhat active, um, looking back that would have definitely helped me I think. No matter what I said, there have been some periods where I was under-active. So I think that such a module that contains some... some sort of, good tips or maybe even more extensive kind of help with exercises, I think that would have helped me.” (R9)</p>
Information needs—peer support	<p>“Yes, of course I always think, yes. But yes, uhm, I would certainly use the app to also see other people's experiences, yes maybe that is also nice, a tab with experiences, hey, that you can also read anonymous interviews of, how do you do it, how do you deal with it, and what are your tips and tricks and that you can learn things from each other, say fellow sufferers. (R5)</p>
Needs for remote patient monitoring	<p>“Yes, I think so. Especially on days when things are not going so well. That you, then you know, if it is implemented in [the mobile app] of course, but that if there really is something that they [healthcare professionals] look at your side effects of, there is something, and then they will contact me, you know that. that you need to worry a little less if they don't.” (R13)</p>

Table 3 (continued)

Theme	Quote
Facilitators and barriers of eHealth applications—information needs	“Right and uhm, but there are also, yes look I am very different from other people, I also have a book about breast cancer. I bought it immediately because it was also written by someone from your institute. And then I put that on the table and I have two other friends who also had breast cancer but they didn't want to read it. They didn't want to know. They dive away from it. But I, precisely, I want to know as much as possible. Yes. Well, and if you are set like that, you want to have good knowledge” (R8, a patient who also had experienced breast cancer)
Facilitators and barriers of eHealth applications—remote patient monitoring	<p>“Yes. But also less worrisome. Because I, when you go into therapy like that, everything is new. And then you don't know if you should call [for reporting side effects] or not. And then, that line [to call or not to call] is just very vague. And if you have such an app where you can just indicate your side effects and it is sent to your doctor by way of example, who can, for example, look through the statistics of everyone every day and think, no, this is all fine, I don't have to do anything with it.” (R13)</p> <p>“I catch myself forgetting everything [symptoms] that I experienced. So it might be nice to have an overview for yourself And to keep track of everything you experience and it might be that the physician finds something useful. (R1)</p>

Theme 3: Use of internet, mobile applications, and eHealth

All patients accessed the internet on a regular basis, and the majority of them used mobile applications. The majority of patients had used the internet to gather information about their diagnosis and treatment. Some patients searched for tips and tricks on maintaining a healthy lifestyle. Eight out of thirteen patients reported using a health-related mobile application, such as fitness apps, the hospital's information portal, and an application developed for tackling cancer-related fatigue.

Theme 4: Information needs

Educational topics and interventions While information was available, nearly all patients experienced unmet information needs. Possible causes included not internalizing information due to the feeling of being overwhelmed and a shortage of time in healthcare provider consultations. Patients would like to receive information about melanoma, systemic therapies other treatments, and prognosis. A majority of patients would like to have access to information regarding self-management (i.e., cancer-related anxiety, sleep problems, nutrition, physical activity, and fatigue), managing work and cancer, and supportive care. Three patients, under 40 years of age, were interested in information concerning employment, income, housing, fertility, and talking to their children about cancer.

In addition, the majority of patients would like to see interventions concerning physical activity, relaxation and mindfulness, such as yoga, creative therapies, and (mindful) walking.

Peer support Ten patients expressed an interest in peer support. Some would like to read about experiences of fellow patients or directly communicate them.

Theme 5: Needs for remote patient monitoring

Eight out of thirteen patients see benefits in reporting symptoms via an eHealth application. The primary benefit indicated was to receive feedback regarding symptom management either from the application itself or from their clinician. Patients expected their motivation to report symptoms would rapidly decline without receiving feedback. Six patients were interested in using sensor measurements during remote patient monitoring, such as vital functions (e.g., heart rate), sleep, and steps.

A complete overview of identified needs and suggestions for content and functionalities of eHealth applications is presented in Table 4.

Theme 6: Requirements for eHealth applications

A crucial requirement for eHealth applications, as noted by nine patients, is ease of use. This includes intuitive design, which is simple and user-friendly for users of all ages, clear login and log-out features and reducing data input effort by

Table 4 Patients' needs and suggestions for eHealth content and functionalities

Need	Suggestions for content in order of importance*
Information and education (text-based)	Side effects
	Nutrition
	Treatments
	Additional care options
	Physical activity
	Managing work and cancer
	Diagnosis
	Tips on managing anxiety and cancer-related rumination
	Medication
	General health and lifestyle tips
	Fatigue
	Prognosis, survival, statistics and clinical trials
	Interventions
Relaxation	
Interventions for physical activity	
Peer support	Experiences of fellow patients
	Contact with fellow patients (social forum/buddy system)
Remote patient monitoring	Symptom (adverse events) monitoring
	Use of sensors/wearables (to track sleep, steps, temperature, blood pressure etc.)

HCP healthcare professional

*Majority of patients mentioned the need for evidence-based content

use of drop-down menus and minimizing free-text fields. Information should be presented concisely and graphically. An additional requirement is accessible language suitable for patients. EHealth applications should show basic medical information at first, with the option to select additional information for viewing to avoid overwhelming patients. Nine patients mentioned compliance to privacy laws as a requirement.

Theme 7: Facilitators and barriers of an eHealth application

Patients mentioned the following motivations for using a supportive eHealth application; information provision, symptom reporting and remote patient monitoring, and receiving practical tools for managing their disease and quality of life.

Information needs Some patients stated that information needs are personal and different for everyone. They

indicated that eHealth applications should allow for a layered structure of information, allowing the patient to decide consciously whether they want to view additional information. Patients were aware of existing information sources and saw an opportunity for an eHealth application to function as an information hub, referring to trustworthy and evidence-based information. Furthermore, one patient felt that the tone should not be too positive but mainly factual, while another patient considered that the tone should not be very formal.

Remote patient monitoring Eight out of thirteen patients saw benefits in reporting symptoms via eHealth applications. Patients are currently expected to call the hospital for reporting their symptoms; however, some patients experience barriers because they perceive their call as intrusive or an unnecessary burden to the clinician. Patients also recalled situations where they were unsure if their symptom was a cause of concern for which they should contact their physician. The main perceived benefit was the increased accessibility of informing their clinician of the experienced symptoms, regardless of severity, in a way that they perceive as non-intrusive for their clinician. A common view among patients was that symptom reporting via eHealth applications would facilitate proactive management of side effects by both clinician and patient. Three patients expected that the use of sensors could facilitate an increased insight in patients' own well-being, while two considered that being aware of these data could potentially cause stress.

A complete overview of identified facilitators and barriers, including requirements, for eHealth applications is shown in Table 5.

Discussion

The results of this qualitative study show that patients with high risk and advanced melanoma treated with immune-checkpoint inhibition experience unmet information and supportive care needs during and after active treatment. Patients expect that eHealth applications can aid in meeting these unmet needs and that these applications will provide a range of benefits. Opportunities emerge for eHealth applications to support disease self-management, potentially increasing autonomy and improving quality of life. Facilitators for the use of such eHealth applications include increased accessibility to evidence-based information and wellbeing interventions, as well as reporting symptoms. The most crucial barrier described was the inability to personalize eHealth applications, in terms of required frequency of use, information presentation and notifications.

Table 5 Requirements, facilitators, and barriers for eHealth applications

Topics/requirements	Facilitators	Possible barriers
Information needs—educational content	App can contain information or refer to existing sources of information and interventions	Currently enough information available about treatment and side effects, making app redundant
	Easier to try out new interventions when accessible in eHealth application	Interventions provided by app do not have social benefits of in-person intervention
	App can present list of basic information, with option to search for additional information	Overload of information can cause negativity and stress
	App can inform patient of new up-to-date information	App never updated and/or outdated information
	App can provide evidence-based information (which increases faith in treatment) including references	None
Remote patient monitoring	Increased accessibility of communicating side effects to clinician via app	App cannot replace “real-life” communication with HCP
	Useful for both patient and clinician to have list of symptoms and overview of health data, collected by app	Increased insight in data could induce stress
	Patient feeling more safe/assured due to distant patient monitoring	Not receiving feedback (from HCP or system) after symptom reporting/data input by patient
Information presentation	App can present information and data concisely and in graphical visualization, more easily understandable	Too much text or unclear data
	App uses accessible language	Language and information too simple or too complex
Availability and privacy	Available for use on platform that patient prefers	Not available on every platform, readability of content is impaired if app is only accessible on phone
	Compliance to privacy regulations	Uncertainty of who views and receives personal data of patients
Ease of use	Clear and simple login and logout	Settings not easily findable
	Text input via drop-down menus	Too many free-text fields
	Intuitive design and use	Unclear where to find content in app
Personalization and notifications	Frequency of notifications is customizable	Too many unwanted notifications
	App can present tips and tricks in positive, practical way	Tone in which information is presented is not suitable for patient
Frequency of use	App use is non-obligatory, and facilitates any frequency of use, as needs for app use are patient- and treatment phase specific	App is only beneficial when used in certain frequency

App application, *eHealth* electronic health, *HCP* healthcare professional

Despite information being available, nearly all patients mentioned that their information needs were not met. Patients were interested in receiving information via an eHealth application and expected to have easier access to a wider range of information than they currently receive. Patients experienced unmet information needs with regard to clinical- and self-management topics, cancer-related fatigue management, and available supportive care services. The need for information on these domains is reflected in previous work concerning advanced cancer patients as well as cancer survivors, indicating a varying information need throughout disease and treatment [14, 16, 20, 28–30]. Additionally, insight in experiences from fellow patients was frequently stated as an important need of patients. This need for peer support is mentioned as well by other studies

in cancer patients and is believed to support patients both socially and to cover unmet (information) needs [31–33]. Regardless of the perceived benefits and positive attitude of patients towards eHealth, a study of Lubberding et al. [9] found that despite the use of an eHealth application during follow-up care, some needs remained unmet, including supportive care needs. EHealth applications implemented in the care of (advanced) cancer patients should focus on comprehensively covering and implementing the needs described by these patients.

Second, patients expect eHealth applications to facilitate gaining insight in their disease and treatment, and developing disease self-management skills. Patients characterized self-management as being informed about things they can do to support their physical and mental well-being, aside from

adhering to clinical treatment. Patients expect their self-management skills to help them feel more autonomous during treatment. Acquiring self-management skills and feeling autonomous are considered as positive drivers for quality of life. Previous research on the effects of eHealth applications on cancer patients' self-management showed mixed results [34]. A recent quantitative trial among 625 cancer patients showed that a web-based eHealth application, facilitating monitoring of symptoms and HRQoL, as well as providing tailored feedback and supportive care options, did not improve knowledge, skills, nor confidence for self-management [35]. However, follow-up in-depth qualitative found that the eHealth application was perceived as providing additional self-management support and fostering individual autonomy [36]. The difference in methodology of measuring the effect of such interventions on self-management and autonomy could be one explanation for these mixed findings. There might also be inherent differences between types of cancer and types of participants that influence the impact of eHealth applications on self-management. Moreover, we have to keep in mind that self-management of patients with advanced cancer is highly personal and multifaceted [37], a common view among the interviewees of this study as well.

Third, the main perceived benefit of symptom monitoring via an eHealth application was the increased possibility of informing their clinician of the experienced symptoms, regardless of severity, in a way that patients perceive as non-intrusive for their clinician. Patients anticipated feeling more secure and re-assured, as they would expect the system or their clinician to alert them for follow-up if their symptoms indicate so. Several studies have shown that web-based monitoring systems intensify symptom management, improve symptom control, improve overall survival, and facilitate patient-clinician communication [9, 38–41]. A recently conducted randomized controlled pilot study in Danish patients with advanced melanoma treated with immunotherapy showed high patient and clinician satisfaction with an eHealth application used for electronic symptom self-reporting, as both patients' symptom awareness and patient involvement increased [42]. However, the use of this tool did not show a reduction in the number of irAEs with the use of electronic symptom self-reporting [43]. As such, the relation between increased self-management skills and reduction in irAEs remains unclear.

This study has several limitations. First, we performed a single center study in a Dutch comprehensive cancer center. Information needs and requirements for a supportive eHealth application might be different for patients from general or academic hospitals, as well as throughout other countries. Second, selection biases could be present in this patient sample. We did not select patients based on health literacy or education level, and patients might have consented to participate because they have a present interest in technology or

mobile applications. Nonetheless, two patients did not use mobile applications and did not intend on using one in the future, but still wanted to participate for the sake of future patients. Strengths of this study include the qualitative methodology. Our semi-structured interview design, including open-ended questions, allowed us to gain a deeper understanding of the challenges patients face during their cancer journey, their perception of quality of life and autonomy, their needs for self-management, and how eHealth applications can support those needs successfully.

The findings of this study have relevant implications for the development and implementation of eHealth applications aimed at cancer patients. With this work, we aimed to gain insight into factors described by the Technology Acceptance Model, including the perceived usefulness, attitude towards, and the behavioral intention to use an eHealth application to support the uncovered unmet needs of patients. A natural progression of this work is to develop an eHealth application incorporating the outlined needed elements. We view this work as a first point of reference in factors pertaining to "prospective acceptability" of eHealth applications that would support high risk and advanced melanoma patients, treated with systemic therapy. As highlighted in Short et al. [44] and Perski et al. [45], it remains a challenge to understand, assess, or predict the acceptability and engagement of eHealth interventions during development and implementation, and as such, researchers should consider both qualitative and quantitative methods to measure acceptability and engagement, depending on the stage of research and development.

In conclusion, high-risk and advanced melanoma patients treated with immune-checkpoint inhibitors have extensive needs for supportive care, information provision, and symptom management, regardless of information and services already provided by the hospital. Patients believe that the use of eHealth applications, facilitating information gathering and symptom management, would increase their self-management skills, which would contribute to patients' autonomy. Patients reported acquiring self-management skills and feeling autonomous as positive drivers for quality of life. The use of eHealth applications may therefore positively affect health-related quality of life in high-risk and advanced melanoma patients during and after immune-checkpoint inhibition.

Abbreviations AE: Adverse event; COVID-19: Coronavirus disease of 2019; eHealth: Electronic health; EHR: Electronic health record; HCP: Healthcare professional; HRQoL: Health-related quality of life; ICI: Immune checkpoint inhibitor; irAE: Immune related adverse event; UCD: User-centered design

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Author contribution I.F., S.G.: conceptualization, interviewing, transcribing, data analysis, writing.

A.B.: conceptualization, data analysis, reviewing, writing.

S.M., M.P., L.vd.P.: conceptualization, reviewing, writing.

S.W., H.M.: conceptualization, recruiting patients, reviewing, writing.

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Code availability Not applicable.

Declarations

Ethics approval Approval was obtained from The Institutional Review Board of the Netherlands Cancer Institute (NKI). The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent for publication Patients signed informed consent regarding publishing their data.

Conflicts of interest The authors declare no competing interests.

References

- Matthews NH, Li W-Q, Qureshi AA, Weinstock MA, Cho E (2017) Epidemiology of melanoma. *Exon Publications* 3–22
- Michielin O, van Akkooi ACJ, Ascierto PA, Dummer R, Keilholz U, clinicalguidelines@esmo.org EGCEa (2019) Cutaneous melanoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up dagger. *Ann Oncol* 30(12):1884–901.
- Larkin J, Chiarion-Sileni V, Gonzalez R, Grob JJ, Rutkowski P, Lao CD et al (2019) Five-year survival with combined nivolumab and ipilimumab in advanced melanoma. *N Engl J Med* 381(16):1535–1546
- Robert C, Karaszewska B, Schachter J, Rutkowski P, Mackiewicz A, Stroiakovski D et al (2014) Improved overall survival in melanoma with combined dabrafenib and trametinib. *N Engl J Med* 372(1):30–39
- Rogiers A, Boekhout A, Schwarze JK, Awada G, Blank CU, Neyns B (2019) Long-term survival, quality of life, and psychosocial outcomes in advanced melanoma patients treated with immune checkpoint inhibitors. *J Oncol* 2019:5269062
- Tan JD, Butow PN, Boyle FM, Saw RPM, O'Reilly AJ (2014) A qualitative assessment of psychosocial impact, coping and adjustment in high-risk melanoma patients and caregivers. *Melanoma Res* 24(3):252–260
- Saw RP, Bartula I, Winstanley JB, Morton RL, Dieng M, Lai-Kwon J, et al (2022) Melanoma and quality of life. *Handbook of Quality of Life in Cancer*: Springer. 439–66
- Kotronoulas G, Kearney N, Maguire R, Harrow A, Di Domenico D, Croy S et al (2014) What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. *J Clin Oncol* 32(14):1480–1501
- Lubberding S, van Uden-Kraan CF, Te Velde EA, Cuijpers P, Leemans CR, Verdonck-de Leeuw IM (2015) Improving access to supportive cancer care through an eHealth application: a qualitative needs assessment among cancer survivors. *J Clin Nurs* 24(9–10):1367–1379
- Chen J, Ou L, Hollis SJ (2013) A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. *BMC Health Serv Res* 13(1):1–24
- Snyder CF, Aaronson NK, Choucair AK, Elliott TE, Greenhalgh J, Halyard MY et al (2012) Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. *Qual Life Res* 21(8):1305–1314
- Jansen F, van Uden-Kraan CF, van Zwieten V, Witte BI, Verdonck-de Leeuw IM (2015) Cancer survivors' perceived need for supportive care and their attitude towards self-management and eHealth. *Support Care Cancer* 23(6):1679–1688
- Davies NJ, Kinman G, Thomas RJ, Bailey T (2008) Information satisfaction in breast and prostate cancer patients: implications for quality of life. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 17(10):1048–52
- Wang T, Molassiotis A, Chung BPM, Tan JY (2018) Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliat Care* 17(1):96
- Marcusen C (2010) Information and communication needs of individuals living with advanced cancer. *Semin Oncol Nurs* 26(3):151–156
- Passalacqua S, di Rocco ZC, Di Pietro C, Mozzetta A, Tabolli S, Scoppola A et al (2012) Information needs of patients with melanoma: a nursing challenge. *Clin J Oncol Nurs* 16(6):625–632
- Husson O, Oerlemans S, Mols F, Smeets RE, Poortmans PM, van de Poll-Franse LV (2014) Satisfaction with information provision is associated with baseline but not with follow-up quality of life among lymphoma patients: results from the PROFILES registry. *Acta Oncol* 53(7):917–926
- Slev VN, Mistiaen P, Pasman HRW, Verdonck-de Leeuw IM, van Uden-Kraan CF, Francke AL (2016) Effects of eHealth for patients and informal caregivers confronted with cancer: a meta-review. *Int J Med Informatics* 87:54–67
- Subasri M, Lemonde M, Mundluru J, Chang J, Koneru R (2021) Assessing the educational and supportive care needs of Canadian metastatic melanoma patients and survivors attending an outpatient clinic. *J Patient Exp* 8:23743735211033130
- Fu H, Teleni L, Crichton M, Chan RJ (2020) Supportive care and unmet needs in patients with melanoma: a mixed-methods systematic review. *Support Care Cancer* 28(8):3489–3501
- Brenner W, Uebernickel F, Abrell T (2016) Design thinking as mindset, process, and toolbox. Springer, Design thinking for innovation, pp 3–21
- O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA (2014) Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 89(9):1245–1251
- Harding J (2018) Qualitative data analysis: From start to finish: Sage

24. Mummah SA, Robinson TN, King AC, Gardner CD, Sutton S (2016) IDEAS (Integrate, Design, Assess, and Share): a framework and toolkit of strategies for the development of more effective digital interventions to change health behavior. *J Med Internet Res* 18(12):e317
25. CAPABLE Project [updated 2021. Available from: <https://capable-project.eu/>.
26. Davis FD (1989) Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS quarterly* 319–40.
27. Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qual Res Psychol* 3(2):77–101
28. Brutting J, Bergmann M, Garzarolli M, Rauschenberg R, Weber C, Berking C et al (2019) Unmet information needs of patients with melanoma in Germany. *Melanoma Res* 29(2):196–204
29. James-Martin G, Koczwara B, Smith EL, Miller MD (2014) Information needs of cancer patients and survivors regarding diet, exercise and weight management: a qualitative study. *Eur J Cancer Care (Engl)* 23(3):340–348
30. Beesley VL, Alemayehu C, Webb PM (2018) A systematic literature review of the prevalence of and risk factors for supportive care needs among women with gynaecological cancer and their caregivers. *Support Care Cancer* 26(3):701–710
31. Park HY, Kim MJ, Kim JY, Kim S, Choi JY, Kim JH et al (2019) Could peer support programs be a good resource for managing the unmet needs of cancer patients? *J Cancer Educ* 34(5):950–957
32. Brodar KE, Carlisle V, Tang PY, Fisher EB (2020) Identification and characterization of peer support for cancer prevention and care: a practice review. *J Cancer Educ* 1–10
33. Villani D, Cognetta C, Toniolo D, Scanzi F, Riva G (2016) Engaging elderly breast cancer patients: the potential of eHealth interventions. *Front Psychol* 7:1825
34. Kuijpers W, Groen WG, Aaronson NK, van Harten WH (2013) A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: relevance for cancer survivors. *J Med Internet Res* 15(2):e37
35. van der Hout A, van Uden-Kraan CF, Holtmaat K, Jansen F, Lissenberg-Witte BI, Nieuwenhuijzen GAP et al (2020) Role of eHealth application Oncokompas in supporting self-management of symptoms and health-related quality of life in cancer survivors: a randomised, controlled trial. *Lancet Oncol* 21(1):80–94
36. Nilsson L, Hellström A, Wennerberg C, Ekstedt M, Schildmeijer K (2020) Patients' experiences of using an e-Health tool for self-management support after prostate cancer surgery: a deductive interview study explained through the FITT framework. *BMJ Open* 10(6):e035024
37. Van Dongen SI, De Nooijer K, Cramm JM, Francke AL, Oldenmenger WH, Korfage IJ et al (2020) Self-management of patients with advanced cancer: a systematic review of experiences and attitudes. *Palliat Med* 34(2):160–178
38. Denis F, Lethrosne C, Pourel N, Molinier O, Pointreau Y, Domont J, et al (2017) Randomized trial comparing a web-mediated follow-up with routine surveillance in lung cancer patients. *J Natl Cancer Inst* 109(9)
39. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P et al (2016) Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. *J Clin Oncol* 34(6):557–565
40. Jensen RE, Snyder CF, Abernethy AP, Basch E, Potosky AL, Roberts AC et al (2014) Review of electronic patient-reported outcomes systems used in cancer clinical care. *J Oncol Pract* 10(4):e215–e222
41. Bennett AV, Jensen RE, Basch E (2012) Electronic patient-reported outcome systems in oncology clinical practice. *CA: a cancer journal for clinicians* 62(5):336–47.
42. Tolstrup LK, Pappot H, Bastholt L, Zwisler AD, Dieperink KB (2020) Patient-reported outcomes during immunotherapy for metastatic melanoma: mixed methods study of patients' and clinicians' experiences. *J Med Internet Res* 22(4):e14896
43. Tolstrup LK, Bastholt L, Dieperink KB, Moller S, Zwisler AD, Pappot H (2020) The use of patient-reported outcomes to detect adverse events in metastatic melanoma patients receiving immunotherapy: a randomized controlled pilot trial. *J Patient Rep Outcomes* 4(1):88
44. Short CE, DeSmet A, Woods C, Williams SL, Maher C, Middelweerd A et al (2018) Measuring engagement in eHealth and mHealth behavior change interventions: viewpoint of methodologies. *J Med Internet Res* 20(11):e9397
45. Perski O, Short CE (2021) Acceptability of digital health interventions: embracing the complexity. *Transl Behav Med* 11(7):1473–1480

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