Online follow-up with a mobile device improves incurable cancer patients’ coping – A qualitative study

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ABSTRACT

Purpose: To examine patients’ experiences regarding the impact of support given by a mobile application on their ability to cope with incurable cancer.

Method: The qualitative research data of semi-structured, face-to-face interviews with 20 adult patients suffering from incurable cancer during disease-controlling chemotherapy or palliative care were analysed with inductive content analysis.

Results: The majority of the interviewees viewed the mobile application as helpful for monitoring relevant symptoms and coping with the disease. The patients’ sense of security was increased by their ability to contact the clinic at all times. As a communication channel, the mobile application was seen as more convenient than the telephone, and it provided a sense of freedom for the patients as contacting the clinic was not tied to time or place. The patients also experienced as well increased involvement with their own care and had a sense of staying abreast with their treatment. A minority of the interviewees reported that there was a certain disease-centredness in using the mobile application.

Conclusions: The present study extends the knowledge of patients using a mobile application as a part of their cancer care and assesses of the acceptance of using this application to provide supportive care. The patients reported that they were better able to cope with the disease when using the mobile application, although some described it as being too disease centred. Overall, this study indicates that the patients’ sense of security and freedom increased when using the mobile application.

1. Introduction

Palliative and supportive care aims to improve the patient’s quality of life. The goal is to prevent or ease the symptoms of a serious disease and to treat the psychological, social, and existential problems related to the disease and its treatment (Hallman and Newton, 2019; Sun and Bakitas, 2019; Olver et al., 2020; WHO, 2020). During challenging life crises, such as coping with incurable cancer, communication is a key element (Hallman and Newton, 2019). The improvement of patients’ experiences during their cancer trajectory can be assisted by utilising the technological advances in communication, including patient-reported outcomes (Moradian et al., 2018). In this regard, the value of using a mobile application is in providing the information that patients need and offering a tool for them to communicate the issues related to their symptoms and ask any questions that may arise during the course of their treatment (Aapro et al., 2020).

The increasing interest in the variety of online support and healthcare services offered has heightened the need for research on this phenomenon. In this area, the potential of telehealth services in palliative care has been identified (Calton et al., 2021; Hancock et al., 2019). There is also evidence that palliative and supportive care, integrated at the earliest possible phase, can improve a patient’s quality of life (Hallman and Newton, 2019; Schenker et al., 2014).

According to the WHO’s (2020) definition of telehealth or eHealth, it involves the use of a telecommunication device to deliver healthcare services outside of hospital healthcare facilities. Among other services, it offers guidance to chronically ill patients and healthcare personnel. By using eHealth, there is the possibility of improving healthcare outcomes,
especially for vulnerable patient groups (WHO, 2020) Telemedicine is defined differently from telehealth as a way to connect users who are not in the same physical location, for example when a patient and a physician consult with another physician on the other side of the country (WHO, 2010).

Earlier research on telehealth has focused on healthcare personnel’s viewpoint instead of patients’ experiences (Bash et al., 2016; Liptrott et al., 2020; Magalhães et al., 2020). Although young people are the most likely to use online support channels (Paul et al., 2012), there are increasing numbers of elderly patients using these services as well (Magalhães et al., 2020; Ware et al., 2017). Previous research has shown that, among other benefits, using patient-reported outcomes increases patients’ quality of life (Bash et al., 2016; Torres-Vigil et al., 2021). Patients want to be aware of their treatment and disease to maintain a quality of life that is sufficiently satisfying to them (Liptrott et al., 2020; Magalhães et al., 2020).

Before conducting this research, a systematic literature review was conducted to determine the factors contributing to incurable cancer patients’ coping behaviours. The results of this review show that the patients’ coping is better when they have the possibility of being in touch with healthcare personnel. This increases their feelings of safety and connection. (Saukkonen et al., 2017.) It is important to take into consideration the complexity and variety of patients’ coping behaviours in enabling them to manage their cancer-related challenges (Glasdam et al., 2020). To proceed with their lives while coping with their disease, cancer patients need various kinds of support (Hallman and Newton, 2019; Saukkonen et al., 2017; van Roij et al., 2019; Viitala et al., 2018).

Support can be understood as strengthening patients’ inner resources and increasing their sense of well-being. The support given to patients by health personnel is crucial. By offering the right support and information at the appropriate time, health personnel can decrease patients’ anxiety and positively affect their quality of life. (Magalhães et al., 2020; Mendonça et al., 2020.) Support and guidance should be given while remembering that during the different phases of illness and life, patients’ goals may vary (Glasdam et al., 2020; Kjerven Haug, 2016). The importance of support provided in ways other ways than face-to-face contact has been highlighted by the physical and social distancing during the COVID-19 pandemic (Torres-Vigil et al., 2021).

Although progress has been made towards achieving the best possible quality of life for patients with incurable cancer, the possible ways to provide support in helping them cope with the disease in everyday living needs to be developed further (Liptrott et al., 2020; Pinto et al., 2017; Stanzè et al., 2019). The aim of the study was to demonstrate the meaning of online support for patients’ coping with incurable cancer by describing their experiences using a mobile application. The results provide valuable information towards developing patient-centred cancer nursing and the offering of timely support, especially during the current challenging times of limited face-to-face contact.

2. Methods

2.1. Design

The study was qualitative and used thematic interviews. It adhered to the Standards for Reporting Qualitative Research (SRQR) guidelines (O’Brien et al., 2014). Inductive content analysis was selected as the data analysis method, based on the literature review, which was conducted before the study to examine previous studies and to Mull over the themes of the thematic interviews. The qualitative health study design allowed us to explore how patients perceived their health status and treatment, and how they experienced their illness. The phenomena related to coping and receiving support were examined and described. It was not possible to prepare meticulously for the collecting and processing of the data, as the study design needed to be flexible, open, and evolve as the research project progressed. It was presumed that the experiences of both the researchers and participants were influenced by their interpretations (Holloway and Galvin, 2016; Kyngäs, 2019b).

2.1.1. The mobile application

The smart cloud-based mobile application studied in this research, called Noona®, was developed by Varian Medical Systems Finland Oy. It is designed to capture patient-reported outcomes regarding their symptoms. The cancer clinic sends an invitation for the patient to use the application as part of cancer care and communication. Through the application, patients are able to report the possible symptoms and side effects caused by their chemotherapy treatment. The application consists of modules tailored for different types of cancer patients to target the most relevant symptoms per specified cancer type during and after the chemotherapy period (Varian, 2021). As it is used in monitoring a patient’s health condition, it is a CE-marked medical device and has regulatory approval (European Commission, 2017). In this study, the participants were asked about their experiences, so the actual diagnosis or the content of the questionnaires that patient’s received through the mobile application did not matter.

2.2. Participants

The participants (N = 20) were recruited at the oncology outpatient clinic of one university hospital. The nurses in the clinic approached patients who met the inclusion criteria to enquire about their willingness to participate in the survey. To be eligible, the participating patient must 1) have been diagnosed with incurable cancer, 2) was over 18 years of age, 3) was receiving disease-controlling chemotherapy or palliative care, 4) was able to give informed consent to the study and participate in the interview, and 5) had over six months’ experience using the mobile application for symptom tracking. Before applying for ethical approval, the targeted number of research participants was evaluated as 20 to achieve enough rich data for the analysis. The participant characteristics are summarised in Table 1. During the data collection, the researcher (AV), with the senior authors (MP, JL, and PÅ-K), determined the number of participants to be sufficient, according to the study design and data saturation.

2.3. Data collection

The data were collected from semi-structured interviews. The interviewer followed the literature-based thematic guide (Table 2) in conducting the interviews. Open-ended and prompting questions were used to encourage participant contributions (Connelly and Peltzer, 2016). The interviews were conducted from December 2019 to March 2020 by the first author (AV), an experienced cancer nurse with qualifications in palliative care and qualitative methods. The participants were interviewed once, face-to-face. The interviewer was not involved in the participants’ cancer treatment nor did she comment on the prior treatment decisions. Regarding treatment-related questions, the participants were guided to contact their oncologist. The interviews were
conducted at the participants’ preferred locations and audio-recorded. Most participants (n = 17) were interviewed in a private room at the oncology outpatient clinic during or after their chemotherapy treatment, one in a private room on the hospital ward, one after work at the participant’s office, and one at home.

2.4. Data analysis

The data was analysed by the first author (AV), using qualitative inductive content analysis. This method was chosen due to the existing knowledge of the research related phenomena being fragmented (Kyngas, 2019a). The data were read many times to obtain an overall view. The interpretation was enhanced with field notes and diaries, which helped in recalling the key interview content when listening to the recordings for transcribing. Listening to the recordings and reading the transcribed data enabled familiarisation with the data. In the transcription process, all personal information was anonymised, and the interviews were coded. In examining the data, particular attention was paid to the factors relevant to the research question and to the similarities arising from the data. During the study, the data were saved in the university hospital database, which was secured with a user account and password. The data were reduced to concepts categorised to describe the phenomenon. Participants’ utterances deemed to describe the phenomenon were utilised as condensed meaning units of analysis and divided into subcategories, and then sorted into two main categories. It was not possible to group the main categories together because of how dissimilar the contents were. An example of the analysis progression regarding one category is presented in Table 3.

2.5. Ethical considerations

This study was approved by the independent local Regional Ethics Committee of the Expert Responsibility area of one university hospital. Organisational permission was obtained as well. The participants received both verbal and written information before consenting to participate in the study.

3. Results

The mobile application promoted the coping of patients with incurable cancer in this study. By using the mobile application, the

(continued on next page)
Table 3 (continued)

| Meaning units | Condensed meaning units | Subcategory | Category |
|---------------|-------------------------|-------------|----------|
| “It is the knowledge that I have a possibility to contact my clinic. I am not alone with this.” | “It is the knowledge that I have a possibility to contact my clinic. I am not alone with this.” | Possibility to contact facilitates feeling of not being alone | (pt id18) |

Table 4

| Main category | Category |
|---------------|----------|
| The mobile application as a promoter of coping | Active involvement in care |
| Sense of security | Sense of freedom |
| Easier communication with professionals | Abreast of the treatment |
| Better symptom management | Useless when no symptoms |

patients experienced increased active involvement in their care and an enhanced sense of security and freedom. The application facilitated easier communication with the involved professionals, better symptom management, and staying abreast of the treatment (Table 4). However, the downside of the application usage was a certain disease-centredness, which the patients experienced as an encumbrance. Patients also viewed the application as useless when they had no symptoms. Also, the assistance provided through the application was sometimes perceived as too abstract (Table 4).

3.1. The mobile application promoted the coping of patients with incurable cancer

3.1.1. Active involvement in care

The mobile application had a meaningful role as a part of patient care. It enabled conversations with professionals about patients’ well-being and patients sharing with other patients—who were not yet users—their experiences using the application; this sharing of their experiences extended to the mobile application company. What was crucial for the purposes of this study, however, was the positive effect the application had on patients’ coping.

The application as a part of care signalled to the patients that they were considered important. They felt that someone was interested in their well-being, which made them feel unique and appreciated.

“Using this application has meant everything to me. It is like ... perfect. I can use it the way I want. It is my memo, my story, and my calendar. I have accepted it with open arms as mine.” (Patient 12)

The ability to inform the clinic in advance of relevant issues to discuss during the clinic visit included using the application as a notepad to jot down treatment-related issues to discuss and writing notes in a diary in order to recall them during the clinic visit. This made it easier to bring issues that needed attention, even difficult ones, into the discussion.

A common view amongst patients was their feeling that they had the chance to take part in treatment decision making and, if allowed, they were keen to participate even more. Also, when the patients received assessment questionnaires about their active symptoms through the application, it gave them the feeling of not being alone. The patients received questionnaires, depending on the cancer type and treatment they had, once a week, every other week, or every three weeks. After chemotherapy, the patients tended to long for the security that the...
3.1.2. Sense of security

The patients described that having the ability to contact the clinic at all times was crucial, and the knowledge of having a reliable way to contact the nurses and doctors gave them a sense of security. Even the awareness of having the application close by gave them a feeling of safety. They valued the fact that they would be answered, if not immediately, at least in a day or two. Receiving regular symptom questionnaires was understood as the professionals having a true interest in the patient’s well-being. As one patient put it, “It feels good and safe to me [...]. It is not useless to send those in if someone is interested in me.” (Patient 19)

The questionnaires were seen as an effective way to control treatment-related symptoms, and the application was viewed as a tool for ensuring the safety of the treatment. The patients saw using the application as a simple way to report possible side effects, which meant these effects would be noticed and taken care of sooner. It thus lowered the threshold for reporting symptoms. The questionnaires had an open text field in which the patients were able to describe their condition in writing, if they wished, for example:

“I had loss of weight, […]. I messaged through the application about that and received a prompt answer of having an appointment with a nutritionist. That’s good, getting a prompt response, even it was not like … a matter of life or death.” (Patient 20)

On the whole, the patients also understood the application also as a way for healthcare professionals to stay up to date on the patient’s health condition at home. In addition, they were convinced that the questionnaire answers they gave were related to the safety of the chemotherapy treatments. All in all, the patients were happy to have the mobile application on hand whenever they needed it. It guided them to monitor the symptoms that the professionals considered relevant to their treatment. They were free to use it the way they wanted and make it their own by using the e-diary feature.

3.1.3. Sense of freedom

It was seen as crucial that using the mobile application emphasised to the patient the importance of using their valuable time for more preferred actions. It was important how they spent their time, and life was understood to happen outside of the clinic. They wanted to spend every moment possible with their loved ones and doing what they wanted to do.

“I aim to take as little as possible of my family’s everyday time with concerns around my disease. I want to spend all the time I have with them. So, it is important that the app is so easy to use, as it does not steal my time from anywhere else.” (Patient 6)

When using the mobile application instead of the telephone, the patients found it easier to plan their day. This way of connecting did not bind the patients’ time. They did not have to wait for the doctor to call and could read the messages whenever they wanted. Also, when patients were working between their regular chemotherapy visits, they might not be able to be reached during working hours.

“Compared to telephone calls, it is a lot less binding to use the app. I might be in the middle of my working day and have no time for answering calls. By messaging with the app, I am able to read the answer when I have time.” (Patient 11)

The application was also viewed as saving them from useless visits to the hospital. This was facilitated, for example, by the patients receiving a message in the application not to come to the hospital due to worsened laboratory test results. They were to have new laboratory tests taken, and their appointment was postponed for a few days. This increased the patient’s quality of life.

3.1.4. Easier communication with professionals

The patients pointed out that communication was easier with the mobile application compared to telephone calls. The possibility of messaging with the clinic through the mobile application made the patients’ daily lives easier. The application was therefore described as a tool for facilitating ease in their everyday lives.

“It is a hundred times easier to message with the mobile application than to call the clinic and receive a call back time. That is why I prefer messaging with the mobile application.” (Patient 4)

Receiving appointment schedules through the application was faster and more useable than with the regular mail. The patients even reported a desire to use the application more for getting information from the clinic. One of the benefits was that the application made it possible to contact a certain nurse or doctor who was already familiar with the patient. The patients felt that the answers they received from a familiar nurse or doctor were more authentic, and also that it was a privilege to contact them directly. The comment below illustrates the importance of having this possibility.

“When I forgot to answer the symptom questionnaire, a familiar nurse called me and asked if I was feeling well. She was worried because I did not answer. So, it really makes a difference what I do in there (mobile app). I feel that they are really interested in how I am feeling.” (Patient 15)

3.1.5. Abreast of the treatment

The uncertainty around one’s treatment was decreased when there was an easy way to contact the clinic regarding treatment-related questions. For example, when a patient received chemotherapy and had many questions upon returning home, they appreciated the ability to contact their doctor or nurse immediately.

“I appreciate the opportunity to ask questions if there is something I am still wondering about or did not quite understand. […]. You sometimes do not have the words to ask when you are at a doctor’s appointment, and you might be a bit nervous, but when you get home, there may be something more you want to know.” (Patient 3)

The patients also highlighted the importance of the answers they received to their application messages. They valued even a few lines written by the professionals, and it made them feel important, noticed, and heard. The major benefit was always being able to follow the treatment and also monitor the decisions made regarding treatment at certain points in time.

“I think that besides the diary notes, the big thing is that there is also evidence for my clinic to monitor how I am doing […]. When there are changes in my condition, they can assess it and ask me the relevant questions. Like … you have been doing so and so. Could you tell something more about your symptoms? So, it is a tool for both them and me.” (Patient 11)

In the example given above, even when the chemotherapy ended, and it was time for palliative care without it, it was seen as important to have notes of what was done and when.

3.1.6. Better symptom management

The application had a beneficial effect on the patients’ management of the symptoms caused by the treatment or the disease. They had consistent
3.2.2. Useless when no symptoms

Desire that this service would somehow be enabled through the application in patients’ everyday life. That is, it stole valuable time.

“One annoying thing is that the symptom questionnaire is always delivered on Sunday morning when I have the children visiting usually. The diary reminds me of how I am doing, and I do not want to think about my disease when I am with my family.” (Patient 14)

Further, the patients mentioned that receiving no response from the clinic to the answered symptom questionnaire made them wonder whether anyone had read it.

3.2.2. Useless when no symptoms

Observing symptoms made one’s condition even worse when others said that their condition would not be improved after answering the symptom questionnaire. Sarcastically, one patient argued that no matter how many questionnaires he might answer, he would not be cured. Therefore, there was no point in filling in the questionnaires. This led the patient to feel there was no point in using the mobile application at all.

“Those symptom options to choose from were so bad that [...] I thought that hopefully I will never feel that bad. There was no right option for me, I’d rather answer ‘no symptoms’ because reading the possible symptoms made me feel even worse. It felt like exaggerating and was somehow too much.” (Patient 19)

A few patients also stated that the main reason they saw no point in using the mobile application regarding symptom assessments is that they had no symptoms. In these cases, they did not value the meaning of the symptom questionnaire. There were also some negative comments about the difficulties in assessing their symptoms using the application due to having no guidance or slow internet connections at home.

3.2.3. Abstract assistance

The help offered through the mobile application was sometimes seen as too abstract. In such cases, the application did not offer relief in the patient’s everyday life, nor did it directly affect their well-being. Some patients felt that help with their housecleaning or grocery shopping would have been more helpful.

“What I mostly long for is assistance making lunch and cleaning when I am tired. You know, those daily help needs are not covered in using that application.” (Patient 4)

A few patients voiced that they preferred the possibility to contact non-public cancer actors, for example the Cancer Society. They voiced their desire that this service would somehow be enabled through the application because, in the last phases of their cancer, there might be situations when they would be too exhausted to seek help through the application on their own.

4. Discussion

These study results increase our understanding of the need for patients to have a support tool at all times during their cancer treatment and palliative care. The ultimate value patients reported from using the mobile application were increased feelings of safety and the satisfaction of being a part of their own care, which promoted better coping with their incurable cancer. Similar results regarding patients’ fear reduction and reassurance through the support of telemedicine were reported by Atrey et al. (2020). To the best of the authors’ knowledge, however, this was the first paper investigating patients’ experiences of online follow-up with a mobile device in relation to cancer care.

To accomplish the goal of placing the incurable cancer patient at the centre of care, there is a need for the provision of consistently available support, which is offered by the mobile application studied in this research. Using this application enables patients to live their lives as fully as possible while coping with their disease. To advance the provision of high-quality care with this patient group, this research revealed valuable information about patients’ coping behaviour. The results clarified the meaning of the online support experienced by the patients and increased the understanding of what kind of support patients truly want and require.

In line with previous studies, our results highlight patients’ desire to avoid unscheduled visits to the hospital. The disease-related information and guidance available through the application promotes patients’ symptom management and therefore enhances their ability to cope with their cancer. This was confirmed in the studies by Schuit et al. (2019) and Biswas et al. (2020).

Issues related to the healthcare personnel’s actions, based on the patients’ questionnaire answers in the application and the responses sent by healthcare personnel, should be discussed based on the basis of the individual needs of the patient. The patients believed that the doctors and nurses monitored their symptoms through the application. However, a few patients felt that some professionals made poor use of their efforts regarding symptom assessment (Coolbrandt et al., 2017) or did not read their answers to the questionnaires at all. This indicates that the new digital health solutions, including the application used in this study, require adoption and acceptance by healthcare personnel (Aapro et al., 2020; Slev et al., 2017).

In addition, according to previous studies, cancer patients often experience receiving inadequate information regarding the continuity of their care (Liptrott et al., 2020) and the management of their symptoms (Biswas et al., 2020). This can be understood as a factor in patients’ feelings of a lack of safety in the course of their treatment. Therefore, developing electronic communication services to better serve patients’ information needs is crucial, and this needs to be understood and accepted in health organisations. Using a mobile application or, for example, telephone calls (Liptrott et al., 2020; Tran et al., 2020) as a part of cancer care has been shown to offer a patient-focused approach, which was also supported by this present study.

Communicating patient-reported outcomes with healthcare personnel through this application was seen as useful by the patients in our study, in line with Coolbrandt et al. (2017). The application provides patients, doctors, and nurses with an easy way to contact each other whenever necessary. Any service offered to patients by health organisations should be evaluated occasionally. Although the majority of the patients in this study were satisfied with the mobile application service, there were some comments regarding the only partially satisfactory or unsatisfying experiences in using the application. This indicates the need to improve the hospitals’ internal guidance to professionals regarding how to communicate with patients through the application.

Similar to other studies, the mobile application used in this study was shown to be a meaningful source of support for patients (Basch et al., 2016; DeRosier, 2020; Tran et al., 2020). Through its use, patients may answer the questionnaires whenever they choose, without having to schedule telephone calls to the clinic and queueing to get an answer. In addition, using the application may avoid unnecessary hospital visits not only in terms of patients’ symptoms during cancer care but also in response to the COVID-19 strain on hospital services.
4.1. Strengths and limitations

This study was conducted in accordance with the Helsinki Declaration (WMA, 2013). The interviews were carried out by a specialist nurse with expertise on the mobile application used, which promoted trustworthiness. The results provide in-depth insights around the experiences of the patients who used the mobile application. The authors regularly discussed together the analysis process and progress, which increased the study’s confirmability. The chosen analysis method allowed for capturing the key concepts driving the relationship between patients’ experiences of using the mobile application and the effect it had on their coping with incurable cancer (Kyngäs, 2019a; Vaismoradi and Snellgrove, 2019).

The location of the interviews, which was the clinic, could be seen as one of the limitations of the study. Interviewing patients during chemotherapy or after a doctor’s appointment is not always the most calming time. In contrast, when the interview was done at the patient’s home, there was no rush, and they felt more relaxed. However, the patients were able to choose the interview location, and their wishes were honoured. Another limitation is, as with other qualitative studies, that the generalisability of the results is limited to a specific population, but they nonetheless shed light and provide insights on important aspects of improving patient support procedures.

5. Conclusions

The present study extends the knowledge of patients using a mobile application as a part of their cancer care. It also assesses the acceptance of this application use in supportive care. The patients coped better with their illness when receiving online follow-up through the mobile device, even though some patients described the application as being too disease centred. Overall, the results indicate that the patients’ sense of security and freedom increased when using the mobile application. It was seen as an easier way of communicating with healthcare personnel. Through its use, the patients experienced increased involvement in their own care and had a greater sense of staying abreast of their treatment.

This research indicates that there is a need in patient care to include the use of mobile applications, such as the one studied in this research. Based on the literature referenced in this article, it appears that the overall use of eHealth applications or similar solutions in incurable cancer patients’ care is increasing.

Disclaimer

The views expressed in the submitted article are our own and not an official position of the institution.

Declaration of interest

The authors declare that there are no conflicts of interest.

CRediT authorship contribution statement

Anu Viitala: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Visualization, Funding acquisition, Writing – original draft. Päivi Astedt-Kurki: Conceptualization, Methodology, Formal analysis, Writing – review & editing, Supervision. Juho T. Lehto: Conceptualization, Formal analysis, Writing – review & editing, Supervision. Mira Palonen: Conceptualization, Methodology, Formal analysis, Writing – review & editing, Supervision, Project administration.

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