

# Patients' experiences with a welfare technology application for remote home care: A longitudinal study

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## Abstract

**Aims and Objectives:** To explore the longitudinal experiences using an application named remote home care for remote palliative care among patients with cancer living at home.

**Background:** Introducing welfare technology in home-based care for patients with cancer in the palliative phase is internationally suggested as a measure to remotely support palliative care needs. However, little is known about the experiences of patients utilising welfare technology applications to receive home-based care from healthcare professionals in a community care context. Although living with cancer in the palliative phase often presents rapidly changing ailments, emotions and challenges with patients' needs changing accordingly, no studies exploring the longitudinal experiences of patients were found.

**Design:** A qualitative study with a longitudinal, exploratory design.

**Methods:** Data were collected through individual interviews with 11 patients over 16 weeks. The data were analysed using qualitative content analysis. The COREQ checklist guided the reporting of the study.

**Results:** Three themes were identified: (1) potential to facilitate self-governance of life-limiting illness in daily life, (2) need for interpersonal relationships and connections, and (3) experiences of increased responsibility and unclear utility of the Remote Home Care.

**Conclusion:** The results showed that remote home care facilitated patients' daily routines, symptom control and improved illness-management at home. Interpersonal relationships with healthcare professionals were considered pivotal for satisfactory follow-up. Infrastructural glitches regarding data access, information sharing and lack of continuous adjustments of the application represented major challenges, with the potential to impose a burden on patients with cancer in the palliative phase.

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**Relevance to Clinical Practice:** By exploring the experiences of patients in palliative care over time as the disease progresses, this study provides constructive insights for the design and development of welfare technology applications and optimal care strategies.

**Patient or Public Contribution:** The remote home care was developed by interdisciplinary healthcare professionals.

#### KEYWORDS

cancer, eHealth, palliative care, person-centred care, qualitative study, telehealth, telemedicine

## 1 | INTRODUCTION

Internationally, patients in palliative care (PC) desire to live meaningful lives based on their own preferences, with support for symptom control, physical functioning and psychological well-being. With limited time to live, patients consider engagement in meaningful activities important (Sandsdalen et al., 2015). Most patients requiring PC remain in their own homes for as long as possible, with some choosing to die at home (Radbruch & Payne, 2010; Sandsdalen et al., 2015; Skorstengaard et al., 2017). Furthermore, patients express preferences regarding continuity and coordinated care and the importance of good relationships with healthcare professionals (HCPs) (Klarare et al., 2017; Sandsdalen et al., 2015). However, patients receiving PC at home report unmet needs such as the lack of continuous communication with HCPs, uncertainty as to who should be contacted in times of need, and poor continuity in care (Ventura et al., 2014). Introducing welfare technology in home-based PC is suggested to provide patients with improved access to HCPs and to increase feelings of safety and security at home (Steindal et al., 2020).

Several terms are applicable to reference technological innovations; however, in this paper, we refer to the term welfare technology. Welfare technology is an umbrella term, mainly used in Nordic countries, that covers technologies with the potential to offer rapid, interactive exchanges of information between patients at home and HCPs. The goal is to sustain or improve individuals' safety, functioning and independence, thereby promoting well-being and reducing the need for formal and informal care (Rostad & Stokke, 2021). By interacting with the individuals involved in the service, welfare technologies do not only support care, but also has the potential to change how care is provided (Star & Ruhleder, 1996). Welfare technology covers a wide range of technology types, structures and processes. Other common terms are telemedicine, telehealth, telecare, e-health and assistive living technology; however, there is no clear distinction between them (Glomsås et al., 2020).

## 2 | BACKGROUND

Welfare technology in PC may aid in symptom control, support psychosocial issues, improve access to HCPs and increase patients' sense of safety and security at home (Head et al., 2017; Steindal

### What does this paper contribute to the wider global clinical community?

- A longitudinal study of patients' experiences of using an application for remote palliative care at home with follow-up from municipality healthcare professionals.
- The study demonstrates that applications for remote palliative care at home has the potential of providing patients with enhanced routines and control when managing their illness at home.
- When applications for remote palliative care are planned and implemented in patients with severe illness, such as cancer in the palliative phase, this study argue that a person-centred approach is crucial for the experiences of supportive care.

et al., 2020; Widberg et al., 2020). Furthermore, research suggests that welfare technology in PC may improve information sharing, decision-making and communication, as well as reduce costs (Finucane et al., 2021; Widberg et al., 2020).

Previous research utilising qualitative methods has explored experiences of video consultations with HCPs specialised in PC, from the perspective of patients with cancer in the palliative phase (Funderskov et al., 2019; Hennemann-Krause et al., 2015; Read Paul et al., 2019; Tasneem et al., 2019; van Gorp et al., 2015). The results from these studies showed that video consultations can facilitate empathic patient-caregiver relationships, which enables professional care and increased patient involvement (van Gorp et al., 2015). Knowing that HCPs would be available through technology promoted peace of mind and relief for patients. Furthermore, patients highlighted benefits such as saving time, allowing more home time with their loved ones, promoting comfort and the possibility of taking an active role in managing their situation (Funderskov et al., 2019; Read Paul et al., 2019; Tasneem et al., 2019). In addition, welfare technology allows for enhanced access to HCPs, which is highly appreciated among patients living in rural areas (Bonsignore et al., 2018; Stern et al., 2012). However, the physical presence of HCPs in addition to welfare technology has been reported to be highly valued by patients (Read Paul et al., 2019). Therefore,

in-person communication combined with video consultations may strengthen the personal relationship between the involved patient, family, and HCPs and allow for the continuous provision of home care (Hennemann-Krause et al., 2015; Hochstenbach et al., 2016).

Some studies have investigated the experiences of patients in palliative care using diverse welfare technology applications for symptom management at home (Bonsignore et al., 2018; Hennemann-Krause et al., 2015; Stern et al., 2012). The results indicate that the remote monitoring of symptoms allows for improved self-management and remote support for cancer pain (Hennemann-Krause et al., 2015). Another study found that the remote monitoring of symptoms led to symptom relief in patients with dyspnoea, depression and poor well-being (Bonsignore et al., 2018).

The majority of previous studies were conducted in a specialised context where the HCPs involved possessed formal education and/or extensive training in cancer care and PC (Bonsignore et al., 2018; Funderskov et al., 2019; Hochstenbach et al., 2016; Read Paul et al., 2019; Stern et al., 2012; Tasneem et al., 2019; van Gorp et al., 2015). None of the identified studies explored patients' experiences of using welfare technology in palliative homecare in a community care context with follow-up from HCPs without specialised training in cancer or PC. Although patients living with cancer in the palliative phase may present with rapidly changing ailments, emotions and challenges with resultant changes in their PC needs (Kaasa et al., 2018), previous studies have mostly collected data at one point in time (Bonsignore et al., 2018; Hochstenbach et al., 2016; Read Paul et al., 2019; Tasneem et al., 2019). Therefore, exploring patients' experiences during the disease trajectory could be of great significance for the development of optimal patient care.

The aim of this study was to explore the longitudinal experiences of using a welfare technology application for remote PC among patients with cancer living at home. The application was named remote home care (RHC), which is a service that enables HCPs to remotely monitor and manage patients' safety, security, wellness, treatment and care (Oelschlägel et al., 2021). The following research questions guided the study: (1) Whether and how does the use of RHC in palliative care influence patients' ability to manage their life-limiting illness at home? (2) What are the facilitators and challenges of using RHC to manage life-limiting illness at home?

## 3 | METHODS

### 3.1 | Design

A qualitative, longitudinal and exploratory approach was chosen to provide knowledge of patients' experiences with RHC (Rahman et al., 2020). Data were collected through individual interviews at baseline, 4, 12 and 16 weeks with patients diagnosed with incurable cancer to describe their experiences of using RHC in palliative home care over a 16-week time period (Polit & Beck, 2020). The longitudinal approach with repeated interviews could allow for exploring continuous experiences and provide patients time to reflect between the interviews which could facilitate the provision of

rich data for analysis (Polit & Beck, 2020). Data were analysed with qualitative content analysis (Graneheim & Lundman, 2004; Lindgren et al., 2020). The study was reported according to the consolidated criteria for reporting qualitative research guidelines (COREQ) (Tong et al., 2007) (Supplementary file 1).

### 3.2 | Setting

The study sample was recruited from one home care district in a municipality situated in the eastern part of Norway where RHC was established to provide remote palliative care for patients with incurable cancer living at home. A home care district is part of the publicly funded community care services and serves the population living in a defined geographical area (Farsjø et al., 2019). The home care district is densely populated, and all participants lived close to the hospitals and other healthcare services involved in their care. The RHC service office is an independent community care service offering only remote home care and is not attached to the traditional homecare services.

### 3.3 | Participants

A care manager associated with the RHC service team was responsible for recruiting patients referred to community care services using a purposeful sampling procedure (Polit & Beck, 2020). The inclusion criteria were patients aged 18 years or older, living at home, and diagnosed with cancer in the palliative phase. To recruit a sample with diverse and substantial experience in the use of RHC, variations in age, sex, living status, and whether they received additional homecare nursing were sought. Once relevant participants had been identified, an assessment meeting was arranged to agree on follow-up and participation in the study. Forty-four patients were invited to participate in the study, of which 18 agreed. Seven patients were prevented from participating, leaving a total of 11 patients. The characteristics of the sample are presented in Table 1.

To provide richer descriptions of experienced presence and severity of symptoms, all participants were asked to complete the Edmonton Symptom Assessment System (ESAS) questionnaire for self-reported symptoms (Bruera et al., 1991) prior to each interview. The questionnaire consists of 11-point numeric rating scales ranging from 0 (no symptom) to 10 (worst possible). All reported symptoms varied greatly among the participants. At baseline ( $n = 11$ ) and 4 weeks ( $n = 10$ ), lack of appetite and best well-being were the most reported symptoms. However, at 12 ( $n = 7$ ) and 16 weeks ( $n = 6$ ), a lower severity of these symptoms was reported (Figure 1).

### 3.4 | Intervention—Remote home care

The RHC was implemented in the home of patients with cancer in the palliative phase with the intention of enabling patients to stay at home for as long as possible, providing individually tailored

TABLE 1 Characteristics of the sample (N = 11)

Characteristics	n
Age, years	
Mean (range)	66 (30–94)
Gender	
Female	5
Male	6
Living situation	
Cohabiting	4
Living alone	7
Receiving homecare nursing	
Yes	3
No	8
Diagnoses	
Pulmonary cancer	2
Ventricular cancer	1
Myleomatosis	2
Cholangiocarcinoma	1
Colon cancer	2
Ovarian cancer	1
Cervical cancer	1
Gallbladder cancer	1
Cancer treatment	
Palliative chemotherapy	4
Palliative immunotherapy	2
None	5
Measuring devices provided	
Tablet	2
Tablet with self-reporting	9
Weight scale	6
Electronic drug dispenser	2
Blood glucose meter	1
Pulse oximetry	1
Blood pressure monitor	1

follow-up, and improve the communication between patients and HCPs. The RHC team was experienced with providing care with the use of RHC as RHC already was implemented in the home of patients with chronic diseases such as chronic obstructive pulmonary disease and diabetes. The RHC service team consisted of multidisciplinary HCPs such as nurses (including one cancer coordinator), social workers, physical therapists, physicians and occupational therapists. The cancer coordinator had formal education and training in cancer care and palliative care. When included in the project, patients received RHC as a supplement to standard healthcare services. After inclusion, an assessment visit with representatives from the RHC service team was conducted in the patients' homes. During the visit, all of the patients received a tablet device containing an application featuring questions from the ESAS questionnaire (Bruera et al., 1991). The tablet device also included a function for patients to chat with

HCPs at the RHC service team. Carefully selected measuring devices for physiological parameters, such as pulse oximeters, blood glucose meters, blood pressure monitors, electronic drug dispensers and weight scales, were also installed in the patient's homes. The tablet device application and measuring devices were adjusted according to each patient's specific situation. Individually adjusted values or measurements were set up to automatically alert so that aberrant measurements were easily captured.

After the assessment meeting, the patients entered a two-week trial period, focusing on getting to know the measuring devices and tablet application. During these two weeks, necessary adjustments to the measuring devices, individual values and questions related to the self-reporting of symptoms were addressed. After the trial period, the intervention was administered by the RHC service team who received patients' self-reported symptoms and medical measurements automatically. The patients reported symptoms and measurements as needed and according to agreements with the RHC service team. The interval for reporting varied from daily to weekly. After transmitting symptom scores and medical measurements, patients received a confirmation that the data had been received by the RHC service team. If aberrant measurements were reported, patients received a telephone call from a HCP within minutes. The patients were then given the opportunity to elaborate on the answers they had submitted and at the same time discuss further assessments in collaboration with the HCP. The RHC service team provided regular contact with the patients via telephone and responded to chat messages from patients or relatives. Some patients had regular face-to-face contact with cancer coordinators. No videos were included in the RHC.

The RHC service team was available for contact from 8:00AM to 3:00PM on Monday to Friday. The patients were followed-up for 16 weeks. However, the RHC continued as a healthcare service for the patients after the data for this study were collected (Figure 2).

### 3.5 | Data collection

A semi-structured interview guide was developed to facilitate reflection and conversation with participants. The interview guide consisted of open-ended and probing questions that covered aspects related to the patients' experiences, such as everyday life and health, the use of RHC, impacts of the RHC on daily life and illness management, and expectations of the RHC and follow-ups. Owing to the limited study population, the interview guide was not piloted. However, the researchers discussed the questions, and revisions were made to facilitate relevant and clear questions in accordance with the aim of the study.

The last author conducted individual semi-structured repeated interviews between September 2017 and March 2019. The initial plan was to interview participants before they received the tablet and medical measuring devices. However, after three interviews it was deemed that approaching the participants before the RHC was implemented did not provide rich data regarding their expectations

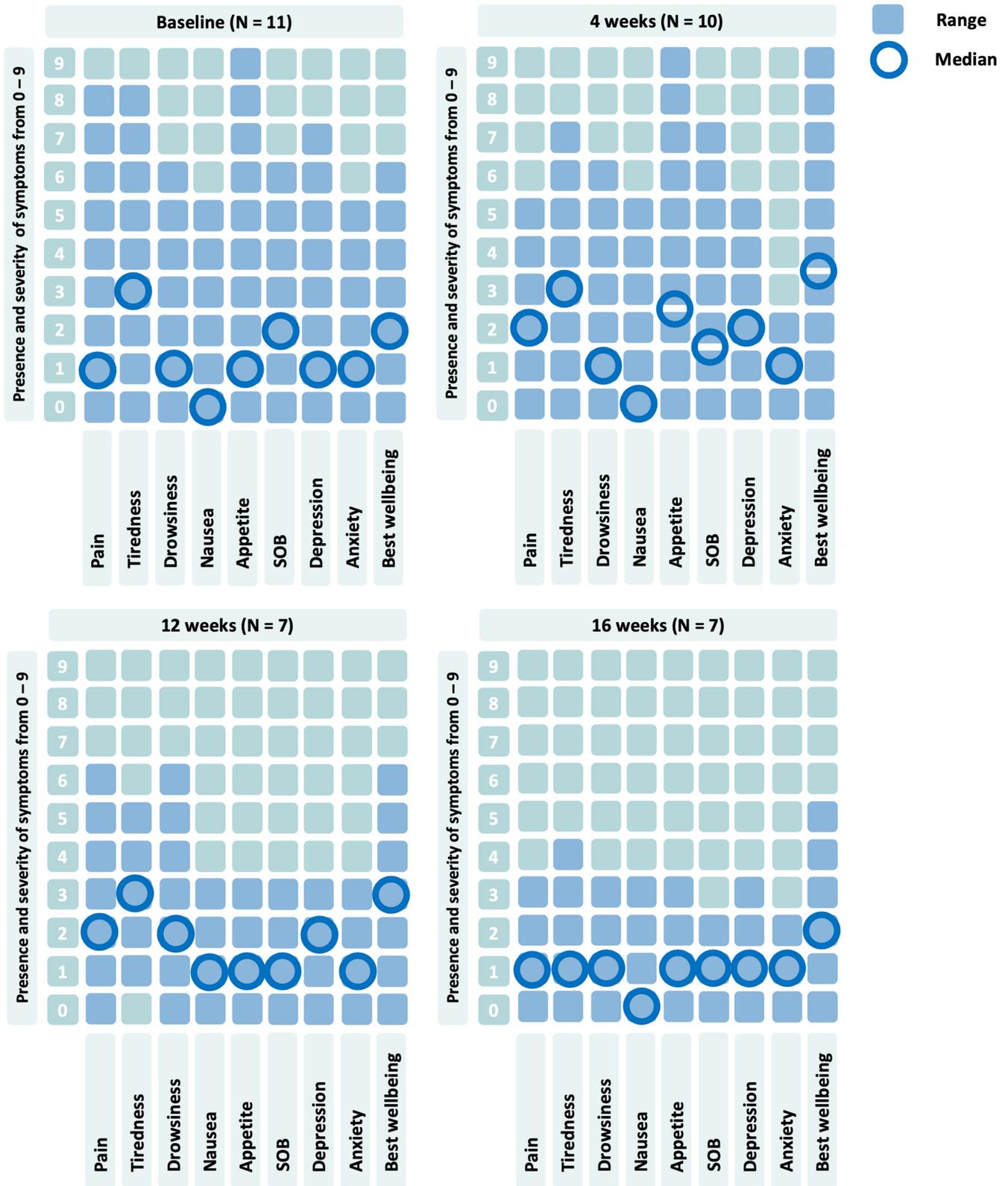
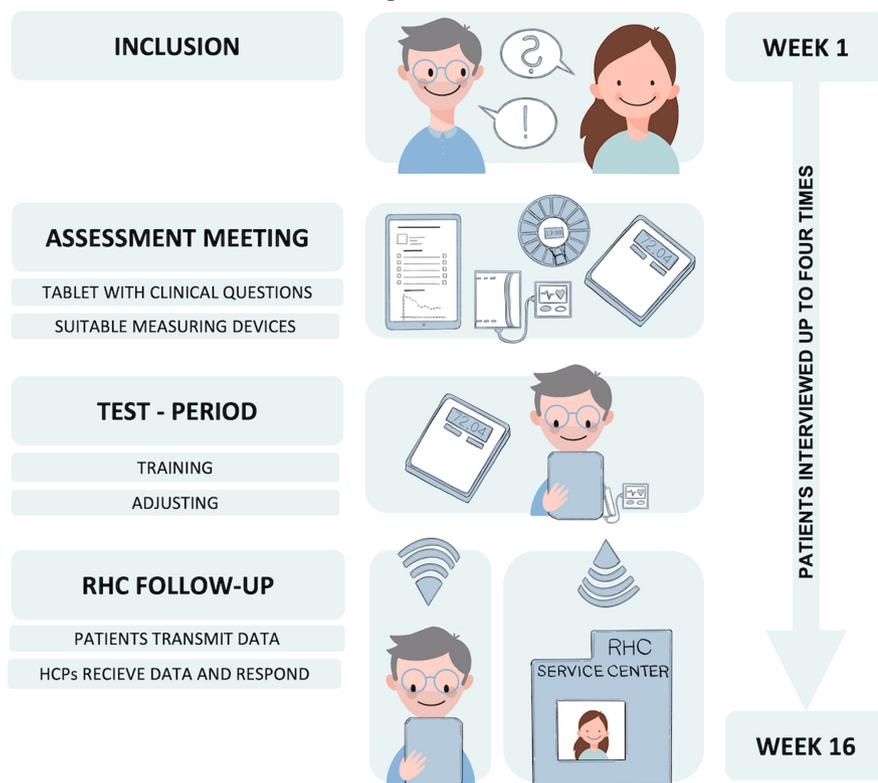


FIGURE 1 Presence and severity of pain, tiredness, drowsiness, nausea, appetite, shortness of breath (SOB), depression, anxiety, and general well-being at baseline and at 4, 12 and 16 weeks of follow-up.

of RHC. Therefore, most of the participants were first interviewed shortly after the RHC home follow-up was established and then interviewed again at 4, 12 and 16 weeks of use. The time interval

of 4–8 weeks between the interviews was considered to put minimum strain on the participants, while at the same time provide time to reflect on the use of the RHC application without important



**FIGURE 2** Remote home care (RHC) inclusion, assessment, test-period, follow-up and interviews.

**TABLE 2** Illustration of the analytic process

Theme	Potential to facilitate self-governance of life-limiting illness in daily life			
Sub-theme	RHC influence on daily life		Monitoring of symptoms provides a sense of being in control	
Categories	Improved routines		Individual control of symptoms	
Codes	Improved monitoring routines	Improved medication routines	Individual control of pain	Individual control of weight
Condensed meaning	The weight monitor has helped with weighing routines	The technology has helped with medication routines	The tablet statistics provide an individual overview of pain development	The tablet statistics help to maintain weight
Meaning unit	The weight monitor has helped me to follow a routine of weighing myself every day with the goal to gain weight. (Patient 1)	The technology helps me stay in control. I messed up a lot before. Sometimes, I forgot the medications for maybe two, three days. But now it is like clockwork. (Patient 9)	I find the tablet useful. Especially for my own part and that I can follow the statistics. I can look at how the pain develops and see whether there is a pattern. Also, to keep up with the weight and make sure it does not drop. (Patient 2)	

experiences being forgotten. The participants were interviewed at a place of their own choice. Most of the interviews were conducted in the participants' homes, except for one of the interviews conducted in a coffee shop. For two of the participants, follow-up interviews were conducted via telephone to avoid risk of infection in cases of neutropenia. The interviews lasted from 9 to 83 minutes and were audio-recorded. No fieldnotes were made during or after the interviews. Due to health-related issues, some of the included patients were unable to participate in all four iterations; 11 patients were interviewed at baseline, 10 patients at 4-weeks, 7 patients at 12-weeks and 6 patients at 16 weeks, leaving a total of 34 interviews.

The authors had no relationship with the patients prior to the study commencement.

### 3.6 | Analysis

The interviews were transcribed by one of the researchers and a professional transcriber. NVivo facilitated the storage and organisation of data. The data were analysed using qualitative content analysis of both manifest and latent content to add depth and meaning to participants' statements (Graneheim & Lundman, 2004; Lindgren

TABLE 3 Themes and sub-themes

Themes	Sub-themes
Potential to facilitate self-governance of life-limiting illness in daily life	RHC influence on daily life Monitoring of symptoms provides a sense of being in control
Need for interpersonal relationships and connections	Initiative to communicate and interact with HCPs Ambiguity in the use of RHC
Experiences of increased responsibility and unclear utility of the RHC	Managing the communicational gap between the different levels of healthcare RHC failure to detect the current situation

et al., 2020). The first author analysed the data. To obtain a sense of the full corpus, the data material was read iteratively before being organised into condensed meaning units. Considering the entire context of the material, the condensed meaning units were abstracted and labelled with a code close to the text. The codes were initially compared in terms of differences and similarities before being organised into tentative sub-themes. Each sub-theme contained several categories constituting the manifest content. Guided by the research questions, the tentative categories, and sub-themes were discussed among the researchers and revised multiple times before the latent content was abstracted and interpreted into three themes. To ensure intersubjectivity, the second and last authors asked critical questions of the first author's preliminary findings during each step of the analytic process (Table 2 illustrates the analytical process).

### 3.7 | Trustworthiness

Sample size was considered using the theoretical model of information power (Malterud et al., 2016). According to the model, sufficient information power for the data material was obtained by the narrow study aim, including patients in the palliative phase receiving RHC, conducting repeated interviews allowing for reflections between the interviews, and by the participants willingness to share both negative and positive experiences. By following these principles, a smaller sample size is needed (Malterud et al., 2016).

To investigate patients' longitudinal experiences, data were collected by time triangulation at four different time points. Investigating the same phenomenon in the same group at different points in time allowed for greater understanding and enhanced trustworthiness (Polit & Beck, 2020; Thurmond, 2001). To enhance dependability, the last author conducted all interviews and used the same interview guide each time. To obtain different perspectives, reduce the risk of biased interpretations and strengthen the credibility of the results, the final analysis and interpretation of results was discussed in its entirety with a group of researchers possessing diverse research expertise in welfare technology, PC and chronic illness. The identification of sub-themes and themes that preserved the underlying meaning of the text was sought. Furthermore, emphasis was placed on highlighting nuances in the results, for example, by referring to disagreements among the participants and using direct quotations in the presentation of results (Graneheim & Lundman, 2004).

The participants were not asked to provide corrections or feedback regarding the transcripts or results. However, during the interviews, questions such as 'Have I understood correctly that you ...?' and 'Do you mean ...?' were asked to validate the immediate interpretations of participants' communication (Polit & Beck, 2020).

### 3.8 | Study approval and ethical considerations

The Norwegian Regional Committee for Medical and Health Research Ethics considered the study to not be notifiable. The study was reported and approved by the Norwegian Centre for Research Data (NSD) (reference number: 429408) and leaders in municipal healthcare services. Prior to participation, the participants received oral and written information regarding the study and were assured that all data would remain confidential throughout the research process and publication of the results. All included patients received and signed informed consent forms prior to data collection. The interviewer was experienced with caring for patients with incurable cancer and allowed for ample time at each interview to accommodate participants' need to express feelings and allow time for dialogue on their experiences with RHC. Data were managed and stored securely. Details of the participants were kept separate and locked following the guidelines set forth by the NSD.

## 4 | RESULTS

Three themes emerged from the data analysis: (1) potential to facilitate self-governance of life-limiting illness in daily life, (2) need for interpersonal relationships and connections, and (3) experiences of increased responsibility and unclear utility of the RHC. The themes and sub-themes are presented in Table 3.

### 4.1 | Potential to facilitate self-governance of life-limiting illness in daily life

Some patients experienced very little discomfort, while others carried a heavy symptom burden and described their everyday life as dominated by illness. Patients became emotional and tearful when addressing the question of general well-being at the start of each

interview. Some patients spoke in detail about the consequences of living with an incurable diagnosis, while others did not address this fact and appeared to divert the conversation to something else if the interviewer touched on their diagnosis. However, patients explained that assessing their symptoms through questions on the tablet established a meaningful routine with a moment to think through their own symptom experiences and overall situation, which again was considered a support for adopting a more active role governing their illness.

It is positive for reviewing symptoms and side effects and to look back and assess how I experienced my symptoms the foregoing week.

Patient 7\_interview 4

Patients were particularly interested in monitoring their weight, and some explained that the visual representation of weight loss provided by the tablet was a motivation to eat, even if their appetites were poor. Some patients expressed that weight loss was not emphasised by their general practitioner (GP) or treating hospital. They felt reassured that their weight was taken seriously through the RHC. In contrast, other patients stated that weight statistics on the tablet provided no meaningful information. One patient expressed that the visual bodily changes were more significant than the numbers on the tablet screen:

It's ok to use the weight monitor, but I don't look at it. I know by my waistband how much I weigh.

Patient 3\_interview 3

According to the patients, the accumulation and visualisation of data over time on the tablet offered valuable insights regarding how symptoms and clinical signs developed over time, especially related to blood glucose levels, weight and pain. For example, patients explained that it was helpful to monitor their pain patterns and the variations in pain intensity, which in turn provided enhanced insight and feelings of control over the situation and prepared them for what may come. Several patients expressed that this type of control was relevant to governing their illness at home, and that it felt significant to have access to facts rather than diffuse assumptions as the illness progressed:

The technology helps because it provides control. You know where you're at. How much I weigh and how much sugar I need to eat. Everything. The technology helps to handle the cancer, I think.

Patient 9\_interview 2

While only a few patients provided concrete responses on how RHC affected their daily lives, many experienced that self-reporting symptoms on the tablet and transmitting measures of clinical signs

as scheduled had a positive impact, helping them govern their daily routines. Two patients received an electronic drug dispenser that alerted them at fixed times and thereby experienced fewer ailments related to improved medication routines. However, both patients experienced the sound from the dispenser's alarm as stressful and expressed that the device attracted unwanted attention when they were outside their homes among other people. One patient experienced this attention as burdensome and eventually stopped using the drug dispenser.

The drug dispenser causes me to feel sick and stigmatized because the alarm attracts unwanted attention (...) It's too visual when the alarm starts ringing outside among other people.

Patient 4\_interview 2

When receiving RHC, patients were able to self-report symptoms, and interaction with HCPs provided the opportunity to channel everything related to their illness and ailments to one place. One patient explained that in this way, he was able to take his mind off illness and everything associated with it, which helped him re-establish meaningful relationships with friends and family. However, some patients experienced the RHC equipment as a disturbing and visible reminder of their illness and death. This experience was not addressed in the first two interviews but was problematised when the patients had used RHC for a longer period. The physical presence of digital equipment in their homes made it difficult for them to ignore the severity of their life situations. One patient had to put away the tablet and weight monitor for longer periods to focus on aspects other than death and illness.

I'm reminded of the disease when I look at the tablet and the weight scale (...) I can't bear being reminded of it all the time.

Patient 2\_interview 3 and 4

## 4.2 | Need for interpersonal relationships and connections

Patients differed in whether they used the opportunity to chat with the HCPs via the tablet. Some patients were unaware of the opportunity to chat with HCPs, whereas others appreciated this as a useful and effective form of communication. These patients often used the chat option to ask questions concerning their illness or to inform HCPs that they were going away for some days and that they would not bring the measuring devices or tablets with them.

Some patients expressed concerns about sharing private information in the chat with HCPs that they had never met in person. These participants preferred contact by telephone as they considered it to be more personal. Patients described the barriers to contacting the HCPs by chat or telephone as being extremely high,

especially regarding their need of support with psychosocial issues such as anxiety or depressive thoughts.

If I'm feeling a lot of anxiety, I think I'd rather make an anonymous call to the mental health helpline than to have a dialogue on that thing [the RHC tablet device]. It feels wrong to bring up psychosocial issues on the tablet.

Patient 7\_interview 1

However, a number of patients considered the possibility of communicating with HCPs by chat rather than telephone as an advantage, making the communication of psychosocial matters less intimidating.

The majority of patients perceived the combination of the self-reporting of symptoms and the option of telephone contact with HCPs as a great advantage, as it provided certainty that the HCPs actually paid attention to their situation. Patients felt confident that the HCPs would telephone them back if they failed to submit measurements or self-report symptoms as scheduled. The option to communicate with someone who knew their situation well made them feel that they were being taken seriously and enhanced their sense of security at home.

The tablet is a form of security. I don't know what kind of people they are – 'those at the other end,' but they do react if they discover something abnormal in my condition.

Patient 5\_interview 4

Patients emphasised that it would have been meaningful to meet the HCPs face-to-face to obtain a personal impression of who they were interacting with regularly and to be assured that the HCPs were fully aware of their individual care needs. These patients expressed uncertainty about whether the HCPs were able to obtain an overall picture of their situation via telephone, chat or the RHC application without physical meetings:

I miss home visits where they can consider my needs; not just looking at the statistics.

Patient 1\_interview 2

Furthermore, some patients expressed scepticism about whether the intention to introduce RHC in home care was for their own benefit or as a procedure to reduce costs in the healthcare system. These patients worried that RHC could contribute to a 'colder society' with less human touch.

Personal contact was considered by the patients as important for managing illness and everyday life. Relatives were seen as a significant resource in this regard, and by several patients perceived as their most important supporters in everyday life. Some patients, especially those who lived alone, expressed feelings of loneliness and missed opportunities for social contact during the day. Some

patients had regular contact with the cancer coordinator, often just to talk or obtain assistance with daily life issues. Patients who received follow-up from the cancer coordinator agreed that this person played a significant role, both in coordinating the health services and as a provider of personal support and dialogue. One patient walked regularly with a cancer coordinator and expressed that this was beneficial for both her physical and mental health. These findings demonstrate the necessity of including physical meetings when delivering customised and comprehensive PC using RHC.

### 4.3 | Experiences of increased responsibility and unclear utility of the RHC

As they did not receive in-person visits by HCPs, patients felt responsible for transmitting answers via the RHC system which provided a clear image of their situation. Furthermore, patients worried that skipping transmissions or answering incorrectly would have an impact on the care they received, and described the accurate use of the RHC as a significant responsibility:

The technology is an excuse for not visiting people. The human contact is gone. You sit there alone. And you alone are to blame for the answers you transmit.

Patient 6\_interview 2

The patients received various follow-ups by HCPs in both the specialist- and municipal healthcare services and expressed confusion about knowing who was responsible for what regarding their health. Furthermore, the sharing of information between various healthcare services was perceived as unsatisfactory, and patients called for improved systems with the ability to integrate significant data related to their disease and improved interaction between the various HCPs involved in their care. To remedy unsatisfactory documentation systems, patients physically brought their tablet to appointments with the hospital and GP to show trends in their symptom data on the tablet. Furthermore, patients agreed with the district's nutritionist to log their daily food intake. This was not integrated in the tablet's application and needed to be noted manually on paper, making a visual overview of nutritional intake less accessible to the patients. The patients experienced this as cumbersome and non-innovative and requested improved solutions, such as being able to log daily food consumption on the tablet.

I have to write down what I eat and drink on a piece of paper. It would've been much easier to just register everything on the tablet. Then everyone would know.

Patient 11\_interview 2

Due to these organisational glitches, patients felt a significant responsibility to ensure that the various HCPs possessed the correct information regarding their current situation. Patients explained that

they frequently used the chat option on the tablet to update or inform the HCPs or the RHC service team when changes in treatment or medication were made, for example. One patient elaborated that she was required to explain aberrant measurements of weight caused by intravenous treatment at the hospital. The RHC service team had no knowledge of this because of the unsatisfactory information sharing of patient data across levels of care:

The nurses use the chat to make small comments on my measurements. For instance, weight gain. Then I write back that I've had four liters of intravenous to explain the cause.

Patient 2\_interview 3

Some patients expressed that they spent much valuable time taking responsibility for managing their care and asserted that the introduction of RHC had no impact on this aspect. Furthermore, patients felt insecure about where they should turn for help with various issues such as the exacerbation of symptoms or fever induced by palliative chemotherapy. Patients appeared unsure whether potential situations could be prevented or caught early by transmitting symptoms or measurements to the RHC service team, allowing for early assessments and intervention. Few patients believed that the RHC service team could help with such events. However, most patients were able to obtain hospital admission without referral and relied on the hospital to help in acute situations.

The city district [RHC service team] has said that maybe they could help so I wouldn't have to go to the hospital. Then I just wrote back that I must go to the hospital if I get a fever or become very sick.

Patient 8\_interview 2

Some patients perceived the questions on the tablet as static and inflexible. Patients were concerned that the tablet questions only requested the occurrence and severity of symptoms and felt responsible for elaborating on the symptoms they reported, especially regarding pain. On their own initiative, these patients frequently used the chat option on the tablet to inform and explain the pain location and its variation in character to the HCPs. Over time, some patients experienced the questions on the tablet as monotonous and boring to answer and requested changed wording to make the routine self-reporting of symptoms more inspiring. Some also experienced large variations in their illness trajectory during the day or week, such as rapidly fluctuating ailments, and felt uncertain whether the RHC was able to detect these changes. This was especially challenging during palliative cancer treatment periods when the burden of troublesome ailments was greater. During the interviews, these patients expressed uncertainty regarding the RHCs' personal utility and requested more flexibility regarding when and how they could report their symptoms and measurements.

I answer questions once a week (...) It can be difficult to answer because the pain and symptoms vary all the

time during the day. I'm not sure if they catch these variations by me answering once a week.

Patient 9\_interview 2

During the 16 weeks of follow-up, patients experienced changes in their health conditions. Despite this, patients noted that the content of the RHC was not adjusted accordingly. This was only achieved if the patients explicitly informed the RHC service team that changes needed to be made. In general, the clinical questions on the tablet and digital medical devices remained the same even though their symptoms and needs improved or worsened. Some patients had several ailments that were not captured by the questions on the tablet, whereas others experienced the questions as too specific and missed questions that addressed activities of daily living.

There's no further development, no change. It's the same questions from week to week. They need to get their finger out and do something more. Other questions concerning life and health (...) There must be a meaning behind the questions. What are the definitions of the questions? Do you have pain? What does that mean?

Patient 6\_interview 4

Some patients questioned the purpose of RHC and how it could benefit their situation and requested more information, while others experienced improvements in their health condition and did not have the same need to report symptoms or follow the development of physiological parameters, such as weight, as before. Several patients requested improved communication with the RHC service team regarding plans for future follow-ups with RHC.

## 5 | DISCUSSION

This study aimed to explore the longitudinal experiences of using a welfare technology application named RHC for remote palliative care among patients with cancer living at home. Our results suggest that RHC may strengthen patients' ability to manage their life-limiting illness at home by providing enhanced routines and control in their daily lives. Personal relationships and close connections with HCPs were considered by patients as prerequisites for illness management. However, over time, patients felt responsible for informing HCPs about details regarding symptoms and experienced the lack of flexibility and deficient tailoring of the RHC content as severe challenges, which further contributed to making the utility of the RHC unclear.

In our study, patients described that RHC facilitated management of their illness at home by contributing to improved routines regarding symptom management. This was facilitated by establishing fixed times for symptom assessments, medical measurements and medication, which aided in symptom control and patients self-governing their illness at home. This result concurs with prior

research suggesting that technology-based monitoring and management of symptoms may be both useful and feasible for patients (Bonsignore et al., 2018; Hennemann-Krause et al., 2015; Stern et al., 2012). Furthermore, the patients in our study considered the individual follow-up of HCPs, either via chat, telephone or face-to-face (the cancer coordinator), as pivotal for the experience of a beneficial follow-up. By channelling everything regarding the illness onto the tablet and receiving a response from the HCPs, the illness became less all-consuming and allowed patients to focus on more positive experiences with significant others. Most technology-based communication strategies in cancer care have focused on information exchanges between patients and their providers (Ansari et al., 2022). Introducing technologies to monitor patients' symptoms in the palliative phase at home may provide more information about patients. However, there is a potential risk that HCPs have less time to interact and gain knowledge of the patients, which is considered unfavourable in a PC context in which relationships are key (Payne et al., 2020).

The human component of the RHC was regarded as a facilitator that allowed for the elaboration of symptoms and provided patients with the sense that someone was paying attention to their situation, which enhanced feelings of safety and security at home. Previous research suggests that the possibilities of communicating feelings and problems and the knowledge that someone will respond may be beneficial (Capurro et al., 2014). The significance of the physical presence of HCPs in patients' homes is in accordance with the results of previous studies investigating technology-based communication between patients at home and HCPs (Gorst et al., 2014; Rykkje & Hjorth, 2017; Steindal et al., 2020). However, the establishment of trusting relationships between patients and HCPs and the possibility of providing and receiving a caring touch is challenged when the care is provided remotely (Dorsey & Topol, 2016; Sandsdalen et al., 2015; Steindal et al., 2020). Although patients in our study had regular physical contact with the cancer coordinator in the home care district, they wanted to know more about the HCPs sitting on the 'other side of the tablet' and to have met them in person. Supplementary face-to-face contact and physical follow-ups were highlighted as preferable to video as an addition to the existing RHC service. Thus, great demands are placed on the service when the patient and HCPs do not meet face-to-face to assess, discuss and clarify the reporting of symptoms or other ailments.

The patients in our study experienced complex and fluctuating symptoms that were challenging to describe on an analog scale. To compensate for this challenging deficiency of the RHC, some patients accepted the responsibility and used the chat function in the application to inform the HCPs and elaborate on aspects such as the location and type of pain. Similar results were emphasised a decade ago (Lind et al., 2007; McCall et al., 2008) and summarised in a recent scoping review (Steindal et al., 2020) which stress the importance of welfare technology applications being substantially tested prior to implementation and the need for innovation when planning and designing digital follow-ups of patients living at home.

Although all patients in this study suffered from cancer in the palliative phase, they differed in terms of their life situations, disease burdens, treatments and futures. The patients expressed that their symptoms fluctuated and differed during periods of treatment. Tailored questions for the self-reporting of symptoms and measuring devices were applied when the RHC was installed. However, our results from data collected at various points in time showed that despite the patients' experience of variation in their illness trajectory over time, very few or no adjustments were made to the RHC content, such as questions for the self-reporting of symptoms, settings for aberrant measurements, measuring devices and agreements for telephonic contact. In addition, patients noted that the symptoms they reported were not always detected by HCPs or that they answered questions regarding symptoms that no longer occurred, which in turn led to the unclear utility of the RHC service. For example, patients continued to measure their weight daily even when satisfactory weight gain was achieved. This error in detecting patients' perceived symptoms and changes in clinical signs as time went by and the disease progressed was perceived as a major challenge regarding the use of RHC. Such challenge may further inflict an unnecessary burden on the patient and contrasts with the definition stating that PC promotes quality of life by the comprehensive assessment and management of physical issues, including pain and other distressing symptoms (Radbruch et al., 2020). Furthermore, patients reported experiencing barriers contacting HCPs with matters of a psychosocial nature. Based on the patient's constant changes with regard to the illness, the requirement for RHC changes over time. Emphasis on efforts to facilitate a person-centred approach with continuous, systematic dialogue with the patient is necessary to ensure the continuous relevance of the service (Hansen et al., 2017). Österlind and Hensch (2021) developed a model for person-centred PC, the 6S-model. With self-image as a central concept, the model encompasses patients' personal experiences of the situation as a starting point for care. The concept of self-image is complemented by the five interrelated concepts of self-determination, symptom relief, social relationships, synthesis and strategies. When developing technologies for remote palliative home care, it would be appropriate to consider models that include a person-centred approach, such as 6S, rather than pure symptom assessment scales, which may lead to an increased responsibility and burden on patients.

Our results indicate that patients felt responsible for remaining updated on medication and for informing the RHC service team if changes in treatment or medication had been administered. To remedy unsatisfactory documentation systems, patients physically brought their tablets to the hospital or GP to demonstrate trends in the symptom data on the tablet. This finding concurs with Hochstenbach et al. (2016) stating that by accepting technology interventions, HCPs abandon fragments of their present role, previously delivered face-to-face, to the technology itself, but also to patients on which they have to rely for information. As described by Oelschlägel et al. (2021), little is known about RHC among various health service providers involved in the care of

patients which has led to communication issues and further shifted the responsibility of significant care aspects, such as an overview of medications, to the patients. Our results show that patients felt strained by the consequences of unpredictability and the heavy burden of having to put on an administrative role to manage appointments, treatment and care. To enable patients to relinquish their perceived responsibilities as administrators and shift the responsibility back to where it belongs, focus must be placed on the digital infrastructure regarding information exchange, available documentation and clear communication between the various levels of healthcare service.

## 5.1 | Limitations

A limitation of this study is that gatekeeping behaviour occurred during the recruitment process. In this context, the term gatekeeping refers to HCPs making their own considerations of the burden that possible participation in the study may entail for the patient (Sharkey et al., 2010; Snowden & Young, 2017). As a result, the sample may have been affected to the extent that patients with a complex life situation or a large degree of burden from the illness may have been excluded. When discovered, actions were implemented to eliminate gatekeeping behaviour, and the inclusion of patients proceeded as planned. Another limitation may be that the interview guide was not pilot tested. The reason for this was partly the limited study population, but also that the participants had an incurable diagnosis with an uncertain life expectancy, which led to a time pressure to complete the data collection. Nevertheless, all included participants had diverse cancer diagnoses with different symptoms and ailments. They also received individualised follow-ups, which meant that they received different questions regarding symptoms, diverse measuring devices and different agreements about contact with the HCPs. These experiences allowed for a large range of topics to be deliberated and for the collection of more comprehensive responses relevant to answering the research questions (Graneheim & Lundman, 2004). Finally, all participants were recruited from the same home care district. It is possible that the experiences of patients living in more rural areas of Norway could have differed from those of the urban patients contributing to this study. Therefore, the transferability of the results to other contexts may be limited.

## 6 | CONCLUSION

Our study on RHC for patients with cancer receiving palliative care at home indicates that patients experience improved daily routines, allowing for aid in symptom control and engaging in a more active role in managing their illness at home. The visual representation of symptoms and clinical signs may enable patients to plan for and anticipate unforeseen events as a result of living with a serious and incurable disease. However, technology is not considered a facilitator in itself; interpersonal care is highly appreciated by patients as

pivotal for the experience of satisfactory follow-up and enhanced feelings of safety and security at home. Finally, the lack of continuous adjustments of RHC content and infrastructural glitches regarding data access and sharing may lead to feelings of unsatisfactory utility of the service and represent major challenges with the potential to impose a burden on patients with a limited time to live. These elements should be considered in future research projects exploring the implementation of new technologies to care for patients with severe illness living at home.

## 7 | RELEVANCE TO CLINICAL PRACTICE

The offering of RHC entails a great responsibility for assessing whether the potential burdens outweigh the benefits of palliative homecare. A person-centred approach with close collaboration and routine contact between patients and continuous adjustments in digital applications for remote homecare are crucial for supporting patients with cancer in the palliative phase living at home.

### AUTHOR CONTRIBUTIONS

SAS developed the study design, with contributions from all the authors. SAS, KH, AD and JÖ developed the interview guide. SAS conducted the individual interviews. LO, SAS and VLC contributed to analyses and interpretations. LO drafted the manuscript. All authors (LO, VLC, AM, KH, JÖ, AD and SAS) provided significant intellectual content, constructive comments and revisions in the development of the article manuscript. All authors approved the submitted version.

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### CONFLICT OF INTEREST

The authors declare no conflict of interest.

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### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available upon reasonable request to the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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