Monitoring Patients in Ambulatory Palliative Care: A Design for an Observational Study

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Abstract. We present the setup of an observational study that aims to examine the application of wearables in ambulatory palliative care to monitor the patients' health status – especially during the transition phase from hospital to home since this phase is critical and often patients are re-hospitalised. Following an user-centred design approach, we performed interviews with patients recruited at the Clinic of Radiation Oncology of the University Hospital Zurich, Switzerland. The patient group was perceived as very vulnerable and varied largely in physiological burden and mental aspects. Special needs concern primarily obtrusiveness of the system and sensitivity in the work with this vulnerable patient group.

Keywords: Palliative Care · User interviews · Remote monitoring systems · Real-world deployment · Wearable sensing

1 Introduction

Palliative care (PC) is a set of practices aiming at relieving patients with a life-threatening disease from physical symptoms (e.g., pain, fatigue, breathlessness, sleeplessness), and to support them in the perception of their psychosocial and spiritual needs [1].

Monitoring remotely PC patients would be beneficial in the transition phase from hospital to home, when the patients lose the continuous support of professional teams and have to adapt to changing conditions. A monitoring system would help physicians react in case of decline in patient conditions.

Since PC patients are a unique group combining physical and psychological weakness, existing monitoring systems for other patient groups may not be usable/accepted.

We present a patient-centric design of a new monitoring system tailored to PC patients, where the patients are fully involved in the design of the part of the system which affects them the most, i.e., the patient interface. The design process is carried out through guided interviews. The patient interface consists of

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questionnaires and feedback mechanisms, while the monitoring system also logs various sensor data relevant for predicting changes in patient conditions. Sensor data are collected both through a smart-phone and an armband equipped with sensors. Since the system will be used in a future clinical trial, we involve patients for the system design with the same inclusion criteria as the future clinical trial, thereby maximising the representativeness of the outcome.

In this paper we present the patient-centric design procedure, the lessons learned and the final monitoring system, along with the protocol for the observational study which will be carried out.

2 Related Work

Mobile health, without the use of wearable sensors, has been explored in many diseases and patient groups, e.g., in cardiovascular diseases [2], mental disorders [3,4], stroke rehabilitation [5] and stressed persons [6]. The collection of patient subjective reported outcome using mobile health is already established in oncology and has been proven feasible in younger palliative care patients [7].

Monitoring systems including also wearable sensors have been developed for specific patient groups, e.g. patients who suffered from a heart failure [8], and to measure stress, activities or health status in less specific groups [9]. The application of monitoring systems has been proven beneficial for patients with schizophrenia [10] and heart failure [11], resulting in reduced hospitalisations and mortality.

For the specific case of PC patients, until now monitoring systems are limited to the digital collection of questionnaires or self reports through a smart-phone [12]. While the usability of smart-phone-based questionnaires was investigated [13], to our knowledge no study was conducted with a system including other wearable sensors, like an armband. Furthermore, it was not yet investigated which type of feedback (if any at all) would be desirable for PC patients.

We aim to fill this gap with an unobtrusive monitoring system designed specifically for and with the help of PC patients, using a patient-centric design approach. We advance the state of the art with an observational study to examine a real-world deployment of our system with this vulnerable patient group, which will lead to a future clinical study.

3 Procedure and System for the Observational Study

In this section we present the goals of the observational study with the resulting requirements for the monitoring system. Furthermore, we outline the procedure envisioned for the study.

Goals. The observational study aims to evaluate feasibility and acceptance of monitoring by means of wearable devices within the vulnerable palliative care patient group. The system should provide data whose analysis will allow to find correlations between subjective patient ratings concerning distress, quality of

life and pain and objective measurements from the wearables in order to detect deterioration of symptoms.

Procedure. Similarly to related work [3,14], we choose a sample size of 30 participants. Patients will be recruited at the radio-oncology ward of the university hospital Zurich, Switzerland, under the condition that they are aged > 18 years, have an estimated life expectancy < 12 months (physician's estimation) and > 8 weeks, are able to de-ambulate and to perform all self-care. Patients may be unable to carry out any work activities for up to at least 50% of the time they are awake [15].

Study participants receive a smart-phone Samsung Galaxy S5 (if not already using an appropriate device) and a commercial armband, (i.e., non-obtrusive devices in contrast to e.g., chest belts or adhesive electrodes) to log their physical and social activity as well as vital parameters. For that purpose, the participants shall wear the devices with them all day long. They shall charge the smart-phone over night and the armband once a day. Once a day, the smart-phone will ask patients to rate their current level of distress according to the NCCN[1] distress thermometer ([16]) and their level of pain on visual scales from 0–10. Distress and pain mainly influence the quality of life of palliative patients and are also regularly assessed by physicians [17,18]. The design of the interface between the smart-phone app and the patient (patient interface) will be investigated thoroughly in Sect. 4, leading to a patient-centric design approach.

In case of consent, patients will receive the devices and will be introduced to them while still hospitalized. Three days after hospital discharge, a member of the scientific staff will visit patients at home to clarify questions of the patient and to ensure accurate data recording. We will call patients weekly for questionnaire-based interviews, e.g., EORTC QLQ-C30[2] and to verify device usage. Patients will be tracked over 12 weeks ending with a final interview about the device usage and their experiences.

System overview. Figure 1 sketches the technical system to be deployed in the study. The smart-phone provides sensor data (motion sensors) to monitor what patients are doing and how they are doing it as well as phone usage to monitor social activity. The armband, probably the Biovotion Everion, provides vital parameters, e.g., heart rate, stress from photoplethysmogram and galvanic skin response to monitor symptoms, e.g., pain, stress and anxiety.

4 Interviews with Palliative Patients and Resulting User Interface

Given the requirements outlined in Sect. 3, we now proceed with the patient-centric design of the patient interface and we define possible feedback channels.

[1] US National Comprehensive Cancer Network.

[2] EORTC: European Organization for Research and Treatment of Cancer, QLQ-C30: standardised questionnaire to measure quality of life of cancer patients.

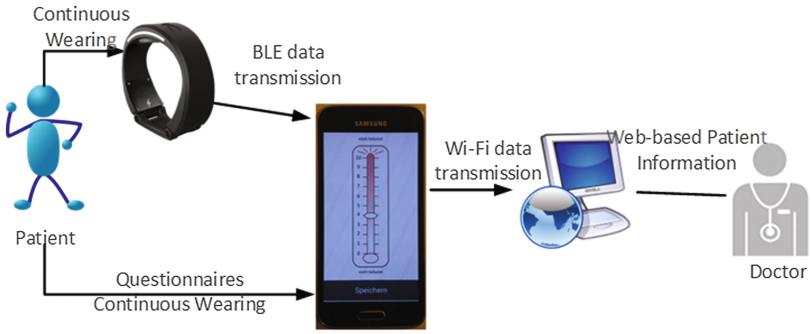

Fig. 1. System overview: body-worn, non-obtrusive sensors, regular encrypted data upload to a secured server, secured web interface for data analysis.

Since usability and convenience of the devices are crucial factors influencing the study, we involved potential users in our iterative system development. After receiving the ethical vote, we conducted qualitative interviews [19] in form of guided conversations. Furthermore, we showed patients different smart-phones of the Samsung Galaxy series and commercial armbands (Fitbit Charge HR and Angel Sensor, since Biovotion Everion was not available at that time) and let the patients choose between different design variants and control concepts. Finally, we asked them to use a prototype app on a Samsung Galaxy S5.

We present the observations in topical subsections together with our conclusions.

4.1 Characterization of Patients

We conducted interviews with 12 cancer patients between 49 and 80 years old (median: 63.5, standard deviation: 10.07). Table 1 shows descriptions of the patients. We encountered a broad spectrum of patients differing in many facets. Concerning the physiological aspects, the spectrum ranged from symptoms not observable by a non-expert to physiological burdens like tracheotomy. Concerning mental aspects, we encountered patients fully aware of their situations and patients blocking out that they are terminally ill. Also the mood of the patients varied strongly, from unhappy or depressed to happy and even euphoric.

4.2 Usability of the Smart-Phone App

- After a short introduction, all patients but one were able to use the smart-phone and to answer the questionnaire as shown in Fig. 2 autonomously – including patients who never used a smart-phone before (25% of the sample).
- Special needs came from co-morbidities or age (e.g., limited visual skills).
- Confirmatory gesture: All patients but one chose to have an extra confirmatory tap to save the questionnaire values. The confirmation dialogue was evaluated positively as providing reassurance and not as annoyance.

Table 1. List of interviewed patients; f=female, m=male

ID	Gender	Age	Interviewer's assessment
1	f	51	Autonomous and independent person; background in programming
2	f	71	Euphoric mood due to recovery from acute symptoms and aware about illness; technical background
3	f	80	Patient told off-topic stories, interview aborted after few questions about attitude toward smart-phones
4	m	68	Self-reported suffering from pain not noticeable during interview
5	m	72	Patient suffered from acute symptoms, interview aborted before talking about wristbands due to difficulties to speak
6	m	52	Very positive, optimistic despite progressive disease. Maybe blocking preoccupation with limited lifetime
7	m	50	Optimistic to recover; helpful despite critical towards research projects
8	m	68	Impressive entrepreneur with good profiling skills; handles his situation with humour in the outer world
9	m	63	Not that experienced with technology, but adventurous; hoping to have at least some years left despite divergent physician's guess
10	f	61	Values good quality and aesthetics – therefore critical; main symptoms: fatigue due to progressive disease, treatment and pain
11	m	49	Hopes for some years; very positive vibes despite of high symptom burden (weight loss of 25 kg, swollen belly, jaundice); interested to contribute to research
12	m	64	Fatigue due to disease and treatment

– Design: Patients of all ages preferred big numbers. The topic of smiley usage evoked emotional statements, e.g., *"I hate smileys."* (no. 8), *"I think smileys are sweet."* (no. 11). In our sample, all the patients who preferred smileys also preferred a colourful design of the distress thermometer and pain scale.

Conclusion: *Palliative care patients are willing and capable to use smart-phones. Concerning the app design, we could not find any requirements constituted in the palliative situation. Based on the interviews, we finalized the design as illustrated in Fig.* 2.

4.3 Feedback Through the Smart-Phone App

– Eight out of 10 patients understood what is meant with feedback through the app.
– Three out of those 8 (no. 8, 11, 12) would be interested in feedback concerning their physical activity – but not more often than once a day. Those three patients already had experiences with fitness tracking apps.

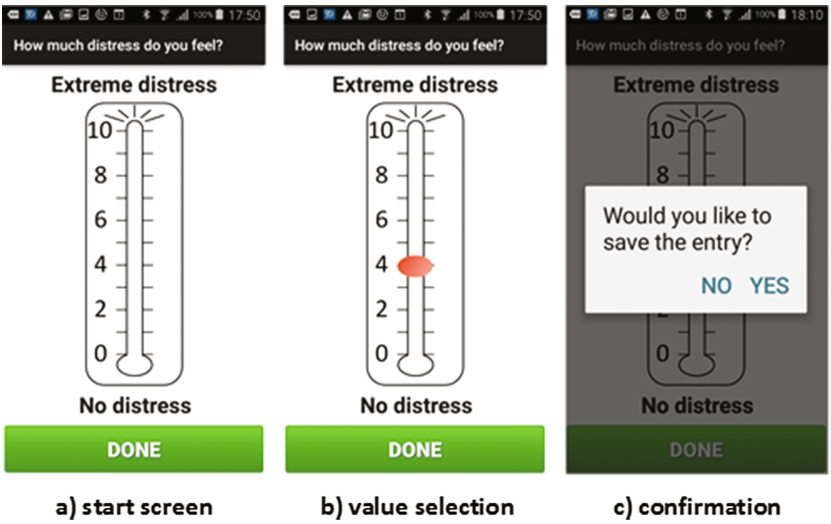

Fig. 2. Digital version of the NCCN distress thermometer: (a) graphical design is based on validated paper version of the NCCN Distress Thermometer [16], (b) value selection by tapping and sliding, (c) confirmation dialogue

– Depending on the patient, the feedback serves more for information and support and encouragement (no. 11, 12) or has an entertaining character (no. 8).

Conclusion: *Most of the patients of our sample were not interested in direct feedback through the app – at least as long as it was not experienced before. However, feedback serves an informational, encouraging or entertaining purpose for some patients. Insensitive feedback could destabilize easily palliative patients since they carry already a high mental burden.*

4.4 Motivation to Use a Monitoring System

– Nine out of 12 patients gave positive comments on the presented monitoring system, e.g., patient no. 2 said: *"I take the smart-phone always with me when I am leaving home. It gives me a more secure feeling, e.g., when driving alone. Such a system is useful, it makes me feel more safe."*
– Patients no. 7 and 10 were concerned about data security and privacy.
– Patients no. 10 and 12, suffering from fatigue (they are chronically exhausted) commented the task to take the phone with them the whole day long: *"I imagine it really cumbersome."*

Conclusion: *In the sample, a positive attitude towards a monitoring system was dominant. Sceptical statements concerned mainly privacy issues. Comprehensibly, fatigue reduces the willingness to use the presented monitoring system. Important requirements towards the armband are easy to handle closing and charging mechanism and no user interaction in terms of buttons required.*

4.5 Vulnerability and Sensitivity of Palliative Care Patients

- Not all patients are conscious about their health situation, e.g., patient no. 7 stated: *"I already survived cancer once and I am confident to recover again."* Thus, the monitoring system is not named as a system for palliative care, but as a system *for patients like you, when you leave hospital.*
- Interviewer and interviewees met for the first time. The exceptional situation of the patients and the chosen interview technique (guided conversation) yielded to a momentum in the relationship that required mindfulness and an open attitude and willingness to get involved in those relationships.
- Nevertheless, all patients with a severe cancer illness are in extreme and very demanding situations. Patient no. 10 stated: *"I would like to enjoy the time I have left and such stuff should not limit myself."*
- Some patients appreciated the opportunity to talk. When planning interviews with vulnerable user groups the aspect of "time to merely talk" should be taken into account (median of gross duration 62.5 min vs. 48 min net duration).

Conclusion: *To equip palliative patients with tracking devices requires sensitivity. The goal of palliative care is to provide the best quality of life possible, not only with respect to medical, but also to psychosocial and spiritual needs. A monitoring system should not interfere with these profound human wants.*

5 Conclusion and Outlook

In this work, we presented a monitoring system that was developed with early participation of vulnerable patients and that will be fully evaluated by means of an observational study. The interviews demonstrated the huge variety of the patient group. A first test with one patient delivered data and we were able to analyse the data manually. For trend detection, we need data of longer collection periods as will be provided by the main study. We will optimize the app with respect to battery consumption and memory needs by replacing the csv file based storage system through a binary file based system with buffered data queues reducing the file sizes and number of file accesses.

The next steps consist of patient recruitment and data collection. We will automate the data analysis using statistics and machine learning methods. Patients' experiences will be used to improve the monitoring system.

Based upon those results and the experiences gained through the observational study, we will develop a feedback strategy that respects the required sensitivity.

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