Home Monitoring Service for Critically Ill Children

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Abstract—**Although the benefits of remote patient monitoring (home monitoring) are widely recognized, there has been no large-scale integration into regular healthcare delivery. The paper describes a home monitoring service aimed at severely ill children. A smart algorithm detects if parameters have exceeded pre-defined thresholds and thus may imply a critical situation. The service has been developed by a team of medical, technological and research partners and is offered by professional nurses employed by an ambulatory care association. The paper describes the technical solution of the monitoring service, its infrastructure, and relevant processes as well as its integration into the healthcare market. The paper finishes with outlining possible future developments that could help promote the uptake of such a service.**

Keywords–healthcare; eHealth; digital health; home care; remote monitoring; support service.

I. INTRODUCTION

Thanks to recent technological advances, such as smart devices, sensors and mobile technologies, the remote monitoring of patients who suffer from chronic disease or who can be taken care of at home instead of being hospitalized has become feasible. Remote patient or home monitoring has come to be an attractive option because healthcare systems are under intense pressure due to an ageing population with chronic diseases and comorbidities, demographic and lifestyle trends, and shortage of healthcare personnel [1][2]. Besides, due to the Corona crisis, there appears to be an increasing willingness to accept and pay for services delivered online, such as teleconsultations, remote monitoring, etc.

Improvements in quality, efficiency, and accessibility of care, especially in rural or remote areas, have been identified as the main benefits of home monitoring. Potential beneficiaries include patients, who can stay at home, but also healthcare personnel, such as physicians or nurses who may monitor the status of their patients continuously. This allows early recognition of health problems or exacerbations (e.g., in the case of obstructive pulmonary disease) as well as monitoring the effect of medication or a therapy plan as well as a patient's adherence to it. Remote monitoring may also encourage patients to take on an active role in the delivery of the service, e.g., by monitoring their vital functions or carrying out necessary interventions on their own.

Despite the known benefits, many remote patient monitoring projects do not develop beyond the initial pilot phase [3][4]. Quite often the initial funding comes from research grants or special digital health initiatives. Not surprisingly, there is an abundance of successful pilot projects, which fail to be introduced into the regular healthcare delivery systems, i.e., the so-called 'first healthcare market', which includes reimbursable products, medicines, and services. Because of the widespread reluctance or inability of patients to pay for telemedicine services, adoption in the *first healthcare market* is a prerequisite for the long-term success and sustainability of a home monitoring service.

To succeed in the first healthcare market, country-specific requirements and characteristics have to be taken into account. For a home monitoring service provider to have its services reimbursed by the health or invalidity insurance, this will usually imply furnishing evidence for the cost-effectiveness, impact, and usefulness of a particular service. According to [5], the *second healthcare market*, i.e., privately financed health services, is primarily helpful as a launching pad for new solution into the primary healthcare market.

In this paper, we present a home monitoring solution that was especially developed for remotely monitoring severely ill children and thus relieving their parents from many nights of interrupted sleep or no sleep at all. Section II provides an overview of related work. Section III describes the methodological approach we have adopted to develop the solution. In Section IV we outline the technical aspects of the monitoring solution and how it has been embedded in an organizational context and a process infrastructure. We especially focus on the challenges that we encountered during the project and how we met them. In Section V we go on to discuss the hurdles, prerequisites, and opportunities of introducing our home monitoring service into the first healthcare market. Finally, Section VI sets out possible future developments to extend the services offered by a home monitoring system. In this section we also present some policy considerations (e.g., reimbursement approaches) that could help promote the uptake of home monitoring services in general.

II. RELATED WORK

Our home monitoring solution has been inspired by a general trend towards digital, and in particular mobile, health systems based on the use of sensors and medical devices [6]. These applications include monitoring systems which collect data either with sensors embedded in smartphones, such as accelerometers, gyroscopes, GPS, microphones or cameras [7] or by means of wearables, such as smartwatches, and are able to measure physiological parameters like heart rate, blood pressure, respiration rate, oxygen saturation, body temperature or electrocardiogram [8].

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Reference [6] conducted a comprehensive literature review of remote patient monitoring systems which covered remote monitoring systems based on sensors attached to the body, ambient sensors and systems based on contactless camera-based methods. The authors show that remote monitoring is suitable for a wide range of conditions. Among the most common are those directed at chronic diseases, such as diabetes, the cardiovascular and respiratory systems, fall detection and mobility-related diseases, which are addressed mainly at the elderly, as well as neurological disorders and mental health [9][10].

It appears that only a few monitoring systems address children, in particular, who tend to have special requirements, e.g., with regard to the size of sensors or how these can be attached to the body [11]. In [12] a camera-based monitoring system for hospital environments is discussed, which measures respiration rates and detects apnea using a Kinect camera. Reference [11] proposes a smart monitoring solution based on wearable sensors and a smartphone that continuously monitors a child's activity and vital signs. Whenever the system detects any deviations, it sends an alert to the caregivers (e.g., parents or teachers) as well as the physician in charge. A similar system based on wearable vests is presented by [13].

III. METHODOLOGICAL APPROACH

We relied on a design science approach [14] for the development of the monitoring system. We evaluated the monitoring prototype in various field tests and conducted several iterations, evaluating and refining the prototype and the processes relevant for the remote monitoring solution.

In line with a participatory human-centred design approach, we conducted semi-structured interviews with the nurses who would be in charge of monitoring the sick children in the headquarters of the ambulatory care association for children. The results were analysed and subsequently translated into a set of detailed functional and non-functional requirement specifications for the monitoring application.

We decided early on to use existing devices that had already obtained medical approval. We then examined how these could best be integrated into the application scenario. Apart from medical approval, devices had to meet additional requirements, most importantly providing access to raw, non-aggregated data measured in real-time. Moreover, the option to switch off the video and audio recording of the monitoring devices on the patient side was required so as to ensure people's privacy.

The results from the iterative testing were continuously fed into the further development and adjustments of the various components, be it the adaptation of the thresholds, the alert process, or the graphic user interfaces of the dashboard. The processes relevant to remote monitoring were identified in close collaboration with representatives of the ambulatory care association, validated in the tests and adapted to the findings.

With a view to the later acceptance of our solution in the health care sector it was essential that our monitoring solution should not be inferior to a hospital setting in terms of reliability and accuracy, which is why we conducted an equivalence test in a children's clinic. The test included a comparison of all triggered alerts, a video analysis of both monitors as well as an observation of the test persons by experts.

We furthermore examined different approaches to measure respiration rate, which included impedance pneumography and respiration rate estimation, both from electrocardiogram (ECG) and from audio signals. For the latter we used a microphone attached to the throat, a measure which because of its obtrusiveness, was only applied in the pre-tests. The respiration rate values showed some deviations compared with the manual counting performed on both systems. Besides, we found artefacts in all measurements, which is why we decided to use this parameter just in combination with other parameters to reduce the rate of false alarms.

The hospital test was followed by a test on healthy children in a home setting and further tests in a special home for seriously ill children which is supervised by the ambulatory care association and offers their parents temporary relief from their care responsibilities. Such a scenario comes closest to the home setting, which for both time constraints and ethical considerations could not be implemented during the project period.

IV. DESCRIPTION OF HOME MONITORING SOLUTION

The solution is composed of the following components:

- the medical devices and sensors,
- the data transfer architecture,
- an on-demand audio and video surveillance system.

Since the home monitoring solution must not be inferior to monitoring in a hospital setting, we opted for a multipurpose HEACO monitor which is also used by clinics. It allows to observe physiological parameters including an electrocardiogram, SpO2 (oxygen saturation), PR (pulse), RESP (respiration) and TEMP (temperature).

The need for the audio-visual components only emerged in the course of the project. The nurses involved in the project are employed by an ambulatory care association which initiated the project. Besides, a software development company and a children's hospital participated in the project. The task of the hospital was to make sure that the solution to be developed was on par with the monitoring service in the hospital with regard to reliability, safety and accuracy of measurements. Apart from the technological challenges, the solution had to be embedded in a process landscape and be associated with a detailed organizational plan with regard to authorization, roles and tasks.

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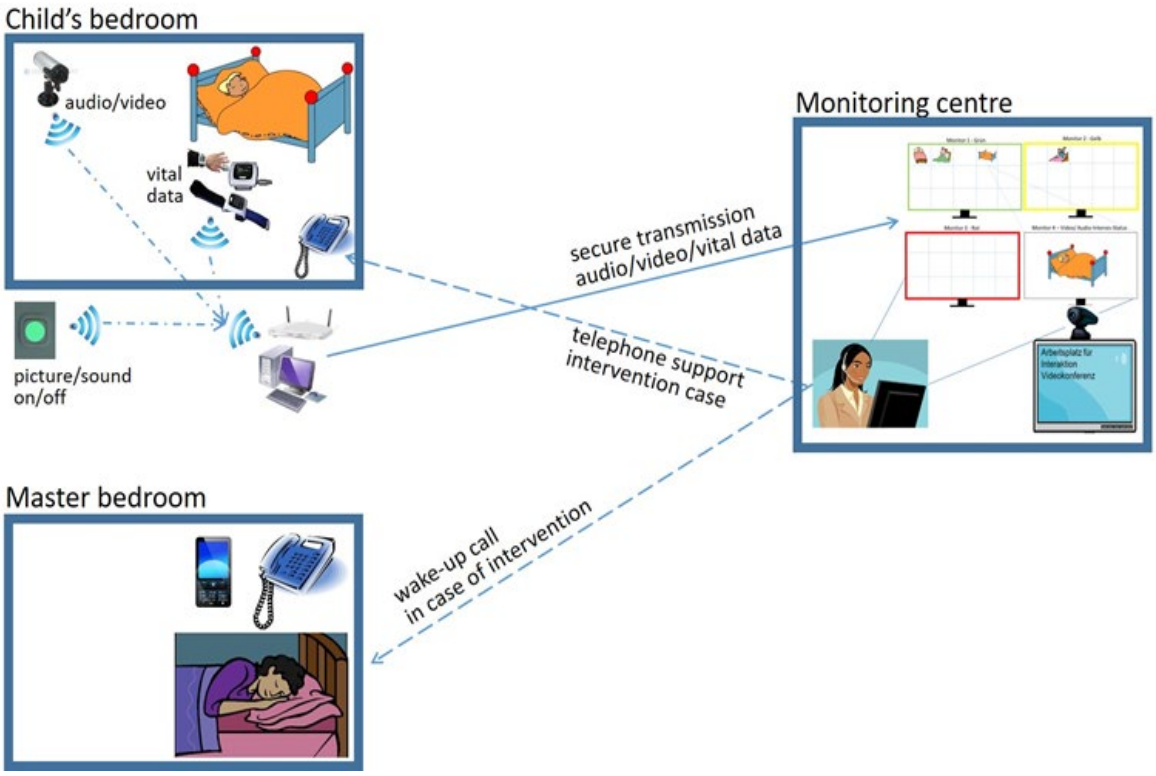

Figure 1. Application scenario for remote monitoring.

For the purpose of monitoring, sensors are attached to the body of the child and the values of the vital parameters are continuously transmitted to a monitoring center based at the headquarters of the ambulatory care association. There, experienced nurses watch the data streams on a dashboard (see Figure 1). Comparable to a traffic lights system, the color red indicates a potential danger or possible emergency, yellow stands for caution and green means 'ok'. If vital signs exceed or fall below the thresholds set by a doctor or the vital parameters are not transmitted, the color turns yellow or red. In the case of a red alarm, the nurse can wake the parents and, if necessary, talk them through the appropriate measures by phone. In severe cases, the professional staff in the monitoring center may contact the ambulance straight away. To prevent false alarms, a video surveillance system enables the nurse to observe the child and judge, for example, if an epileptic seizure is imminent or if the parents should be wakened.

The choice of vital parameters was largely determined by the physician involved in the project and the parameters usually monitored in the hospital, i.e., respiration rate, heart rate and oxygen saturation. These parameters tend to be relevant for the majority of diseases. Besides, they swiftly respond to changes in a patient's condition.

The proposed solution includes a smart algorithm that detects if a certain combination of parameters has exceeded predefined thresholds and thus may imply an emergency.

A. Monitoring infrastructure

The tests carried out with the prototype showed that an infrastructure could be established that is comparable to a stationary monitoring system as used in hospitals. The test in the hospital which involved running two systems in parallel showed that the monitoring system developed for the home setting was not inferior to the hospital setting.

After extensive discussions and testing with the nurses to be in charge, the following quantitative parameters or the monitoring unit were defined: Depending on the case mix and the expected number of alarms, up to 20 patients can be monitored simultaneously. Based on organizational constraints, a child can be placed under surveillance for a maximum of 12 hours. The service is offered from 8pm to 8am, with two active nurses and one nurse on stand-by. The set-up consists of a central dashboard and three individual surveillance stations as depicted in Figure 2.

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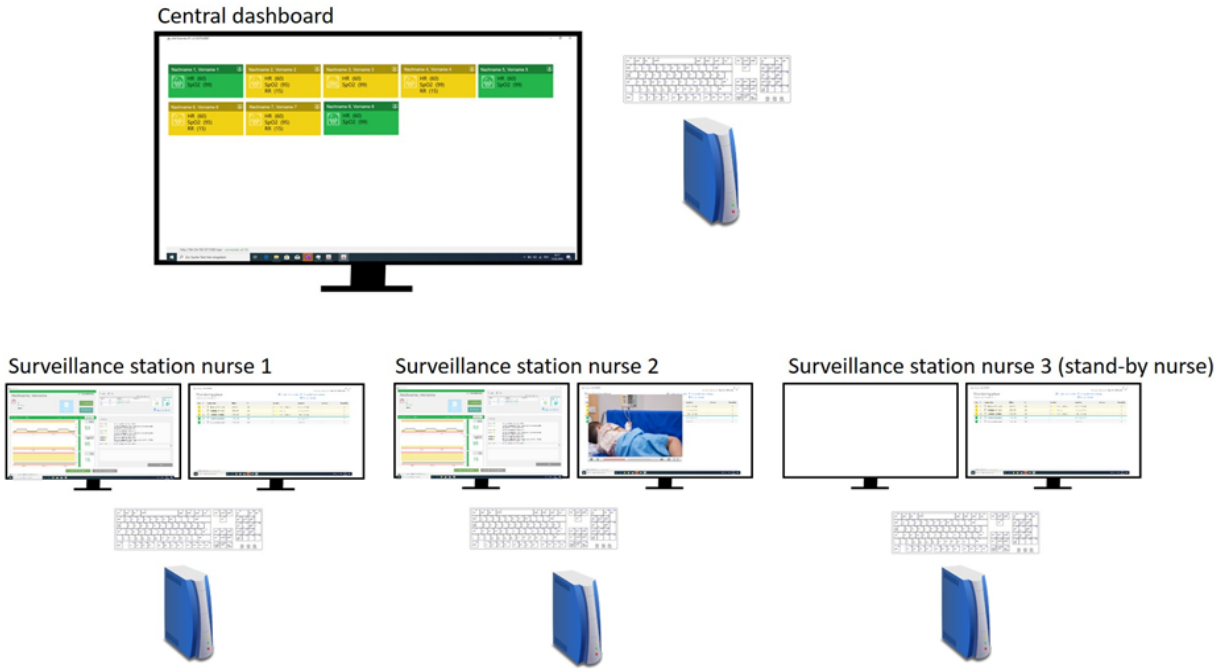

Figure 2. Schematic overview of monitoring unit.

The central dashboard provides an overview of all the patients that are being monitored, giving their names, the most recent values of each vital parameter and the status colors (green, yellow or red). A patient's status color can only be downgraded from red to yellow or to green if the patient has been inspected in one of the surveillance stations. The status of yellow does not trigger an acoustic signal but exhorts the nurse to look at a particular patient more closely. The thresholds for triggering the alarms have to be pre-defined by the physician for each individual patient.

The partner network is especially important in the proposed service: The ambulatory care association for children offers the remote monitoring service. Its specialist nurses operate the monitoring units and monitor patients in real time for up to 12 hours during the night. The same nurses pay regular visits to the families for treatment and basic care services. They have established profound relationships with the families. Another important partner is the paediatrician who defines the thresholds for the vital parameters that are measured and transmitted to the monitoring unit.

Finally, an infrastructure partner provides the monitoring infrastructure and platform, supports the set-up of operation at the patient's home and assures the operability of the monitoring units.

B. Relevant processes

A major task consisted in defining the processes to accompany the implementation of a monitoring system. The processes relevant were identified in close collaboration with representatives of the ambulatory care association, validated in the tests and adapted to the findings. These included authorization and login, the actual monitoring process, informing/alerting parents, alerting emergency services, and contingency plans. It was above all defining the interaction processes between nurses, caregivers at home and emergency staff, e.g., when to issue an alert and whom to alert whenever there was an emergency, that caused lengthy discussions.

The implementation of the planned monitoring solution therefore required developing a detailed *process reference model* that described the relevant processes associated with remote monitoring. A central issue is related to the question what to do if a threshold is exceeded. For example, should the nurse alert the parent immediately or first make sure that it really is an emergency?

The concept of emergency itself proved to be far from unambiguous and triggered extensive discussions in the project team. It is closely related to the definition of thresholds for the various parameters, which tend to differ considerably between individuals. It also involved defining the number of children that a professional nurse might monitor simultaneously.

The main challenge consisted in reducing the high number of alarms per child per night. In the beginning, we registered up to 250 alarms per child and night. We were able to halve that number by adjusting the algorithm. By fine-tuning the thresholds, we further managed to bring the number down to ten to 35 alarms per child and night. In addition to that we decided to introduce audio-visual inspection to be carried out by the professional nurses. The inspection serves as a preliminary check so as not to obliviate the whole purpose of the project, which is facilitating a good night's sleep for the parents. Finding the right balance between safety or caution and running the risk of missing an emergency proved to be a major challenge.

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V. INTRODUCTION OF HOME MONITORING INTO REGULAR HEALTHCARE DELIVERY

The overall purpose of the service offered is to support the family caregivers (parents) during the night hours as the responsibility of caring for a severely ill child often comes at the cost of lack of sleep as well as physical and psychological strain, which may lead to chronic stress and eventually physical and mental break-down [15]. This has been confirmed by the findings of a research report commissioned by the Swiss Ministry of Social Insurance, which shows that one in five caregivers never or only rarely enjoys a good night's sleep [16].

Given the importance of introducing our home monitoring service into the first healthcare market, the business partners attached a great deal of importance to the organizational aspects required for the eventual reimbursement of the service. Therefore, medical approval by the relevant body is necessary (the Swissmed in the case of Switzerland). To achieve this, evidence must be furnished to prove the usefulness, cost-effectiveness and efficiency of the solution.

Usefulness: Every year, the ambulatory care association of Eastern Switzerland is responsible for around one hundred mentally and physically handicapped or chronically ill infants, children and young adults. Its clients also include prematurely born children as well as sick, injured, convalescent children and those recovering after surgery. The purpose of the home monitoring service is both preventive and therapeutic: it should detect exacerbations of the child's state of health on the one hand and enable early interventions on the other. Providing more restful nights and guidance by a nurse in an emergency helps to increase parents' endurance as a caregiver. The remote monitoring service also has a therapeutic effect since care at home tends to contribute to the recovery and enhance the quality of life of children with severe illnesses or disabilities [17][18][19].

Cost-effectiveness: Home monitoring is a service offered by the ambulatory care association in addition to its on-site services and replaces night watches by nurses as well as the children's parents. It can therefore be considered an extension to its current portfolio. Due to their 1:1 setting, night watches are very expensive because of the high cost of labour. Night watches are recognized by the Swiss Ministry of Social Insurance and thus a tariff item number exists. This tariff item number is a prerequisite for invoicing the service. However, a remote monitoring service currently has no tariff item number and therefore cannot be invoiced.

This is why it is crucial that the Ministry of Social Insurance as well as the health insurance introduce, such a tariff item number. Otherwise, the business model for the home monitoring service will not be sustainable in the long run. As a result of the Corona crisis, chances are good that this might happen in the near future.

Efficiency: In the preliminary business plan, the service provider calculated the savings due to the productivity increases as a result of remote monitoring. The new home monitoring service allows the simultaneous monitoring of up to 20 patients by three nurses (two active nurses and one nurse on stand-by) in the central monitoring unit, whilst for traditional night watches, only one patient can be monitored at a time. As a result, the fully inclusive fee for the remote monitoring service turns out to be about five times cheaper than an on-site night watch performed by a nurse.

Given the fact that severely ill children usually need to receive intensive care to monitor their health state, the costs tend to be even higher. The experience of the ambulatory care association shows that without their services, children in need of care have to be transferred back to hospital twice as often. In short, as the home monitoring service would substantially support the parents, readmissions to hospital could be prevented.

A further effect of the home monitoring service is the reduction of the secondary costs of stress of the caring parents. In a survey of the stress experience of parents of severely handicapped children, 86.6% of parents stated that taking care of their child costs them a lot of strength and energy [20]. Avoiding or at least reducing these health care costs, which may also include loss of income from paid work, is a further argument in favour of introducing home monitoring.

There is further potential in the more efficient use of scarce nursing staff. At present, nurses take over night watches to provide relief and a good night of sleep to the parents. This activity is very monotonous and according to the ambulatory care association for children, quite a few nurses would therefore be very interested in taking over the remote monitoring of several children instead. Thus, a home monitoring service would make more efficient use of the short supply of nursing staff [21].

It is above all the technical partner who may be interested in exploring new business opportunities, e.g., by extending its services to other partners, user groups or healthcare providers.

VI. CONCLUSION AND FUTURE WORK

From a medical point of view, continuous remote monitoring has proven to be feasible and, if implemented properly, is equivalent or not inferior to monitoring in a hospital environment. Audio-visual inspection in the case of possible emergencies crystallized as a central element in remote monitoring, which had not been considered in the original study design.

Furthermore, it has been shown that during the first nights close supervision by the attending physician is desirable so as to be able to adjust individual threshold values.

In the future, it is conceivable that the home monitoring service might evolve in the direction of self-learning systems for decision support as well as automated generation of recommendations for interventions. However, to be accepted by consumers, the algorithms and thus the decision-making process behind the recommendations would have to be made transparent.

Besides, the analysis of the captured vital data may lead to the development of a decision-making aid for adjusting treatment or medication. The storage of vital data is a central component of the prototype and the basis for analysing the test data. However, any such tool will have to conform with data protection legislation, which implies anonymizing the data and/or obtaining the consent of both parents and the child to use their data.

As far as the long-term sustainability of the service is concerned, home care agencies appear to be a promising avenue

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to pursue as also pointed out by [22]. The business model associated with home care agencies is largely dependent on fixed case-rate reimbursement. This could also be applied to our solution provided that home monitoring is officially recognised. This might involve maintaining patient contact, assessing needs, counselling caregivers while reducing staff travel time.

A major challenge faced by home care agencies is finding a way to share in the much larger savings they generate, e.g., by taking care of chronic care patients or sick children at home instead of hospitalizing them. However, the recent introduction of Diagnosis-Related Group (DRG) system in Switzerland might help persuade hospitals as well as insurance companies to enter into partnerships. Because of the DRG system, hospitals are interested in making sure that care at home is of such a quality that the likelihood for a patient to be readmitted within 30 days is minimized. Any expenses incurred by a 'premature' readmission will have to be covered by the same flat amount, i.e., the hospital is not entitled to any additional payments.

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