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The Role of Nurses in E-Health: the MobiGuide Project Experience

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Abstract. Leveraging the experience of the European project MobiGuide, this paper elaborates on the nurses' role in developing, delivering and evaluating e-health based services. We focus on the home monitoring of atrial fibrillation. Patients enrolled in our study are provided with a smartphone and an ECG sensor, and receive recommendations, reminders and alerts concerning medications and measurements that they should perform through a mobile decision support system that is constantly updated by a backend system. Patients' data are sent to health care personnel that may visualize them, and act accordingly. Nurses play a central role in such setting. After being involved in the design of the caregiver interface, they are responsible for the patients' enrollment phase (which includes patients' complaints, and for the final phase of the study where patients are interviewed about their experience with the system.

Keywords. nursing informatics, telemedicine, atrial fibrillation

1. Introduction

The MobiGuide project (<u>www.mobiguide-project.eu</u>) develops a ubiquitous, distributed and personalized decision-support system (DSS) for patients and their care providers. It is based on computer-interpretable representation of clinical practice guidelines (CIG, [1]), which allows executing the guideline knowledge with a patient's data to produce patient-specific recommendations. While previous CIG-based DSSs were aimed only at clinicians, MobiGuide targets patients as well. Motivated by the fact that chronic patients, such as atrial fibrillation (AF) patients, want to lead a clinically-controlled safe life while maintaining their individual freedom outside clinically-controlled environments, patients are provided with mobile monitoring devices (e.g., ECG sensor) connected with their smartphones, upon which the DSS system operates. Once a CIG is selected for a patient, the patient's relevant hospital electronic health record (EHR) data is imported into a personal health record (PHR) that is maintained by the system and records all data collected from the sensors, from patient self-reporting and also includes DSS recommendations delivered to the patient and his care providers.

Doctors use the DSS system to set guideline-based therapy prescriptions for their patients. At the enrollment, nurses, together with patients, define regular times for

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reminders for taking medications, and for performing and recording measurements (e.g., weight, blood pressure), mobile ECG monitoring sessions, and exercise sessions. These directions are saved in the PHR and allow the system to advice the patient when he is in his normal environment. Based on the patient interview, the nurse can further customize the CIG by defining different contexts (e.g., irregular routine due to travel), which can be dynamically set and influence the recommendations for therapy.

To increase compliance, the system generates reminders at the times set by the patient or his care provider. To maintain patient safety, the DSS analyses the sensor data in real time and identifies clinically-relevant patterns, such as AF episodes or non-compliance to therapy. Once identified, recommendations are provided to the patients, via the smartphone interfaces as well as to their care providers, via web interfaces.

Nurses have important tasks when following the patients: assuring that they understand therapy instructions, find out how well they manage to comply with therapy recommendations, and follow up their health states. They are the ones who alert the doctors if they feel that a therapy change should be considered. When introducing a patient telemonitoring system such as MobiGuide, the nurse's workflow changes. She has access to valuable data that are collected daily from the patient and include summaries of ECG monitoring sessions and exercise sessions, daily and weekly measurements, and patient-reported symptoms, and medications consumption. She also has a new role in assisting patients in using the MobiGuide technology. To assess the feasibility of using the MobiGuide telemonitoring system with patients, we have conducted a pilot study with ten patients, one nurse and one doctor. We report our experiences from this study, focusing on the nurse's role.

2. Methods

A pilot feasibility study has been carried out in the cardiology ward of the Fondazione Salvatore Maugeri research hospital in Pavia, from April to October 2015. The study involved the monitoring of 10 patients using the system over a period of 3 months. The pilot preparation included 3 training sessions for nurses regarding system usage. Patients were recruited on a voluntary basis, and met the following enrollment criteria: (i) a diagnosis of paroxysmal, persistent or permanent AF, (ii) NYHA² < III, (iii) ejection fraction>35%, (iv) stable clinical conditions since at least 3 months. Additional enrollment criteria like motivation, technological skills and clear understanding of the project goals were also included, in the effort to minimize drop-out rate. Exclusion criteria only consisted of severe comorbidities (e.g. cancer, neurological disorders) that could prevent continuous use of the system for the planned 3 months of the study.

In agreement with previous literature [2], nurse's workflow was affected by the presence of the system. In our study, one part-time research nurse was specifically dedicated to manage patients using MobiGuide. She was responsible for the patients' enrollment phase (including patients' training), for the daily checking of incoming data, triage of patients' complaints, and for the final encounter where patients are interviewed about their experience. Figure 1 summarizes the main activities the nurse is responsible for in each phase.

Interviews were used to collect the nurse's feedback on system usability and perceived usefulness. Patients' data was extracted from the PHR and from paper-based

² New York Heart Association class

questionnaires filled out by patients during the study. Finally, analysis of the logs of the care-provider's interface provided data about monitoring sessions duration, their frequency, and other statistics about system usage.

At enrollment/un-enrollment, a checklist helps the nurse to remember all the documents to be filled-in and/or provided to patients. They are: (1) the Informed Consent; (2) a form to collect any additional data not included in the PHR; (3) "Ten motivations for using MobiGuide" to be scored by the patient, aimed at capturing patients' expectations before and after the system usage; (4) EuroQOL; (5) AFEQT, measuring how much AF affects the patient's Quality of life; (6) receipt of the delivered devices; (7) A folder containing the user guide and a notebook for the patient

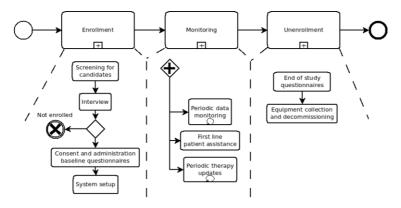


Figure 1. A business process (BPMN) diagram of the workflow for the nurses involved in MobiGuide.

3. Results

Evaluating the requirements in terms of effort spent by nurses in telemedicine initiatives is an essential step to understand the impact of their widespread adoption. In this section we report our estimate of this effort in the various phases of the study.

3.1. Enrollment phase

The nurse spent significant time searching for patients to be enrolled. During 4 months, 10 individuals were enrolled, out of 35 patients screened and invited for a meeting. Among these only 5 did not meet the formal enrollment criteria defined in the protocol while others were excluded for other reasons. In particular, people who were still employed felt that they would have to dedicate much of their time to the study; the length of the study was considered a barrier to participation. Similarly, patients who lived far from the clinic were concerned that using a system like MobiGuide would imply the need of managing some technical issue, leading to more frequent interactions with the hospital and thus an increased need for travel or phone calls.

As most telemedicine interventions, MobiGuide implies operating devices and using interfaces for patients. Given the significant amount of technology involved and the fact that AF patients are usually older than 65 (mean age of the 10 enrolled patients is 66.3 ± 9.2 years) some patients refused to enroll because they did not feel skilled enough to operate the system on their own at home. The presence of a caregiver able to

help the patient with the smartphone might mitigate this perceived barrier and indeed allowed the enrollment of one of the patients who was being assisted by her daughter.

Devices and hardware can also impose some limitations on the possibility to enroll certain patients. One example comes from the technical specifications of the BioHarness ECG sensor used in the MobiGuide project, which did not guarantee that the sensor would not interact with cardiac implantable devices like pacemakers [3].

Enrollment of eligible and interested patients is also a labour-intensive process. Usually, the cardiologist is present for a limited amount of time needed for the clinical assessment of the patient, which is usually followed by a data-entry phase carried out by the nurse alone. In the MobiGuide pilot, enrollment visits lasted 150 minutes on average (90 minutes for completing paperwork and filling out enrollment questionnaires, and 60 minutes for system setup and training of the patient for system use). Another 30 minutes were spent by the nurse alone for data entry tasks like input of therapy prescriptions or completing patients' clinical history.

3.2. Remote monitoring and patient support phase

During the main phase of the study, nurses' tasks revolved around two main areas: remote monitoring of the patients and patients support, both technical and clinical. Patients enrolled in our study are supposed to record a 30min ECG session once or twice a day. Even more data is available on a daily basis if a patient spontaneously starts an ECG monitoring when feeling a symptom. Other parameters like blood pressure and weight complete the collected data. Thus, the nurse checked patients' data on a daily basis. The time spent on this activity depended on the specific diagnosis and varied between a minimum of 5min for patients in permanent AF (where checking for AF occurrence is not needed) to a maximum of 20min for paroxysmal AF. A set of patients that need further attentions from the nurses are those taking oral Vitamin K antagonists to prevent risk of stroke. These patients have their blood tested every two weeks and report back their INR value and possible dose adjustments to the nurse, who then inputs the new therapy plan to enable the system to send the appropriate therapy reminders. This activity takes about 10 minutes of the nurse's time for each patient.

The activities regarding patients' support also cause an increased interaction between patients and nurses. Nurses are the first contact point for both patients' clinical needs and, with the introduction of MobiGuide, also for technical support. Table 1 summarizes this effort for the 10 patients during the first 6 months of the study. Note that patients were enrolled at different times and, according to the protocol, they used the system for 3 months, so that the maximum number of contemporary patients was 6.

Table 1. Number of patient-nurse interactions. The number of technical problems that the nurse was able to solve alone is reported in brackets. For the other ones second level technical support was needed.

	Clinical	Technical	Other
Calls	5	13 (6)	37
Visits	8	10 (3)	14

Obviously, the nurse had to allocate time for solving each of these interactions. However it is important to point out that the same data also highlight a positive effect on patient participation and accountability. In fact, most of the calls in the "other" category were spontaneous calls made by patients that wanted feedback about an ECG recording they just made or to notify the nurse that they have just used the system to report new symptoms (interestingly, this could mean that patients do not fully *trust* the communication capability of the system). Also, the 14 visits reported in the "other" category represent patients interviews to check how they were doing and ask about the overall results of the project. Another benefit of the increased interactions between patient and nurse is the improved quality of data available for the clinical visits, which ultimately leads to time saving. Nurses reported that when not using MobiGuide, 2 out of 10 visits in the cardiology ward at FSM were affected by missing data that could only be solved by re-scheduling. The use of MobiGuide increases compliance to monitoring prescriptions and allows to collect measurements in the PHR as soon as they are taken. This, together with the daily monitoring of data performed by the nurse, positively affects data completeness and eases data preparation for doctor appointments.

3.3. End-of-study phase

The un-enrollment phase also involves the nurse in an end-of-study visit that consists in the administration of end-of-study questionnaires and the collection of all the devices previously assigned to patients. The final visit duration was about 30 minutes.

4. Discussion

The adoption of a telemedicine system such as MobiGuide has important implications on nurses' workflow and needs to be carefully considered for proper allocation of time resources. Some findings of the pilot trial experience pointed out that additional tasks have to be performed by nurses, which ultimately lead to increased effort. However, previous studies about a similar domain (hearth-failure) point out that, in a setting where proper facilitators are present, benefits like an improved sense of security for both patients and nurses, and timely information about the patient status, are also expected [4]. Some facilities are however necessary to ensure longer-term sustainability of telemedicine initiatives. The addition of more selective patient enrollment criteria (applied by nurses) has proven to be successful in our experiment, in which all enrolled patients have completed the study. This is in agreement with recent research findings [5], which also pointed out that the availability of appropriate technical support is required "to ensure the success of telehealth" [5]. This was also the case in our experience where a significant number of interactions between nurse and patients needed second level technical support. Limitations of our study include the number of patients involved in the pilot trial (10 in total, with a maximum of 7 actively managed at the same time) and the presence of only one nurse. Higher numbers would be needed to confirm statistical significance of the results in a follow-up study.

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