Self-Management of Complex Chronic Patients: Needs and A Proposal

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Abstract. Patient self-management plays an important role in an effort to deal more effectively with chronic conditions helping shifting resources into the community. This paper addresses self-management of complex chronic patients. General needs resulting from the literature are described together with concrete needs from the CONNECARE project. Finally, a proposal based on *µservices*, currently adopted in clinical trials running in 3 sites (Lleida, Israel, and Groningen), is presented.

Keywords: self-management · chronic patients · patients' monitoring · *µservice*-based architecture · clinical studies.

1 Introduction

Chronic disease is the major cause of disability, the principle reason why patients visit physicians, and the reason for 70% of health care expenditures [25] [2]. Current healthcare systems, designed early in the last century to cope with acute disease, did not change when chronic disease became the major issue [26]. As a consequence, discontinuity and fragmentation of care are widespread. Community and home-based care are poorly developed. Costs mount without obvious commensurate benefits for patients. A large segment of the population is unable to obtain appropriate health care. Integrated care models are designed to respond to such challenges, through defragmentation of health and social care systems, promotion of collaboration and continuity among care settings, and a move from institutional, reactive care to a home-based, patient-centred, preventive model.

In this scenario, facilitating new forms of active participation by patients and consumers in the collection of personal health data will improve the quality of care delivered to patients through better diagnoses and targeted therapies. In that direction, patient self-management plays an important role, especially when patients are elderly, widowed, and/or with economical-social restrictions [50]. Many works have been presented in the literature on the subject of self-management of chronic disease and there is the evidence that effective self-management has a major impact on physical and psychological health status [14]. Two distinct approaches characterize existing research: (i) investigating remote management tasks relevant to specific chronic diseases [46] and (ii) identifying effective coping strategies and differentiating between coping patterns in response to chronic illnesses [42].

Under the umbrella of the CONNECARE project[1] and with the aim of designing and developing a self-management system for complex chronic patients, first, we performed a literature review to collect needs and requirements. Subsequently, we performed a co-design phase in which clinicians, technicians, patients and their carers were asked to participate. At the end of that phase, specific requirements and needs were collected and the system developed. For the sake of scalability and adaptation to changes, from a technological point of view, we adopted a solution based on μ*services* [56] [39]. The aim of this paper is twofold, from the one side, to discuss needs and requirements of self-management tools for complex chronic patients and, from the other side, to propose our solution currently adopted in in clinical trials running in 3 sites (Lleida, Israel, and Groningen).

The rest of the paper is organized as follows. In Section 2, a literature review on self-management and self-management systems is given to highlight the general requirements corresponding to developing a self-management tool. Moreover, specific requirements from the CONNECARE project are presented and discussed. Section 3 presents the proposed approach from the general perspective of the adopted software solution and its current implementation. Section 4 ends the paper with conclusions, discussion, and future directions.

2 Needs

The idea of patient empowerment is not new, it was introduced to health care in the 1970s [48]. Nevertheless, its popularity emerged in the mid 1990s [44], and became a feasible reality only in 2000s thanks to the advent of Web 2.0 [10]. In general, strategies to increase patient empowerment have tended to address two aspects of patients' experience [45]: (1) disease management and (2) relationships with health care providers [3]. Approaches to increase patient empowerment vary from patient self-management programs [32], [21], to promoting patient involvement in treatment decision-making [16], [27], to facilitating the physician-patient interaction [30], [36].

2.1 General Needs

There is not a universally accepted definition of self-management [6]. Alderson et al. refers to it as "an inter-disciplinary group education, based on the principles of adult learning, individualized treatment and case management theory" [1]. On the other hand, in [38], authors define self-management as a treatment that combines biological, psychological, and social intervention techniques, with a goal of maximal functioning of regulatory processes. In contrast, in [14], authors interpret self-management as the "day-to-day tasks an individual must undertake to

[1] http://www.connecare.eu/

control or reduce the impact of disease on physical status.". Accordingly, four kinds of self-management approaches have been identified, depending on the role of the patient [7]: subordinate, structured, collaborative, and autonomous. Subordinate are those tools that provide modest patient discretion through controlling and supervisory technology. Structured tools require more active, though still limited, patient participation. Collaborative ones involve patient drawing on their own knowledge and making decisions jointly with clinicians. Finally, autonomous tools support patients take matters in hand without much participation from clinicians.

Many studies have shown that patients who engage in healthy diet, exercise, or other aspects of self-management have physical benefits in terms of fewer symptoms, better functional capability, and fewer complications than those who do not in various diseases (e.g., HIV/AIDS [15], rheumatoid arthritis [43], asthma or chronic obstructive pulmonary disease [4], diabetes [55], and heart failure [29]). Most relevant studies have examined the association between poor adjustment and poor self-management. On the other hand, there are studies that investigated the connection between good adjustment and engagement in self-management practices. These studies show evidence of a bidirectional association between wellbeing and adherence to self-management regimens. Patients who can maintain good moods seem to be more willing to engage in lifestyle changes, and those who practice self-management behaviours also report improved wellbeing [17].

Clark et al. [14] identified the main features to give support in chronic diseases by older adults: maintaining exercises and activity levels [52]; monitoring physical indicators by objective means [41]; recognizing and responding to symptoms and controlling triggers to symptoms [28]; drug prescription and follow-up [23]; maintaining nutrition and dietary recommendations [18]; giving up smoking [33]; using strategies to relax and reduce stress [51]; managing emotions and psychological response to illness [17]; adapting to work [47]; interacting with healthcare professionals [24]; managing alerts and emergencies [9]; seeking information and using community resources [31]; and managing relations with significant others [22].

Mobile phones and other mobile information and communication technology applications and technologies hold great potential as a basis for powerful patient-operated self-management tools. They are increasingly recognized by policy-makers as a potential medium for supporting self-management of long-term conditions [40]. Huckvale et al. [28] performed a systematic review methodology to the assessment of apps for the management of asthma. Seemly, Marcano et al. [35] performed a study to assess the effectiveness, cost-effectiveness, and feasibility of using smartphone and tablet apps to facilitate the self management of individuals with asthma. Focusing on diabetes, Breland et al. [12] evaluated the extent to which existing self-management apps address the seven self-management behaviours recommended by the American Association of Diabetes Educators (the AADE7$^{\mathrm{TM}}$)[2]. From a wider perspective, Withehead et al. [54] performed a sys-

[2] https://www.diabeteseducator.org/living-with-diabetes/aade7-self-care-behaviors

tematic review to assess the effectiveness of self-management apps in long-term condition management. Results show the effectiveness of adoptig mHealth solutions and apps have been enthusiastically adopted by the patients in all the studies.

2.2 Specific Needs from the CONNECARE Project

CONNECARE is a R&D project aimed at co-designing, developing, deploying, and evaluating a novel integrated care-services model for complex chronic patients with smart adaptive case management and self-management support. The CONNECARE system is a federation of subsystems each devoted to provide a set of goal-oriented functionalities, whose main components are the Self-Management System (*SMS*) and a Smart Adaptive Case Management system (*SACM*) for case modelling and execution, specifically tailored to the healthcare domain[3].

According to a co-design approach, generic requirements for the self-management system have been defined. Moreover, the following activities to be monitored have been considered as the more relevant:

1. **Physical activity.** Healthy lifestyles, including physical activity, have proven efficacy in the prevention and treatment of many chronic conditions [5] [49]. Accordingly, a self-management tool should monitoring walking activity and its intensity through an activity tracker. In CONNECARE, physical activity monitoring is done by relying to off-the-shelf activity trackers. In particular, the following parameters have to be monitored: steps, distance (km), calories, and minutes of activity by intensity.
2. **Questionnaires.** In the literature, several questionnaires have been defined and are currently applied to monitor the status of a given patient in terms of, for instance, anxiety and depression, quality of life perceived pain, self-care, and mental disorder. To empower patients is important to give them the possibility to fill one or more questionnaires. Once filled a questionnaire, the patient has to receive a suitable message with the corresponding result. At the same time, the professionals have to be automatically informed on the filled questionnaire.
3. **Health-status.** As also pointed out in the literature, to better follow-up the status of a patient, several vital signs should be monitored depending on the disease and the associated co-morbidities: temperature; blood pressure; heart rate; weight; blood oxygen saturation; blood glucose level; and ECG. In particular, the professional should prescribe when and with which frequency to make the measurement, as well as put thresholds to monitor anomalies. In so doing, both the professional and the patient will receive alerts in case a given threshold has been overcome.
4. **Simple tasks.** Apart from rehabilitation in hospitals and specialized centres, clinicians agree that daily life activities performed at home radically

[3] The *SACM* is out of the scope of this paper. In the following, we will refer to it only if necessary for the sake of clarification of the overall description.

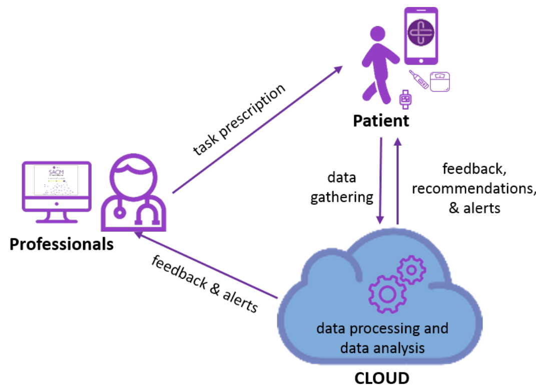

Fig. 1. The closed loop approach.

improve patients' recovery. With this aim, clinicians want to prescribe simple tasks to be performed during the day (e.g., dancing, cooking, reading). Moreover, depending on the disease and the kind of patient (e.g., in case of elderly people) the professional may ask to perform healthy activities such as drinking or eating a fruit. Through the self-management system, the patient can accept or reject the request and inform when the activity has been performed.

5. **Drug prescription.** Chronic patients are used to take several drugs during the day. Forget to take any may provoke serious problems. Thus, the professional need to prescribe all the drugs to be taken and the patient will receive a reminder any time s/he has to take one.
6. **Advices and training material.** Education is a really important issue to be provided to improve follow-up of a therapy and to empower the patient. Thus, the professional can select advices and training material in form of text, images, or videos and the patient is asked to see it.
7. **Virtual visits.** Several studies show the role of professionals and carers in supporting patients, especially when remote solutions have been adopted. [20]. Thus, apart providing direct communication via a textual messaging system, in CONNECARE also virtual visits have been considered as a basic functionality to be provided. In so doing, patients may stay more safely at home without needs to move to the hospital any time a recall visit is needed.

3 A proposal

With the aim of providing self-management to chronic patients –the ultimate goal being patient's empowerment–, we propose a solution based on *μservices*. The corresponding system, installed in the patient's smartphone, allows the patient to monitor her/his activity, receive recommendations to improve the treat-

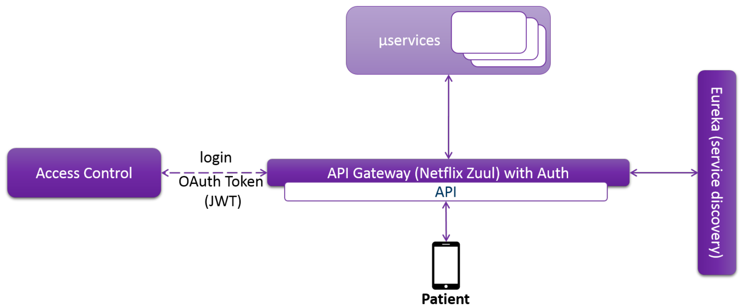

Fig. 2. The *µservice*-based architecture.

ment and to be encouraged in following it, access to her/his data and information, as well as communicate to the medical staff in charge of the case. According to a closed-loop approach (see Figure 1), it is the medical staff who prescribes any kind of task to be performed by the patient. Data gathered by the interaction of the patient with the system (automatically through the devices or manually through direct input) are sent to the cloud where are processed and analysed in order to give the corresponding information to both patient and professionals. In fact, on the one hand, an activity performed by the patient may require automatic recommendations to be sent to her/him. On the other hands, anomalies or low-adherence may require generation of specific alerts to be sent to the patient for her/his empowerment as well as to the professionals for better follow-up. In so doing, keeping informed the professionals about the treatment follow-up gives the possibility to change something in case of worsening of the health status of the patient, preventing and avoiding re-hospitalization. Moreover, in case high improvements are registered, informing the professionals could help in better follow-up reorganizing the care plan, if needed.

3.1 The *µservice*-based System

Figure 2 sketches the overall *µservice*-based architecture. It is composed of a set of *µservices* each of them in charge of performing a simple task. Complex tasks may be achieved by the collaboration, interaction, and coordination of one or more simple *µservices*. When changes are needed in a *µservice*, they do not affect the rest of the system. Moreover, when a new functionality is required, a new *µservice* (or set of *µservices* collaborating together) is defined and simply added to the system. In so doing, the proposed solution is robust to changes and improvements.

For locating *µservices*, with the purpose of load balancing and fail-over of middle-tier servers, *Netflix-Eureka* service discovery is adopted[4]. Eureka is a REST based *µservice* for locating *µservices* with the purpose of load balancing and failover of middle-tier servers (the Eureka Server). Eureka also comes

[4] https://github.com/Netflix/eureka

with a client component (the Eureka Client), which makes interactions with the μ*service* much easier. The client also has a built-in load balancer that does basic round-robin load balancing.

As a front door for all requests from the app installed in the patient's smartphone and the μ*services*, we rely on *Netflix Zuul*[5]. Zuul is the front door for all requests from devices and web sites to the backend of the Netflix streaming application. As an edge μ*service* application, Zuul is built to enable dynamic routing, monitoring, resiliency and security. Zuul uses a range of different types of filters that enables to quickly and nimbly apply functionality to the edge μ*service*. These filters help performing the following functions: authentication and security, identifying authentication requirements for each resource and rejecting requests that do not satisfy them; insights and monitoring, tracking meaningful data and statistics at the edge in order to give an accurate view of production; dynamic routing, dynamically routing requests to different backend clusters as needed; stress testing, gradually increasing the traffic to a cluster in order to gauge performance; load shedding, allocating capacity for each type of request and dropping requests that go over the limit; and static response handling, building some responses directly at the edge instead of forwarding them to an internal cluster.

Management of roles, rights, authentication control, and login is implemented by relying on Spring Cloud Security[6]. It offers a set of primitives for building secure applications and services with minimum fuss; as well as a declarative model which can be heavily configured externally (or centrally) lends itself to the implementation of large systems of co-operating, remote components, usually with a central identity management service.

Right now, for all the functionalities listed above but "virtual visits" a suitable μ*service* has been defined and developed. Moreover, 5 additional μ*services* have been provided to give support and prove further functionalities:

- Patient's monitoring services
    - **Physical activity**. Given a prescription, the μ*service* automatically calculates the adherence day by day and sends recommendations to the patient and feedback to the case manager. Two families of activity trackers are currently integrated in the system via the Third party μ*service* (see below): the Fitbit wristbands and smartwatches by Nokia/Withings.
    - **Questionnaires.** The following off-the-shelf questionnaires have been implemented in the corresponding μ*service* to: follow-up anxiety and depression (Hospital Anxiety and Depression Scale (HAD) [57]); evaluate the condition of patients with osteoarthritis of the knee and hip (The Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) [37]); assess quality of life (SF-12 [53] and EQ5D [13]); measure the perceived pain (S-LANSS [8]); evaluate self-care (Barthel index [34]); and self-report in case of mental disorder (TiC-P [11]). Moreover,

[5] https://github.com/Netflix/zuul/wiki
[6] https://cloud.spring.io/spring-cloud-security/

suitable questionnaires for self-care, health-status, asthma control, illness perception, and self-assessment have been properly defined inside the project.

- **Health status.** Medical devices from by Nokia/Withings have been integrated in the system via the Third party *µcroservice* (see below). Moreover, the patient may manually add a measure taken with a device without connection. The patient receives a reminder any time s/he has to take a measurements. Collected data are stored in the self-management system to be accessed by the patient for revision as well, as sent to the professionals for follow-up.
- **Simple tasks.** The following activities may be prescribed to be performed by the patient at home: straightening and bending the knee while lying on the back; keeping the leg away from the body while lying on your back; lifting the pelvis lying on the back with bent legs; lifting the leg upright while lying on a side; bending the knee and bringing it to the stomach while lying on the back; bending the knee in the sitting; bending the knees standing with the back to the wall; straightening and bending the seated knee; getting up from the chair and sitting back; walking outside at moderate speed; up and down stairs; strengthening the thigh; strengthening the elbow, buttocks, and fingers; training session for physiotherapy; drinking water; easting a fruit; playing cognitive games; and visiting a nurse at the clinic.
- **Drug prescriptions.** The CONNECARE project involves 3 countries: Spain, Israel, and The Netherlands. Accordingly, the *µservice* aimed at following-up drug prescriptions is connected to the lists of drugs available in the corresponding hospital information systems in the 3 countries. In so doing, the professional may select the drugs to be prescribed from an granted list. The patient receives that prescription and confirms when s/he takes it. In case of low adherence a message is sent to both patient and professional.
- **Advices and training material.** Each clinician in charge of a case may select a document, video, image to be shared to the patient for consultation. The patient may create her/his own list of bookmarks to have a direct access to relevant information any time is needed.

– Supporting services
  - **Notifications.** This *µservice* receives the notifications generated by any of the rest of *µservices* and which recipient is the patient (e.g., a new prescription has been generated). Through the Notifications *µservice*, the corresponding message is sent to the app for its visualization. Moreover, complex notifications that come from the interaction with the patient's monitoring *µservices* may also be sent. In fact, a reminder is sent before any required task (e.g., 15 minutes before taking the blood pressure) and a confirmation given after any performed task with suitable information (e.g., the value of the blood pressure).
  - **Alerts.** Monitored data are continuously analysed at runtime. As soon as a patient's monitoring *µservice* finds an anomaly, it interacts with the

Alerts μ*service* and a suitable alert message is sent to both the patient to be aware of the issue and the clinical staff to be informed and act accordingly. In particular, anomalies are triggered any time data gathered from the patient (e.g., through the medical devices or a questionnaire) exceeds a given threshold defined at prescription time (e.g., a critical heart rate value).

- **Recommendations.** All data gathered by the devices worn by the patient are automatically analysed to give an intelligent support. The Recommendation μ*service* provides suitable recommendations to patients. In particular, this μ*service* is designed and developed to provide support to patients in each of the required tasks. Both a distributed and central solution is adopted. On the one hand, each patient's monitoring μ*service* will contain its own recommender system. On the other hand, thanks to the interaction and collaboration of all the patient's monitoring μ*services*, advanced recommendations could be given aimed at giving support at a broader level. Currently, a specific recommender system for physical activity support has been defined and designed. The description of the recommender system is out of the scope of this work, the interested reader may refer to [19].
- **Third party.** In order to provide patients' monitoring, also the integration with third parties elements, such as wearable and medical devices, has be considered. This μ*service* has two main functionalities: managing the connections to the external providers and the standardization of the data model. By using standard communication and authorization protocols, such as OAuth[7], data shared by the patient from these third parties can be gathered. The μ*service* saves all the connection information and hide the details to the μ*services* that need information from them. Regarding the standardization of the data model used inside the system, each third party uses its own data model to obtain the information from them but this μ*service* transform the model to a common model used by all the connected third parties. In this way, the μ*services* only have to ask for the information to the third party connector and wait for a well-known message with the data of the patient without to worry about the communication process and the different data model used. In so doing, the *Third party* μ*services* works as an abstraction layer.
- **Messaging.** This μ*service* offers a bidirectional communications tool that allows patients to interact with the member of the medical staff in charge of the case. Similar to the well-known Whatsapp app, patients may send/receive text, images, videos, links, and documents.

3.2 The Current Prototype

The corresponding self-management system is an app currently available on the markets (both Android and iOS are supported). It is currently adopted in clinical

[7] https://oauth.net/

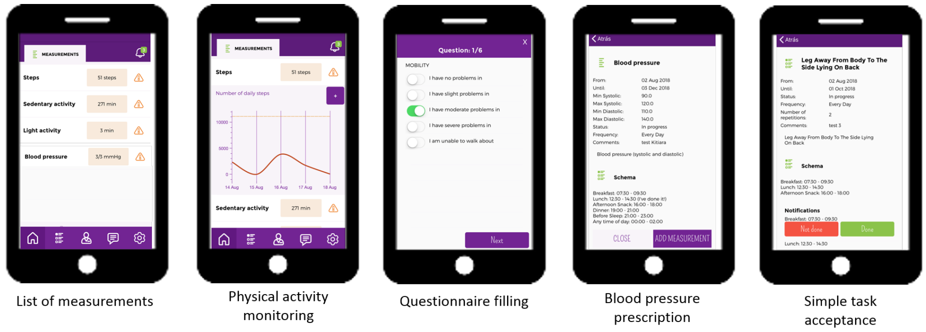

Fig. 3. Screenshots of the current prototype. From left to right: list of measurement under monitoring; physical activity monitoring of the last 5 days; first item of the EQ-5D questionnaire; prescription of blood pressure with the possibility to add a measurement by hand; and acceptance/rejection of a prescribed simple task.

studies started in May 2018 in Lleida, Israel, and Groningen. At writing moment, about 30 patients are using the self-management system and are monitored by the corresponding clinicians.

The current version of the app implements the first 4 monitoring functionalities listed above: physical activity, questionnaires, health status, and simple tasks. Figure 3 shows some screenshots of the current prototype.

4 Discussion and Future Directions

Researchers on patient's self-management agree with Clark et al. on the main features that a self-management tool has to implement to give support in chronic diseases by older adults. In the EU project CONNECARE, following a co-design approach, professionals, technicians, and patients defined the requirements of a self-managament system aimed at empowering complex chronic patients. Most of the features identified by Clark et al. have been listed also in CONNECARE: maintaining exercises and activity levels; monitoring physical indicators by objective means; recognizing and responding to symptoms and controlling triggers to symptoms; drug prescription and follow-up; using strategies to relax and reduce stress; managing emotions and psychological response to illness; interacting with healthcare professionals; managing alerts and emergencies; and seeking information and using community resources. Starting from these requirements, a technological solution based on the concept of *µservices* has been defined and developed. The corresponding system is currently running in 3 sites (i.e., Lleida, Israel, and Groningen) throughout real implementation studies. About 30 patients are using it.

Future work is planned following three directions: 1) from the backend perspective, the *µservice* for providing virtual visits is under definition; 2) from the front-end point of view, the app is under development to include the drug prescription and the advices and technical material *μservices*; and, 3) for the sake of evaluation, after the studies patients will be asked to answer to the User Experience Questionnaire.

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