

iCARE - Telematic Platform for Network Management of Pediatric Patients with Incurable Disease and High Complexity Care

The Ligurian Experimental Model

Luca Bianconi, Cristiana Degano, Matteo Toma

R&D Business Unit
Gruppo SIGLA S.r.l.
Genova, Italy

e-mail: luca.bianconi@grupposigla.it,
cristiana.degano@grupposigla.it,
matteo.toma@grupposigla.it

Riccardo Berta

Elios Lab, DITEN, Università di Genova
Genova, Italy

e-mail: berta@elios.unige.it

Luca Manfredini⁽¹⁾, Federica Penco⁽¹⁾, Sandro Dallorso⁽²⁾, Paolo Petralia⁽²⁾

⁽¹⁾Centro Regionale di Riferimento di Cure Palliative e Terapia del Dolore Pediatrico,

⁽²⁾Istituto Giannina Gaslini
Genova, Italia

e-mail: lucamanfredini@gaslini.org,
federicapenco@gmail.com
sandrodallorso@ospedale-gaslini.ge.it,
paolopetralia@ospedale-gaslini.it

Abstract— The Information and Communication Technologies (ICT) support service to the activities of home care has, as its main objective, the creation of a technological tool aimed at improving the operation and the quality of home care services for pediatric palliative care. In particular, it will provide a tool to support the performance of the core activities required to provide assisted home care of excellent quality and, to clinicians, a whole process management system able to ensure simplification and efficiency.

Keywords-Telematic; mHealth; IoT; Home Care.

I. INTRODUCTION

iCARE has been designed and is under development within Health@Home (H@H) project, funded by the Italian Ministry of University and Research (MIUR) as part of the Smart Cities and Communities Call, and whose goal is to create assistance services to citizens based on a network of integrated services in the health, territory, and society filed, through the use and implementation of interoperable devices and systems [1].

The development of information technology solutions for the collection, processing and use of critical data, can provide a very useful support to the young patient, family and clinicians. Furthermore, the telemedicine, so as the m-Health applied to the field of Paediatric Palliative home-care may allow the patient and his family to interact effectively and real-time with the medical team (local and the one of reference center) through a remote control of the different phases of the care process, from diagnosis to treatment.

In this context, iCARE will be a telematics platform for the management of pediatric patients with incurable disease and with high-complexity care needs.

Particularly, iCARE platform firstly aims at the realization of a system able to ensure adequate quality of services by improving and optimizing the situations described previously and the process that characterizes them.

Secondly it aims to avoid unnecessary house calls, reducing the feeling of hospitalization and, while ensuring security in the continuity relief, facilitate the stay of patients at home and reduce improper hospitalizations.

Because the research project is currently in progress, we can here propose a short presentation of the iCARE platform dealing with the main end users' required functionalities and the first application implemented.

This paper is composed of Section II that describes the clinical context and functionality, and of Section III, in which the two main applications are described: *Home Care management system* and *Mobile Diary*.

II. CLINICAL CONTEXT AND FUNCTIONALITY

The context within iCARE platform will be developed for the home-care services and is for the palliative care at home of *Giannina Gaslini Institute* that treats pediatric patients at their residence or at care facilities (in the case of children coming from outside the region), administering first-line treatments and, if necessary, appropriate palliative care.

In this context, one of the main objectives of the research is the development of a tool based on the so-called *Family Centered Care* [2].

Since iCARE belongs to the so-called *Digital Medicine*, the system will provide the following functionalities:

- Communication among patient and Medical Doctor (MD)
 - Doctor's visit
 - Drug prescription and administration
 - Warning of complicated health status
 - Knowledge exchange about therapy
 - Visit recording with automatic generation of the report
 - Storing and sharing of visits performed
- Communication among MD and MD

- Management of the patient's medical staff
- Sharing of not solved problems and important information about
- Countersign of drug prescription
- Patient's electronic diary (clinical events, therapeutic events, etc.).
- Patient's information management.
- Automatic and semi-automatic warning of MD actors relating with particular situations.

III. APPLICATIONS

It is mandatory that iCARE platform must satisfy the following requirements:

- Appropriate interface between the biomedical devices at home and the data transmission systems.
- User friendly system providing clinical information to the young patient e family (taking into account cultural and linguistic differences).
- IT protocols for the storage of data, coming from home devices, in the medical record system belonging to the *Reference Palliative Care Center*.
- Clinical and Information Technology (IT) protocols to analyze the collected data and to verify their accuracy and quality.

In order to provide the functionalities mentioned in Section II and to satisfy the abovementioned requirements, two applications have been developed: *the Home-Care management system* and *the Mobile Diary*.

A. Home-Care management system

The main functional requirements provided by the *Home-Care management system* are:

- Management and tracking of therapy.
- Management of clinical intervention at home.
- Noninvasive data collection about health status of the young patient.
- Efficient communication among the young patients (young patient and his family) and the medical staff (oncologist, pediatrician, nurse, healthcare assistance, etc.).
- Sharing of therapy data among the actors belonging to the medical personnel (MD of *Reference Palliative Care Center*, specialized MD, MD of palliative care, pediatrician, etc.).

The system is accessible through the family's device(s) such as personal computer, tablet and smart phone, while data will be processed and managed centrally via cloud technologies. Furthermore, the system is composed by a front-end, dedicated to users, and by an administrative back-end. Back-end access to the different functionalities is regulated through roles and authorizations based on the users' categories.

B. Mobile Diary

The *Mobile Diary* is the first application implemented. It is the user's (patient, family, medical personnel) interface providing the described functionalities. Particularly, it is an

application that has been developed to record and monitor the daily clinical and psychophysical status of the patients.

The use of *Mobile Diary* allows the patient, family and medical staff to answer to ad-hoc questionnaires through a dedicated interface, and to fill information related to the clinical parameters and drug therapies associated with the pathology and the adopted treatment protocol. On the other hand, the *Mobile Diary* allows the MD staff to create and manage new kinds of questionnaires, to analyze collected data and to export them in different format through a back-end that is accessible by the MD staff only.

Then, the application is composed of two different interfaces: the interface devoted to the patient and the administrative back-end devoted to the MD staff.

The interface for the patient is available in two ways: as a Web application (thus accessible through a common web browser) or as a mobile application itself. Both client types provide the same functionality.

To the contrary, the administrative back-end takes the form of a Web portal for administration and management of both questionnaires and data collected. Its natural means of fruition is the Web browser.

The application is still accessible via the mobile device (smartphone and tablet) so as from any other device equipped with a browser and Internet access.

The data generated and processed by the system will be managed centrally via cloud technologies.

The system provides the following features:

- Interaction with questionnaire (creation, management, publication, response).
- Data analysis.
- Monitoring of physical/psychophysical status of critical events.

IV. CONCLUSIONS

The reduction of the residence times in the hospital and the costs associated with them will result in an improvement of the conditions of patient's safety and comfort.

Particularly, the home-care service will allow to:

- rationalize and improve the management of clinical and therapeutic data of the patient by ensuring appropriate access to people involved in the various phases and assistance situations.
- improve the availability of communication between assisted care facilities and patients, ensuring efficiency in communications and non-invasiveness of the same.
- improve the lifestyle of patients, each actor of the care process will help, according to the tools provided by the system, to provide additional data in support of care activities, sometimes also as a preventive perspective.

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