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Modelling, designing, and implementing a family-based health record prototype

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ABSTRACT

Within the arising and fast growing trend of the personalized healthcare, the promising Personalized Health Informatics (PHI) asks to be understood, modelled, implemented, and tested. The central idea of "keeping healthy lifestyle", that grounds the development of PHI systems, needs to be extended to the digital family group, where the middle generation (the "parents") manages the responsibility of taking care and improving the health of the weaker members (children and grandparents). The family environment is also a fundamental indicator of disease risk. We modelled, designed, and implemented a prototype for the health data management in a multigenerational family environment.

1. Introduction

1.1. Personalized Health Informatics

Personalized Health Informatics ("PHI" thereafter) is the aggregation of the Information and Communication Technology (ICT) tools – concepts, methods, and devices – able to help the gradual but comprehensive making of the personalized Health (pHealth) [1]. PHI products aim at making easier at the patient level the use of his healthcare data—anywhere, anytime, anyhow, also when stored into institutional data warehouses. An additional aim is to charge the patient of the ancillary and peripheral caring of his clinical documents and data, involving him at a suitable responsibility level.

Through a huge number of capabilities, stemming from the micro and nanosciences, Information and Communication Technologies (ICTs) PHI can be accomplished. The electronic health record (EHR) is one of them. EHR in PHI lead to the definition of the *personal* health record (PHR): "An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment" [2]. The idea of individuals collecting, organizing, and keeping in file folders their own, historically paper-based, medical documentation is not new. The spread of the ICTs and the Internet has made this idea feasible using personal computers, personal digital assistants or smartphones. Something to be "consumer centred", open to something more than illness – e.g., lifestyles, nutrition, health information, evidence-based guidelines, drugs assumptions, etc. – and designed for keeping the citizen healthy is needed.

Compared with EHR's definition, the proposed definition includes several aspects characterizing PHRs. First, there is no reference to the "patient", but the main actor is the "individual", i.e. a "consumer". Second, PHR systems are intended for providing information on individuals' healthcare, whereas EHR systems provide the information needed by healthcare professionals. Third, PHR can be used for maintaining health and wellness of an individual, but also of all the others for whom this individual is authorized [2]. Finally, PHR cannot be considered as a static data repository, but it is composed by "data, knowledge, and software tools" for helping people in taking an active role in their own health. A further point relates to the reliability of data stored in the PHR: PHR architecture requires that the individual who uses the system enters data. This implies that the quality of entered data strongly depends on what is stored, on the individual's general and health literacy, and on his personal motivation for collecting health documentation.

1.2. Recent approaches to personalized health record

In the international scenario several approaches to PHR were proposed, each focusing on a specific aspect of health-data management.

In a consumer-perspective study [3], authors evidenced the elements perceived as most important by the users when approaching computer-based medical records. These include

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individual control on data, information sharing and integration, security, and flexibility.

Many systems were designed according to these indications: in [4] authors proposed a system able to overcome the so-called "digital divide": they implemented and evaluated a web-based patient-centred electronic health record system at the housing authority setting. The system was tested on an elderly and computer-inexperienced population that, thanks to the use of community-based resource sharing and support strategies, and thanks to the assistance from graduate nursing students, demonstrated to be able to manage personal health information. This work demonstrates that training and technological support are essential aspects for the success of a PHR system, especially when the target user does not have enough ICT skills to manage the system, as in the case of elderly people.

The family/house as a preferential environment for healthcare was fully described in [5]. Authors found that the work of health information management in the household is largely the responsibility of a single individual, primarily engaged in the tasks of acquiring, managing, and organizing a complex set of health information [5]. Paper-based tools are common, and residents develop strategies for storing information in the household environment aligned with anticipated use [5]. Web based applications for compiling PHRs are described in [6]. All these systems were not specifically designed for the family, as a single entity, and even though they address the access security requirements for PHR systems, they do not implement methods to verify the accuracy of entered data. Furthermore, the family was always considered as a set of unrelated individuals, without taking into account the common elements that characterize the family environment and relationships. In addition, the recent development of "My Family Health Portrait", a web-based tool for family health history storage has pointed out the family history as one of the cheapest, easiest, and affordable ways to monitor disease risk, both at the genetic and environmental levels [7].

1.3. The "family PHI" approach

The idea of "keeping healthy lifestyle" resides in each of the individuals belonging to a family. Of course, each of them declines such an idea according to own concepts, strength, and weaknesses. However, in any multigenerational family group ("vertical family"), the middle generation – let us name them "the parents" – usually has the responsibility of monitoring the health development of all the vertical-family components, i.e. children and grandparents included. In the pre-digital era, they already kept in order the textual paper-based and the film-based clinical documents. Parents are still requested to do such arrangement now, as a general aim. Of course: according to their skills. Fortunately, some of these skills are already digitally oriented. So, why not to use them for the better benefits of healthcare concerns of the vertical (multigenerational) entire family? In addition, besides the own personal health history, personal habits, and living environment that each member of the family has, some of the relevant elements are shared within the family.

For example, let us consider the family medical history of all the sons and daughters of a given couple of parents (Fig. 1). Such history is substantially the same for each sibling. Therefore, we may fill it once for all. Let us also consider that the living environment is frequently the same too, for parents and children. Again, we may fill it once for all. In addition, the domestic lifestyle frequently is almost the same for each member of the vertical family. Finally yet importantly, there could be health-related events able to affect the health of the whole family, such as a baby suffering of an infectious disease and inducing contagion. These are examples of "fill once and use many times" model, where ICT tools have been proved as useful. Further, data belonging to the family health history can enable the support to clinical decisions and requirements that EHR/PHR software applications should be satisfied have being defined [7].

It is common experience that who most needs medical care in a family group (children and elders, e.g. grandparents) cannot be granted to be skilled in ICT, at least enough to use a computer application for organizing and archiving their own medical data into a digital personal health record [8]. Conversely, the middle generation of the vertical family uses ICT instruments daily, at work or for personal interest, thereby being eventually able to organize the entire family healthcare data into a PHR computer application. The level of ICT skills is of course dependent on the educational level, on the position hold or the occupation, and on the general interest of the individual towards ICT issues. However, with a proper specific training, the basic knowledge and ability they have is enough for using a computer-based system for archiving and managing the digital clinical data of the family.

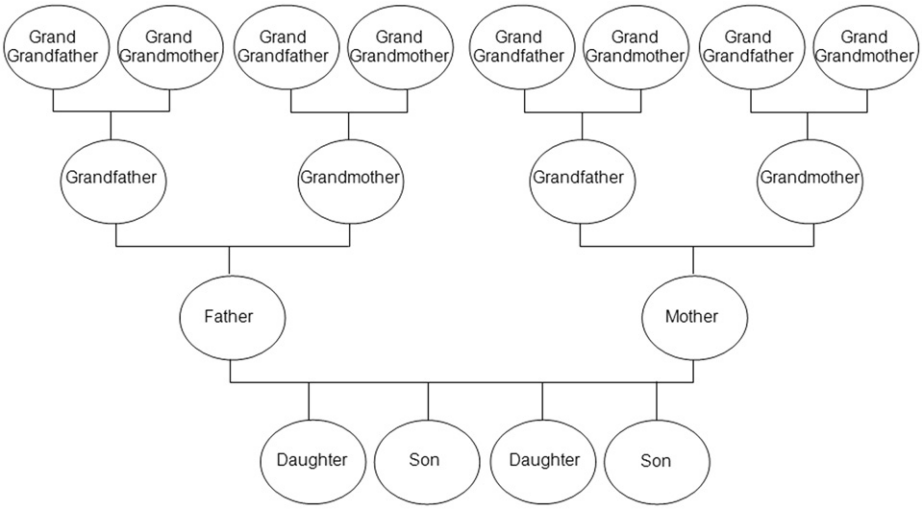

Fig. 1. A family tree for a multigenerational family (four generations are represented).