



Personal Health Records in Support of Anticipatory Care

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Abstract: In today's world, health and care data are held by doctors, patients, pharmacists, physician assistants, medical lab technicians, smart devices, etc. To provide high-quality health care, it is necessary to integrate an individual's health and care data into a single place. Such integration not only helps patients and doctors but also assists researchers in making significant studies. Personal Health Record (PHR) technology is a strong candidate for an integration point. Compared with other healthcare areas, the literature shows a lack of research that benefits the anticipatory care area. Thus, this study demonstrates the capacity of PHR as an integration point in supporting the anticipatory care area. This paper introduces a designed prototype that uses PHR to support anticipatory care. The prototype also includes aspects from a personalized care planning process model and a shared decision-making model. After testing against a patient scenario, the results demonstrate the ability of PHR to support the interested stakeholders strongly. Interested stakeholders include patients, health professionals, and patients' families and friends. PHR as an integration point resulted in better planning, coordination, shared decision making, and controlling of patient's health condition. The interested stakeholders would be able to make plans that evolve as the patient's health condition evolves. Any patient who needs anticipatory care can benefit from this study as it is not limited to certain diseases. In addition, this study presents fruitful results that help researchers and developers in the area.

Keywords: PHR, anticipatory care, care planning, health condition

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I. INTRODUCTION

Personal Health Record (PHR) is a medical record that is controlled by the individual. The difference between PHR and Electronic Health Record (EHR) is that health care institutions are the ones who own and control EHR [1]. The American Medical Informatics Associations College of Medical Informatics and other researchers recommended to include data such as personal information, major illnesses, allergies laboratory tests, appointments and family history in PHR [1, 2, 3, 4, 5, 6].

PHR stores complete health information that enables patients to control their health conditions better. PHR helps in tracking diseases effectively and responding early to problems. In addition, it equips health professionals with valuable information. PHR resulted in improved

communication between patients and health care professionals [1, 7]. This study addresses anticipatory care area which focuses on preparing for anticipated changes that might affect the patient's condition negatively [8]. Anticipatory care is often used with patients who suffer from long term health problems [9]. In this paper, we first review the most important concepts that are related to anticipatory care: care planning and shared decision making. We review two important process models that are used in this study and a relevant existing example. We then propose a prototype that includes the two reviewed process models' aspects. The prototype overcomes the limitations of the existing example. We conclude the paper by a discussion and suggestions for future work.

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II. LITERATURE REVIEW

A. Care Planning

Care planning is an important concept, especially in anticipatory care area. It encourages providing health care that considers both health professionals' knowledge and patient's preferences. Care planning is done by having a discussion between a patient and his/her health professionals about an action plan. It includes deciding on the roles and responsibilities of team members [10, 11, 11]. [12] presented a personalized care planning process model that tailors support and planning to patient's concerns. The model has seven steps: preparation, goal setting, action planning, documenting, co-ordinating, supporting and reviewing. The purpose of the preparation step is to recognize the patient's health condition. This might include discussing relevant information such as treatment options and diet. The aim of goal setting step is to identify a set of goals that take into account the patients preferences. A plan is developed in action planning step. This is followed by documenting step to document the needed actions.. In co-ordinating step, the patient is provided by all the inputs that come from other members or organization in a well-co-ordinated way. In supporting step, a schedule for follow-up sessions is set to provide the needed support that can take any form depending on the patient's condition. The purpose of reviewing step is to check patient's progress and decide on future actions. Such personalized care planning model is suitable for

anticipatory care area context due to several reasons. It is obvious that it makes planning and coordination easier and more efficient. The model follows an organized way and helps to capture sufficient information. In addition, it gives high priority to the patient's preferences. Thus, this study includes this personalized care planning model in the designed solution.

B. Shared Decision Making

Because decision making is a key concept in anticipatory care, it is necessary to explore ways to apply it in the proposed solution. One way to ensure shared decision making is to follow the model proposed by [13]. The model aims to move from initial preferences position (based on existing knowledge) to informed preferences position (based on understanding after discussions). The model begins with choice talk step to inform the patient that there are available options. The second step is option talk which aims to describe the available options in more detail. Finally, decision talk step focuses on providing the needed support that enables a patient to decide and form preferences [13].

C. Option Grids

Option Grids is an existing tool that can be used to give more information about options. It lists the available options in a tabular format and compares between them. The comparison is based on patients' frequently asked questions [14].

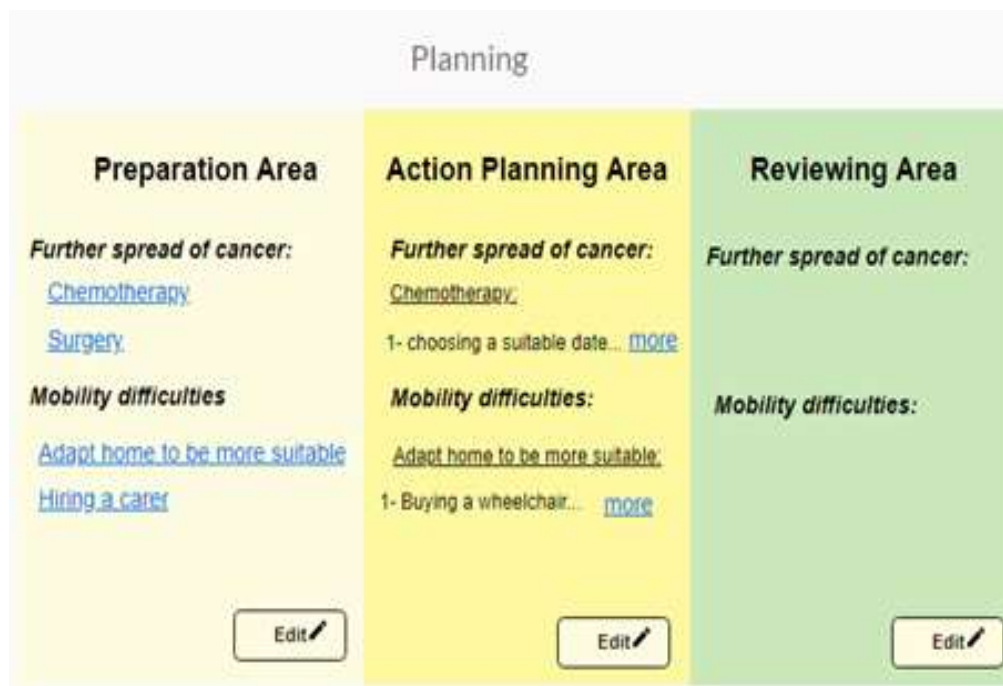


Fig. 1. Planning interface

While Option Grids tool has several advantages, it is not able to work effectively with anticipatory care context. It needs some modifications to improve its performance. One serious problem with Option Grids tool is that it is static. Patients who suffer from a certain health condition are provided with the same information. Such an approach is not accurate as it does not consider other health problems and the stage of the condition which might limit the availability of some options. Another drawback is that the only members who identify the comparison criteria are health professionals. It is better, especially with anticipatory care, to allow patients, social workers, and families to identify their criteria.

III. METHODOLOGY

For the purpose of this study, a simple prototype which consists of a set of interfaces has been designed. The aim is to design a solution that combines several important concepts and models to improve the quality of anticipatory care. The designed prototype can be implemented later as part of hospital systems or as a standalone application. The prototype embodies that important concepts discussed in this paper. It is designed so that each stakeholder has an account and different interfaces. The patient account enables the patient to write goals and preferences. It also contains the PHR which consists of several categories (such as lab results, appointments, etc.). The most important interface for patients is planning interface which consists of three sections: preparation area, action planning area and reviewing area (Figure 1). In the preparation area, a health professional adds the expected changes that might occur to his/her patient. A health professional adds the available options for each expected change. In order to compare between options, each option has a list of criteria that can be edited by any stakeholder. Action planning area contains the agreed plans for the chosen options. Reviewing area illustrates plans reviews. The prototype also includes interfaces that allow a member to add other members to his/her profile and exchange messages with other members.

IV. DISCUSSION

A scenario has been used to test the capability of PHR in supporting anticipatory care and the important concepts that surround it (planning and shared decision making). The scenario has been written to cover a health condition for a patient who needs anticipatory care. The scenario is as the following:

Steve is sixty nine years old. Steve is married to Sharon. He suffers from lung cancer, arthritis, and

diabetes. He also has breathing difficulties. Steve takes medications to treat anxiety. Sharon is worried about managing Steves condition, especially that his doctor (Dr. Nelson) does not have enough information about Steves current and previous health conditions.

The idea of this study is able to support a patient with such a scenario by using PHR. Dr. Nelson can use Steve's PHR to be aware of Steve's previous and current condition and problems. Dr. Nelson would be able to provide better options and decisions after viewing such a clear and coherent record. This would also bridge the annoying gap between Steve and Dr. Nelson. Steve and Sharon would be more comfortable because they know that Dr. Nelson is familiar with Steve's condition. They would also be confident as they will be informed early about the expected changes, available options, and suitable actions. It would be able to set and review plans that are based on scientific evidence and consider Steve's preferences.

Steve can add his preferences in his account to make them clear for other team members. To start planning, Dr. Nelson needs to refer to Steve's PHR. This would help in adding the expected changes in the preparation area section. Each expected change needs to be supported with the available options. In order to list the available options, Dr. Nelson also needs to check Steve's PHR that might limit the availability of some options. Dr. Nelson might add "further spread of cancer" as an expected change and "chemotherapy" and "surgery" as options. For chemotherapy option, Steve can add "Does it have side effects?" as a criterion to chemotherapy option. Dr. Nelson can answer by writing "yes, this includes weight and hair loss". To add a new plan, Dr. Nelson should refer to Steves PHR to view the recent problems and test results. Also, Steve's preferences that are stated in his profile should be taken into consideration. The team needs to meet to discuss the actions. If Steve prefers chemotherapy option, the actions might be as the following:

1- Choosing a suitable date to start chemotherapy. Assigned to: Dr. Nelson, Steve, and Sharon.

2- Having a meeting to discuss important information about chemotherapy one week before the chosen start date. Assigned to: Dr. Nelson and Steve.

Team members can update the reviewing area to document the progress. For instance, Dr. Nelson can write that the start date of chemotherapy will be on the first of September 2018. Team members can constantly edit preparation, action planning and reviewing areas to get a dynamic plan that evolves as Steve's health condition changes.

V. CONCLUSION

The designed prototype for this study incorporates important concepts such as personalized care planning and shared decision making. It also overcomes the limitations of Option Grids tool. It is clear from the test that using PHR as an integration point plays an important role in supporting anticipatory care. PHR features contribute positively in providing better planning, shared decision making and controlling patients' conditions. The proposed prototype presents fruitful results that assist researchers and developers who are interested in the area. It is suggested to use innovative ways such as data visualization to aid planning and decision making. Also, it would be beneficial to work on the governance of data aspect.

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