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Developing Ghasedak: a Mobile Application to Improve the Quality of Cancer Palliative Care

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ABSTRACT

Introduction: Today, new health care models are being proposed with the aim of reducing hospital beds and providing services in primary facilities and homes. These models are developed with the focus on the patients and towards their self-management and self-accomplishment of the activities. Among these, Mobile Health Technology seems to be appropriate for making a new model in palliative care and in different types of care, in general. Palliative care Application (app) can pave the way for promoting the patients' knowledge and thus improving their quality of life, which, in turn, can provide appropriate care at the end of the patients' life. **Aim:** This study endeavored to develop the initial version of Mobile Application for cancer Palliative care for the purpose of improving the quality of Iranians' life. **Methods:** A mixed method study was conducted in three Phases as follows: 1) comparative study of current mobile applications; 2) developing an object-oriented conceptual model for mobile apps; and 3) developing the initial version of Ghasedak (Ghasedakis the Persian word stand for "Dandelion") approved for production. **Results:** Ghasedak was developed for the appropriate cancer self-care, with such functionalities as user training; including cancer definition, cancer factors, its signs and symptoms, types, prevention, cure, adherence to the constraints, strategies for reducing anxiety and overcoming fear, definition and importance of palliative care, management of physical, psychological, social as well as spiritual complications. Ghasedak also includes Clinicians appointment reminds, personal health, user guide, application setting, and patient notes. **Conclusion:** Ghasedak was developed in compliance with Iranian experts' opinions. It seems it would be of help in self-care of patients with needed to palliative care.

Keywords: Palliative Care, Neoplasms, Mobile Applications, Mobile Health.

1. INTRODUCTION

Patients who suffer from cancer experience multiple physical and mental signs and symptoms such as pain, weight loss, appetite loss, depression and anxiety, which often affect their quality of life. In view of that, one of the most important aspects of caring patients with cancer is an appropriate control of these symptoms, which requires ample interdisciplinary palliative care (1) as the main right of every patient (2) to improve the patients' and their families' quality of life in the face of life-limiting diseases. This way, a scene can be set by preventing and improving the suffering of the patient, early detection of pain and its treatment, as well as other physical, psychological and spiritual problems of the patient (1-3). Every year in the

world, 5.6 million people with cancer need this palliative care (2). More than 90% of patients with fatal illness are in the quest for a calm death in an environment similar to their own home conditions; however, even in developed countries, only 20% to 30% of patients died at home, and it is estimated to decrease by 10% by 2030 (4).

Increasing demand for palliative care, lack of suitable resources, and inadequate investment leads to the utilization of new approaches to palliative care (5). The goals of these approaches include reduction of hospital beds, provision of services in primary facilities and homes, shift to patient self-management, and self-care (6).

Mobile applications (apps) are considered one of the effective tools for achieving these goals and evolution

Figure 1. The applied model of Ghasedak

in palliative care (7). For example, palliative care mobile app provided patients with metastatic breast cancer, a high level of satisfaction, improved care quality and communication, as well as reduced costs and medical errors (8).

Despite the growth of mobile health, a limited number of these apps are devoted to chronic diseases and cancer. For example, a study on the application use rate showed that 63% of them were devoted to diabetes and only 5% of them to cancer (9).

2. AIM

Regarding the need for palliative care for cancer patients and, on the other hand, the effective role of mobile apps in improving health care and their limited number, we developed the initial version of the palliative care mobile apps for cancer patients.

3. METHODS

This mixed-method study was conducted in three phases from 2017 to 2018 as follows:

Phase 1: Comparative study of some existing mobile apps and providing a comparative model for Iran: In the first step of this phase, we searched for palliative care mobile apps and their related articles to identify features of the apps. In this step, we analyzed the content of 27 mobile applications because of the easy installation and availability.

In the second step, the common extracted features were selected for a comparative model of Ghasedak. To confirm the validity of the comparative features, attributes and functionalities, a research-made questionnaire was developed on the basis of the selected entities. The reliability was calculated through Cronbach's Alpha and it was $r=0.92$ and content validity of the questionnaire was confirmed. Then, the questionnaire was distributed through Delphi.17 experts of health information technology and 20 oncologists filled out the questionnaire, which, in turn, set the scene for data analysis.

In the third step of this phase, the comparative model of Ghasedak was developed by the participants.

Phase 2: Developing Ghasedak' object-oriented model: In the first step of this phase, to design the conceptual model of the initial version of Ghasedak, the expert panel decided to choose common features of comparative model (with the minimum agreement of 75%). This way, in this step, 30 features were selected.

In the second step, the conceptual model of Ghasedak was designed through drawing Unified Modeling Language (UML) diagrams, which include three kinds of diagrams like this: Class, UseCase, and Activity diagrams.

Phase 3: Developing Ghasedak: In this Phase, using Android Studio, the initial version of physical model for Palliative Care Mobile Application was developed on the basis of the findings of comparative and conceptual model. The developed application can be installed on Android operating system version 4–8.

4. RESULTS

By content analysis on 27 different models, 30 features were extracted. Some features had commonly been used in different apps, but others had been used unique in some models and received special data from the users. After Delphi technique, the agreement was done on the required features of the initial version of Ghasedak, including, User training (Cancer Definition, Cancer Factors, its Signs and symptoms, Types, Prevention, cure, Adherence to Its Constraints, Strategies for Reducing Anxiety and Overcoming Fear, Palliative Care Definition and Its Importance, Management of Physical, Psychological, Social and spiritual complications), Clinicians Appointment Reminds, personal health, user guide, application setting, and patient notes (Figure 1).

5. DISCUSSION

Findings revealed that there was no proactive palliative care mobile app for cancer in Iran. Hence, Ghasedak was developed as a researcher-made palliative care mobile applications.

Regular training to the patient is recommended to relieve pain of cancer. Over time, Individualized training

can effectively improve pain management for patients from varying diagnostic and demographic groups, who suffers from cancer (10-11). Palliative care can be defined as an umbrella term to cover all needs of patients with cancer to improve their quality of life, relieve their physical pain, boost evidence-based treatment, reduce unnecessary medical treatment and prevent medical errors (12-15). Therefore, in Ghasedak patient training functions was developed; this provides physical, mental, social and spiritual training on a variety of issues, including cancer understanding (its signs & symptoms, types, prevention, diagnosis & treatment, and living with it) and familiar with palliative care (its definition, importance, & managing physical, mental, social & spiritual side effects of cancer. These materials ensure patients of their independence and ability to do things for the rest of their life, especially when current therapies are useless. To achieve better outcomes, spiritual training along with medical treatment can improve patients' mental health, their quality of life and wellness (16).

When a patient encounters with an out of control situation, one attempt to gain a powerful force to control the situation (17). Spirituality, as one of the health care dimensions, can be a strong source of coping and can help patient with cancer to understand the disease, find the goal and hope in life and overcome the uncertain living conditions (18, 19). Ghasedak attempts to boost the spiritual beliefs to obtain a good result from any situation, even a serious condition and it can lead to the transcendence of the person's life. Given the nature of the cancer threat, its diagnosis gives rise to a spiritual crisis for the patient and his faith is compromised.

Lack of communication leads to increase in stress level, reduce satisfaction and accuracy in medical prescribing. To achieve quality care, continuous reporting of signs is essential (10). In palliative care, proper sharing of signs, leads to informed and high quality care, and more patient involvement in care process and encourages one to be treated, as well as reducing transportation costs and repeated treatments and facilitating patient-provider communications (20-26). Ghasedak gathers and shares patient's individual health profile, such as pain, appetite, anxiety, constipation, and nausea and thus, leads to an accurate assessment of signs, and informed continuous care.

6. CONCLUSION

Today, despite the importance of palliative care, providing this kind of care has become a major challenge to the health systems (2) and its inappropriate distribution has given rise to the patients' inadequate access to the services (2, 25). Lack of patients' and their families' knowledge about care plans as well as patients' reluctance to undergo unnecessary tests bring about situations wherein getting care becomes more complicated; so, inefficient care may lead to a progressive degeneration of the disease and to strengthen the taboo of death for the patient (27, 28).

Ghasedak provides cancer-related information, from prevention to treatment, and palliative care from valid

resources, and supports the patient's training and psychological needs to provide a care. Moreover, it can send patient's individual health data to physician to improve quality of care and reduce time spent on examinations and assign more time to patient care. As a result, (t supplements the provision of palliative care and plays an effective and undeniable role in improving palliative care.

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