The Design and Implementation of a Breast Cancer Information System in Iran

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ABSTRACT

Background: Increasing incidence of cancers, particularly breast cancer (the third cause of death in Iran), the role of information in decision making, policymaking and planning, and the need to assess the status of breast cancer in the country and the world necessitated a research to describe the advantages and disadvantages of the existing information on breast cancer patients. The present study examined the effects of implementing an online management system for breast cancer treatment to resolve the current challenges.

Methods: This applied study involved preparing the proposal and designing the study protocol, providing the stakeholders with details, obtaining the required approval from the Policymaking Council of the Ministry of Health, designating the secretariat of the center for breast cancer educational management, research, and treatment under the supervision of the Deputy of Research and Technology, software design and production, determination of laboratories where immunohistochemistry-fluorescence in situ hybridization (IHC-FISH) tests were performed, identification of drugstores distributing Trastuzumab across the country, and presentation of the final software for integrated online recording of breast cancer information.

Results: Lack of integrated information and absence of communication between relevant departments have resulted in inaccurate and untimely (and of course offline) recording of breast cancer information in the country. Launching the designed system and public participation can partly resolve the existing problems.

Conclusion: Our findings underscored the need for the implementation of an information and treatment management system for breast cancer in Iran. Such a system provides a powerful infrastructure for service provision to all laboratories, drugstores, and specialists who are eager to constantly monitor their patients. It also facilitates data analysis and access to information during decision-making by the managers and experts in different geographical levels.

Key words: Knowledge, Attitudes, Practices, Cervical Cancer, Screening

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Introduction

Appropriate management is a prerequisite for efficiency of health services. Facing rapidly growing demands while accessing constant or diminishing resources compels health sectors to achieve maximum results with minimum resources. Meanwhile, proper management requires an effective information system with valid and high-quality (accurate, timely, and comprehensive) information. Obviously, correct application of more suitable information by managers will improve the provided services and ultimately promote health[1].

Cancer is expected to be a greater global burden of disease in the coming decades. The annual number of new cases of cancer is predicted to reach 15 million people among whom nearly 60% will reside in less developed countries.

Cancer is the second cause of death in developed countries and the third in developing countries[2]. Currently, more than 25 million people are suffering from cancer all around the world. Over 11 million cases add to this number each year and the disease is responsible for seven million annual deaths[3]. Studies have shown that cancer is the third leading cause of death in Iran and kills more than 30,000 Iranians every year. Besides, the country witnesses roughly 70,000 new cases of the disease per annum. Still, the incidence of cancer is believed to rise dramatically during the next decade as a result of enhanced life expectancy and increased number of the elderly in the country. Such conditions will not only impose a great burden on the health system, but also exert huge psychological and economic impacts on families and the whole society[4].

Breast cancer accounts for a large percentage of morbidity and mortality in the world. It is the most prevalent type of cancer among women from Iran and all other countries. Its incidence rate is about 38 per hundred thousand people in the world and 25 per hundred thousand people in Iran. In 2006, 6456 Iranian women suffered from breast cancer and the disease caused a higher mortality rate compared to all other cancers. Therefore, breast cancer prevention and management in the country requires the attention of health officials, policymakers, and planners[5-7]. Accordingly, cancer information systems have been developed in many countries. For instance, breast cancer databases in Korea include both cancer stage and tumor size[8]. Similar databases in the U.S. cover information about the affected sites and metastasis[9]. Cancer information systems in Turkey contain a combination of hospital information and demographic characteristics of Turkish patients residing in their own country and abroad, i.e. they have national and international aspects[10]. The rising incidence of cancers, especially breast cancer, in Iran (about eight thousand new cases every year) and the consequent economic, social, and psychological effects on the families and the whole society led to a presidential order to efficiently collect accurate and useful information for policymaking. The Ministry of Health was hence impelled to establish a breast cancer treatment management system for optimal treatment planning and management of the disease through reasonable administration of costly chemotherapy medicines including Trastuzumab. After adequate negotiations, the Minister of Health and the Council of Deputies assigned the Deputy of Research and Technology to implement the mentioned program. Thus, the Deputy of Research initiated the design and execution of a management system for breast cancer treatment. The aim of the project was to collect integrated online recording of cancer incidence and the related mortality.

Methods

After preparing the proposal and designing the protocol of this applied research and providing

the stakeholders with details, the required approval was obtained from the Policymaking Council of the Ministry of Health. Then, the secretariat of the center for breast cancer educational management, research, and treatment was designated under the supervision of the Deputy of Research and Technology. The next steps involved software design and production, determination of laboratories where immunohistochemistry-fluorescence in situ hybridization (IHC-FISH) tests were performed, identification of drugstores distributing Trastuzumab across the country, and presentation of the final software for integrated online recording of breast cancer information. The produced software was installed in drugstores, laboratories, and physician offices and used to electronically register the characteristics of patients with breast cancer since their arrival. In other words, patient records similar to electronic health records were created and patient information, e.g. demographic characteristics, laboratory and drugstore information, and follow-up results, was accurately collected. The information was uniformly accessible and transferrable from the collection site to the center. All users including experts and managers could use the information if they had been granted access.

Organizations and institutions participating in the project were as follows:

1. Deputies of Health, Treatment, Food and Drug, Research and Technology, Management and Resource Development, and Education of Iran's Ministry of Health and Medical Education
2. Statistics and Information Technology Management Center,
3. Universities and faculties of medical sciences and health services in Iran,
4. Medical Council of Iran,
5. Health reference laboratories,
6. Drug stores distributing anti-cancer medicines,
7. Pathology centers involved in cancer registration,
8. Insurance organizations,
9. Radiology, radiotherapy, physiotherapy, and rehabilitation centers.

Result

The implementation of the project resulted in the installation of breast cancer information management and care system in laboratories performing IHC and FISH tests in Tehran (n = 29) and 17 other provinces of Iran (n = 36) (a total of 65 laboratories). The system was also installed in five drugstores distributing Trastuzumab in Tehran and 60 similar drugstores in 17 provinces (a total of 65 drugstores). Moreover, Trastuzumab import and distribution companies were connected to the system and updated about the status of the consumed medicine. The stakeholders could also access the system to obtain the required information and prepare necessary reports. Afterward, the data were extracted from the system, entered into Microsoft Excel and demonstrated in the form of statistics and figures. According to the performed analyses, during the eight-month application of the system, a total of 2240 were registered in the 17 participating provinces. Overall, 229 physicians prescribed Trastuzumab.

Figures 1-4 summarize the data extracted during January-August 2011. The greatest number of tested patients was recorded in March and June 2011 and the lowest rate was observed in August 2011 (Figure 1). On the other hand, although the tested patients were different ages, 46-50- and 26-30-year-olds had the highest and lowest frequencies, respectively (Figure 2). In addition, the maximum number of patients who had received Trastuzumab belonged to February 2011 and the minimum number was seen in December 2010 and August 2011 (Figure 3). The difference between the numbers of tested patients and those who received medicine (Figures 1 and 3)

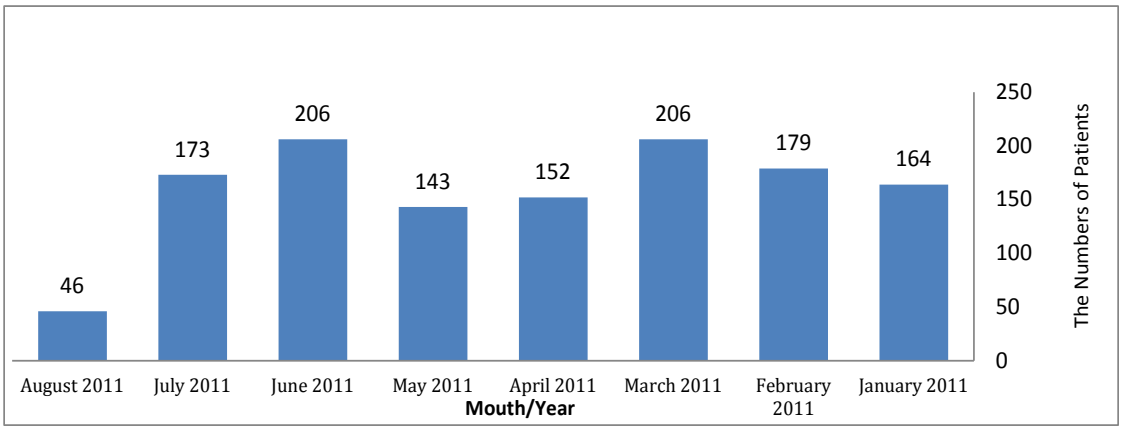

Fig.1: Monthly frequency distribution of tested patients

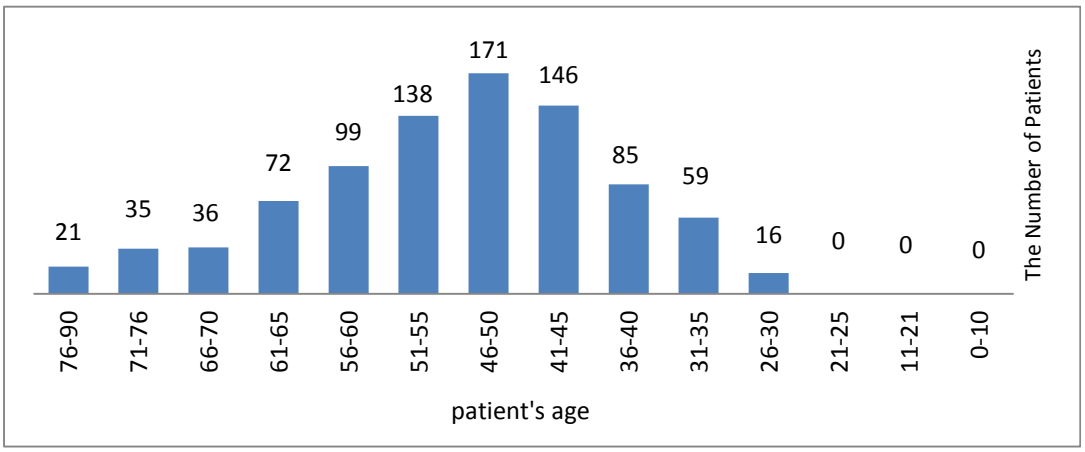

Fig. 2: Frequency distribution of the ages of tested patients

can be justified by the fact that not all tested individuals are obliged to receive and use the medicine. Finally, most patients who received the medicine aged 41-45 years and 76-90-year-old individuals had the least tendency to receive medicine.

Discussion

The majority of developed and developing countries have identified the significance of information systems in public health promotion through proper policymaking and micro- and macro-planning. In 2004, Enow-Orock et al. designed a system similar to ours to record cancer information in Yaounde, Cameroon. Comparison of the two systems suggests that while they both had comparable stakeholders, Enow-Orock et al. established close cooperation with the General Register Office and obtained information about deaths caused by cancer[8]. In 2007, the National Cancer Control Committee in Cameroon added data from centers for hormone therapy, chemotherapy and sero-therapy to their information databases[8].

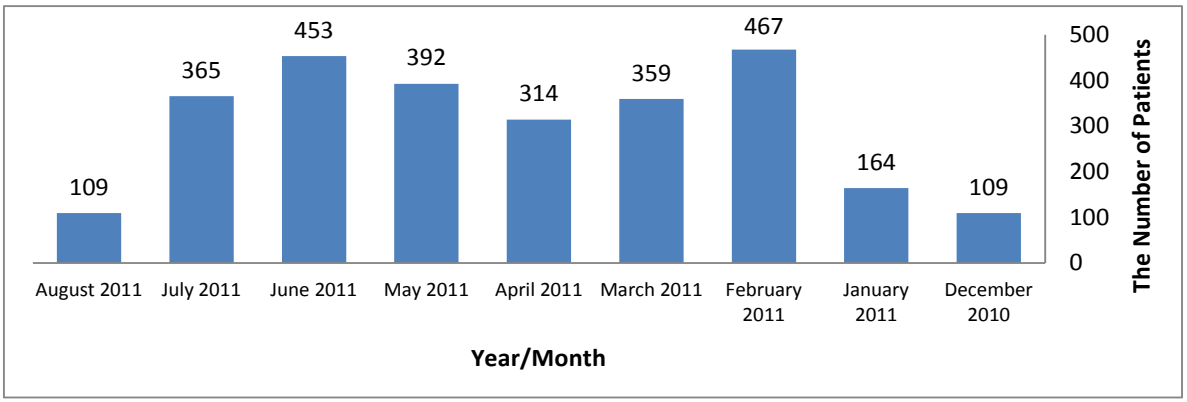

Fig. 3: Monthly frequency distribution of patients who received Trastuzumab

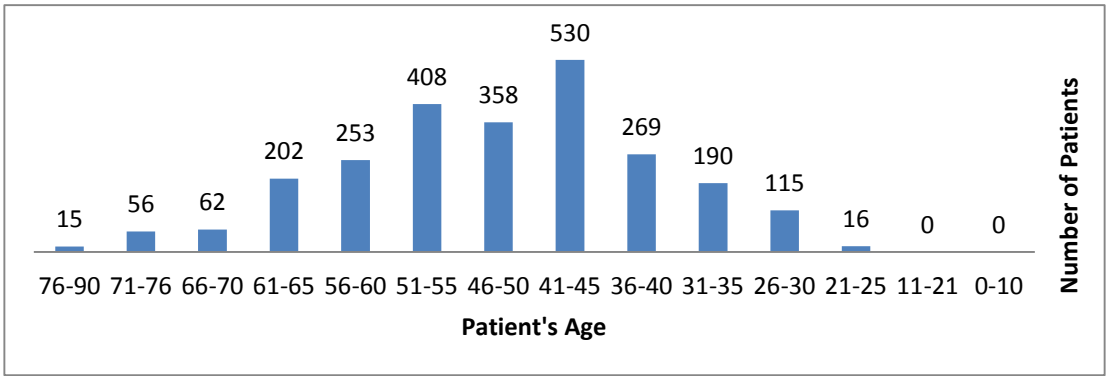

Fig. 4: Frequency distribution of the ages of patients who received Trastuzumab

According to a publication of the Healthcare Association of New York State in 1999, patients' quality of life and sexual issues are critical in designing software systems[9]. These items will be considered in the next stages of our designed software.

Our findings were also consistent with those reported by the National Program of Cancer Registries-Advancing E-cancer Reporting and Registry Operations (NPCR-AERRO) in 2009. The program reviewed the necessary infrastructures to create an information network for cancer care in the U.S. and and proposed that researchers should be supplied with national and international information to information to reduce the financial burden and medical errors faced by patients during prevention, treatment, and follow-up stages[10]. Apparently, all these items were included in the cancer registration system software in Iran.

Esther et al. investigated the registration of breast cancer family information based on genetic studies in the U.S. in 2004 and emphasized the importance of not only genetic factors, but also behavioral patterns of patients and their families[11]. Again, the necessary considerations were given to these issues in preparation of cancer information questionnaires by the Ministry of Health.

The current research mainly aimed to design and implement an information and treatment management system for breast cancer patients in Iran. The Ministry of Health is generally responsible for dealing with such issues at the national level. Our findings highlighted the need for integrated, comprehensive, accurate and up to date information in policymaking and micro- and macro-planning in the field of health which in turn necessitates online information systems. Due to lack of integrated information and absence of communication between relevant service providing departments, online and timely recording of cancer information is impossible. Although the existing problems were to some extent solved by the implementation of our designed system and public cooperation, the participation of all professionals and researchers along with online registration of breast cancer information are still warranted.

On the whole, the findings of the present research confirmed the efficacy of the information and treatment management system for breast cancer patients as a method to resolve several challenges faced by patients, physicians, and health decision-makers. Nevertheless, further steps to prevent, control, and treat breast cancer and thus promote public health cannot be taken unless relevant professionals and public health decision-makers increase cooperation and fully devote themselves to their responsibilities. Moreover, drugstores and laboratories can play a major role in reducing the time and money spent by patients through accurate and timely recoding of the information using the designed software.

As insurance coverage for cancer medicines can be of crucial help to patients, the information obtained from the system will increase insurance organizations' confidence and facilitate the coverage of the medicine. The system can also be used by the Ministry of Health to provide the patients with medical subsidy. The installation of the software in Trastuzumab import and distribution companies assured the authenticity of the medicine and prevented illegal trade of low-quality medicines. Finally, using the mentioned system will diminish the large treatment costs and thus somewhat comfort the patients.

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