Supporting Informed Decision Making In Prevention of Prostate Cancer

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KEYWORD

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ABSTRACT

Identifying and making the correct decision on the best health treatment or screening test option can become a difficult task. Therefore is important that the patients get all types of information appropriate to manage their health. Decision aids can be very useful when there is more than one reasonable option about a treatment or uncertain associated with screening tests. The decision aids tools help people to understand their clinical condition, through the description of the different options available. The purpose of this paper is to present the project "Supporting Informed Decision Making In Prevention of Prostate Cancer" (SIDEMP). This project is focused on the creation of a Web-based decision platform specifically directed to screening prostate cancer, that will support the patient in the process of making an informed decision.

1 Introduction

The decision aids tools are computer-based information systems that are design to improve the process and outcome of decision-making [Arnott, 1998] [Drudzel, 2002] [Drudzel, 2010] [Mohamad, 2010]. One of the areas where decision support systems have been used is in Healthcare [Bemmel, 1997] [Zheng, 2010]. The main objective of these systems in healthcare is to improve the process of care or patients outcomes [Bemmel, 1997]. Therefore these systems are characterized for being an interactive computer based information system with an organized set collection of procedures, models and other type of medical information that help the patients and physicians to take a decision about a certain problem [Haynes, 2010] [Sintchenko, 2004] [Tripathi, 2011]. These platforms play an important role in some medical decisions [Greenes, 2007]. The medical decisions can be very complex because the evidence on outcomes is uncertain or the options of treatment have different risk-benefits for the patient [Garg, 2005] [Hunt, 1998]. Therefore, the practice guidelines recommend that patients should understand and know the probable outcomes of options, consider their personal opinion on risks-benefits and participate with their medical team in deciding the most adequate health treatment. This type of Decision Aid tools has been implemented in healthcare with the aim of help patients to make a decision about a medical problem [Denckamp, 2007] [Hannah, 2005] [O'oconnor, 1999].

Prostate cancer is an increasingly common male cancer, and screening attempts to identify individuals in a broad segment in the population. There are currently two methods used: Digital Rectal Examination (DRE) and Prostate–Specific Antigen (PSA) blood test

[Basch, 2012]. However, some studies defend that the potential risks outweigh the potential benefits associated with screening and subsequently unnecessary treatment in an early stage [Evans, 2007]. These problems are associated with "overdiagnosis" and false positive results. These two concepts can lead to unnecessary treatment that can damage men's health and quality of live and even cause death [Evans, 2010]. Therefore informed decision-making should be made by the patient in question as also by his medical team based on the knowledge of potential risks and benefits [Myers, 2011] [Vedel, 2011].

Web-based decision platform uses "decision aids" or "decision support interventions" tools, that are known to have an effect in important components of informed decision-making, such as knowledge, attitude and behaviour [Joseph-Williams, 2010]. The development of these tools reveals consistent effects on knowledge and participation in clinical decision by the patient and his medical team [Kawamoto, 2005]. The decision aids may be videos or interactive tools, which describe the different options about a treatment or screening test. So, they will help the patient to make informed decisions [Elwyn, 2011].

This paper is organized as follows. Section 2 describes Decision-making to the achievement of prostate cancer screening. The section 3 show the objective of this investigation and section 4 defines the structure of the platform and the technology used. The obtained results are summarized in the section 5. Finally in the section 6 we present some conclusions.

2 Decision-making to the achievement of prostate cancer screening

The aim of prostate cancer screening is to reduce the mortality rate, through early detection of the disease [Basch, 2012]. As referred in introduction prostate cancer, screening is performed by the use of two primary tests: Digital Rectal Examination (DRE) and Prostate–Specific Antigen (PSA) blood test.

The DRE allows evaluating prostate features such as: dimensions, volume, consistency, boundaries and the existence of suspect areas.

However, the use of this practice is conditioned, because, DRE detect, in some cases, only in an advanced stage the prostate cancer [Hoffman, 2005].

The PSA test is a blood test for the quantification of prostate-specific antigen was added. This substance is produced by the prostate gland cells and released into the blood stream of the patient. High amounts of PSA into the bloodstream may be indicative of prostate cancer. The latter test was inserted in methods of prostate cancer screening due to its detection capability tumours at an early stage compared with the DRE [Hoffman, 2005].

The controversy adjacent to prostate cancer screening is associated to PSA test. Although this test can identify a cancer at an early stage, this does not have the ability to distinguish a cancer that is not clinically manifest during the life of the patient with a more aggressive cancer [Wolf, 2010] [Bangma, 2007] [Vedel, 2011].

Overdiagnosis is the diagnosis of tumours that do not manifest themselves during the patient's life, that is, the individual does not present signs or symptoms of the disease and probably die of causes other than prostate cancer [Wolf, 2010] [Bangma, 2007].

The risk associated with overdiagnosis resides in the use of invasive treatments that may cause adverse effects to the patient, such as damage to the urinary sphincter and erectile nerves, causing urinary incontinence and impotence, respectively. This phenomenon is referred to as overtreating [Wolf, 2010] [Bangma, 2007].

Thus, people are faced with some questions, such as: "I can reduce the risk of dying from prostate cancer, but is worth taking the risk of side effects of the treatments?" [Wolf, 2010].

Decision-making, namely on the prostate cancer screening, is characterized by be a complex process, since there is no clear evidence on the potential benefits [Wolf, 2010].

Several efforts have been made to facilitate decision-making in the assessment of prostate cancer screening. However, the decision tools

do not replace a medical consultation [Barry, 2010].
The decision support tools most used for the realization of prostate cancer screening are presented in Table 1 [Wolf, 2010].

Organization	Type of decision tool	Title and online access
Foundation for Informed Medical Decision Making	Video and online resource	"*Is a PSA test right for you?*" http://www.healthdialog.com
Centers for Disease Control and Prevention	PDF document for download	"*Prostate Cancer Screening: A Decision Guide*" http://www.cdc.gov/cancer/prostate/basic_info/screening.htm
Mayo Clinic.com	online resource	"*Prostate Cancer Screening: Should you get a PSA test?*" http://www.mayoclinic.com/health/prostate-cancer/HQ01273
University of Cardiff, U.K.	Online interactive resource	"*Prosdex: A PSA Decision Aid*" disponível em: www.prosdex.com
Prostate Cancer Research Foundation	Online interactive resource	"SWOP: *Prostate Cancer Risk Calculator*" http://www.prostatecancer-riskcalculator.com/assess-your-risk-of-prostate-cancer

Table 1 Decision support tools for screening for prostate cancer [Wolf, 2010] [Basch, 2012].

3 Objectives

The aim of this paper is to evaluate the efficacy and effect of a Web-based decision aid in the informed decision-making in the context of screening prostate cancer.
The first phase goal was to identify a set of requirements to build the web-based decision platform. For this purpose, a set of tools was design that will evaluate the risk of having prostate cancer through the clinical data provided by patient (e.g. risk factors, age group, symptoms, medical and family history). The Web-based decision platform also provides information about potential risks and potential benefits regarding the screening and diagnosis methods, and treatment available.

On the other hand, the web based platform will be composed by medical information about the disease, such as screening tests, treatments and methods of diagnosis. These data will allow the patient to have more knowledge about the disease and understand the information given by the web decision aids.
The second phase of this project aims to analyse the advantages and effectiveness of the Web-based decision platform through its presentation to a target audience. It was focus on users opinions, in this case patients, and level of use of the resource, and evaluate the influence on the process of informed decision making by the patient. The opinions of clinical staff and technicians involved in this study will also be taken in account.

4 Platform SIDEMP

The Web-based decision platform, *"Supporting Informed Decision Making In Prevention of Prostate Cancer"* (SIDEMP) (Fig. 1), was developed to provide the user, more specifically patients and their medical team, knowledge to support a clinical decision. Also, the platform allow the user to calculate the potential risk of have prostate cancer.

Fig. 1 Platform SIDEMP - http://www.mgfamiliar.net/DECIDIR/decidir.html

The platform is divided into six different modules (Fig. 2): "Home", "Prostate Cancer",

"Screening", "PSA", "Treatment" and "Decision". Each module contains different information about the pathology.

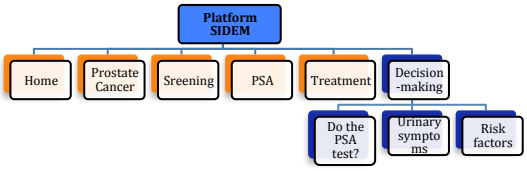

Fig. 2 - Platform Architecture

The first module, "Home", contain the purpose of the platform and present reasons that make the decision making so important in health. The purpose of this module is to encourage the patient to become more participative in his choice of health care.
The "Prostate Cancer" module (Fig. 3) is constituted by the medical information about the prostate, symptoms and risk factors associated with prostate cancer.

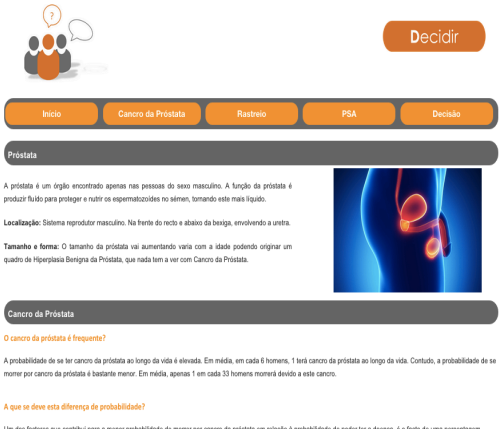

Fig. 3 - Medical information about Prostate Cancer

The third module, "Screening" (Fig. 4) contains medical information about the two screening methods currently used: Digital Rectal method Examination (DRE) and Prostate–Specific Antigen (PSA) blood test.

Fig. 4 – Screening Module

To complete this module, was implemented the sub-module "Decision grids" (Fig. 5).
The goal of the "Decision grids" is to help the patient to evaluate the risk and benefits of each method. The "Decision grids" was composed by a set of questions that the patient has to classify as low, moderate, high).
In the end, the platform provides recommends a decision, based on that classification.

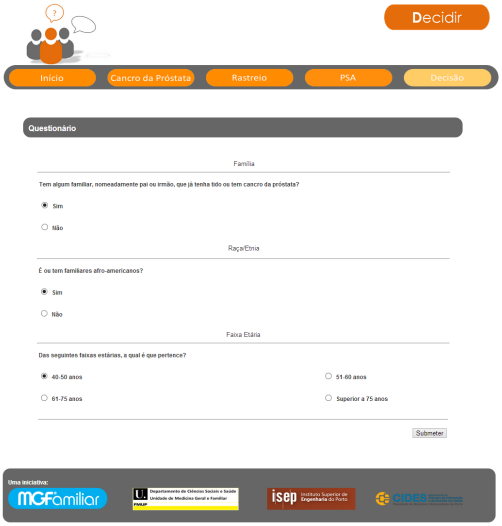

Fig. 5 - Decision Grids module

For example, we have the question relative of the potential benefits of the PSA test: "How much means to you, reduce the risk of dying from prostate cancer?", the patient, based on the information provided by the platform, have to

classify how much he feels about these questions.

In “PSA” module, the patient has access to information about the methods used to detect prostate cancer. Similarly of the module described previously, the present module will contain a decision grid with the risk and benefits of the method used, in this case, the patient have to evaluate the risk and benefits of the biopsy. The secondary effects of a biopsy are for instance: infection, fever and short-term trouble urinating, and all the problems associated with “overdiagnosis”. In this case, there is a risk of diagnose a cancer that probably would not manifest clinically. On the other hand, the patient can also classify how he feels about the benefits associated with the biopsy. These benefits are related with the detection of a high-risk prostate cancer in earlier stage associated to a more effective treatment.

To provide information about the different treatment options we have developed the “Treatment” module. This module will contain information about currently treatments used for prostate cancer (Chemotherapy, Hormone Treatment, Surgery and Active Monitoring) and decision grids. These decisions grids present the risk and benefits associated with the treatments used for prostate cancer.

Finally, the “Decision” module consist in a risk calculator that allows the user to enter his clinical data, such as, medical history, age group, family history, symptoms and race.

At the end the platform evaluate this data and present the potential risk of the patient have prostate cancer (Fig. 6). The evaluation of the clinical data is performed by a set of algorithms that are composed by the decision rules.

These decision rules establish an association between the clinical variables of the patient clinical record. The patient should always consult his medical team about this result.

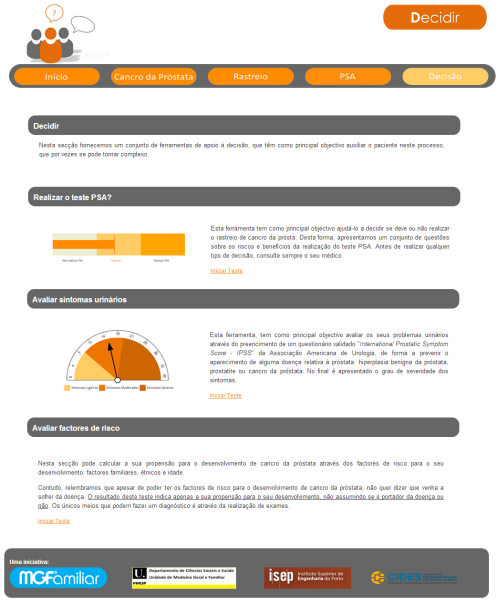

Fig. 6 - Decision Module Interface

The component "Do the PSA test?" of the “Decision” module has as main objective to evaluate the propensity of the user to perform the prostate cancer screening. For this purpose the user must answer a set of questions. This decision support module allows the user to rate the risks and benefits of doing PSA test.

The conclusion obtained in this module describes user predisposition to realize prostate cancer screening.. In this sense, it is used a rating scale set from 0 to 5, which means not important and very important, respectively.

Through the input provided by the user (Fig. 7), the application returns the final result, which can be one of the following: perform PSA test, indecisive and not perform PSA.

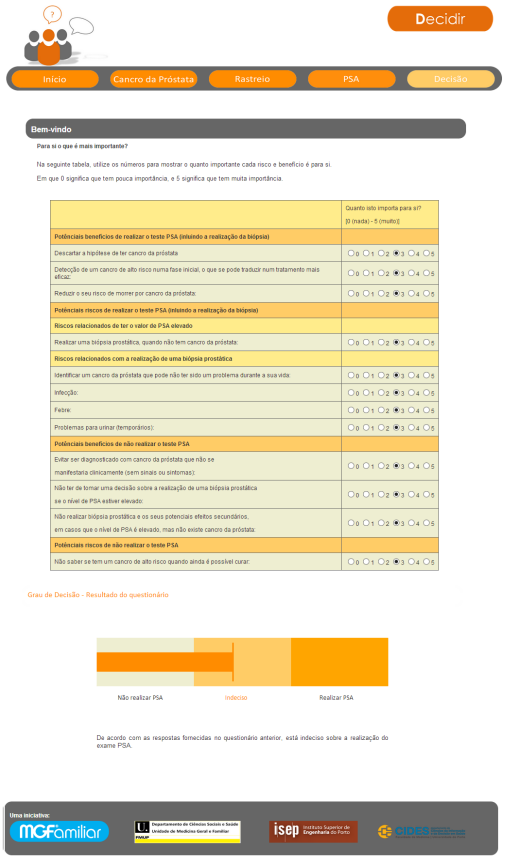

Fig. 7 – PSA Interface

Therefore, through this process is carried out the framework between this value and the limits for each of the conditions referred above: perform PSA test, indecisive and not perform PSA test.
Essentially, the algorithm developed for this component is described as follows: the final state represented by the variable "EF", concerns the final conditions for the realization of the PSA test:

EF = (perform PSA test, indecisive, not perform PSA test)

Each **EF** element corresponds to a range of values, which represents a likely level by the user to perform the PSA test. The levels considered are defined as follows:

- 0 ≤ not perform PSA test≤ 20;
- 20 < indecisive ≤ 40;
- 40 < perform PSA test ≤ 60.

In order to estimate the user tendency to perform the PSA test the value of the variable "result" is evaluate. In others words, this variable is used to identify the level to perform the PSA test. This variable is allocated the sum of the questions answered by the individual. By the level reached by the variable "result" is assigned to the user the recommendation: to do, indecisive and not do PSA test.
In addition of these modules, the platform is populated with videos with testimonials from other patients, which give their opinion about specific treatment or test result, and animation videos. The aim of the animation videos is to present to the patient the chances of dying from prostate cancer based on some clinical variables, for example age group or normal values of PSA test.

5 Results and Discussion

In order to assess the platform impact in the target audience, we have made one survey with the aim to evaluate the features built into the application and verify that the objectives and expected impact are in line with those that were initially defined.
The survey consists of set of questions about the information provided by the application, the interface design, navigation, and the degree of usefulness and difficulty of the decision component.
The target audience chosen to test the SIDEMP platform is composed with 50 men aged between 40 and 75 years. The choice of this age group, due to the fact that most males begin to screen for prostate cancer at 40 years. Also, persons over the age 75 years will not be advised to its realization. With this investigation we were able to provide evidences that only a low percentage of persons had past experiences with this type of applications.. However, a large majority showed a familiarity with the use of computers, as well as access and browsing on the Web. The survey data was stored in a Microsoft Excel file and then was imported into the Statistical Package for Social Sciences (SPSS).

As regards the acceptance of the platform with the target audience, it can be concluded, based on the answers of respondents, the results were quite satisfactory as can be seen in Table 2.

	strongly Disagree	mostly disagree	I agree mostly	totally agree
Platform information, related to prostate cancer was helpful	0,0	0,0	20,0	80,0
Platform facilitates the process of decision on the screening of prostate cancer	0,0	0,0	10,0	90,0
The platform has increased your knowledge about prostate cancer	0,0	0,0	30,0	70,0
The information is well organized	0,0	0,0	10,0	90,0
The platform has a good graphics / design	0,0	0,0	6,0	94,0
You can easily access the platform content	0,0	6,0	20,0	74,0

Table 2 Percentages of the Platform acceptance

In order to verify that the application promotes Informed Decision In Prevention of prostate cancer, the following statements were included:

- "Platform information, related to prostate cancer was helpful";
- "The platform has increased your knowledge about prostate cancer".

80% of subjects agreed completely with the first affirmation and 70% with the second statement. These results indicate that one of the main objectives of the development of this application was completed, as the respondents indicated that this application provides them with helpful knowledge about the prostate cancer.

Associated with decision in prevention of prostate cancer, is the fact that the decision-making process proves seems fairly complex due to the existence of different risks and benefits associated with the implementation of the PSA test. To assess this fact, the statement " *Platform facilitates the process of decision on the screening of prostate cancer*." was introduced in the survey. The results obtained for this assertion (90%) show that the platform can support the decision making process for performing prostate cancer screening through information provided by the system as well as the decision component.

Also, platform usability and graphic aspect, have been evaluate with the questions:

- "The information is well organized";
- "The platform has a good graphics/design";
- "You can easily access the platform content".

In general, the results obtained for the three questions were above 74%, which shows that the platform has a good:

- Graphical environment;
- Accessibility and organization of the content.

Finally, when we ask if "*He recommended the use of the platform*", 90% of respondents said they strongly agree with this statement, which proves a high degree of acceptance of this tool in the target audience.

Also, it was included in the survey a question regarding the aspect of the platform utility: "*The component Implementing the PSA test is useful?*", to which approximately 80% of respondents answered affirmatively. Thus, it can be concluded that there is a possibility of such individuals integrate the platform in their health care process.

It should be noted that the integrity of the survey was determined by Alpha reliability coefficient Cronbach's alpha [Woodward, 1983]. The tool used to calculate this coefficient was SPSS. With regard to the questionnaire that evaluates the usability of the platform, the value of Cronbach's alpha obtained was 0.947. In turn, the questionnaire concerning the usefulness and difficulty, the Cronbach's alpha coefficient was 0.964 and 0.939, respectively. With these values

can be stated that the survey internal consistency is high.

6 Conclusions

The expected results, that has been here summarized, could be important to understand how much this Web-based decision platform affect the knowledge and participation of the patients in decision-making about their one health care. This information is very important to build other Web-based decision platform for different pathologies to help individuals make more informed decisions regarding their health condition.

The implementation of a Web-based decision will provide the patient a wide range of personalized medical information. The use of this type of Web-sites with reliable information adequate to the health condition of the patient will improve the decision-making. The patient will actively participate along with the medical team in the process of screening, diagnosis and treatment of the disease. Other advantages associated to this platform are the improvement of preventive care and the augment of the clinical performance.

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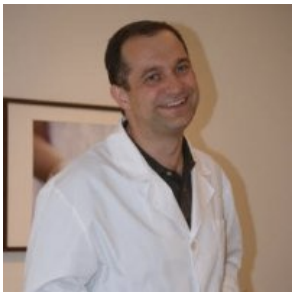

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