Shared decision making in clinical settings: Developing participatory processes to assist patients and surgeons in the medical encounter

Developing a new method for community-shared decision making.

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ABSTRACT

In a world where access to clinical evidenced based information is easier everyday, shared decision making is increasingly being a topic of discussion. It is understood as a sharing of information between parts to reach an option agreement. Typically, physicians share knowledge and patients expose their thoughts and concerns. There are some actions that would need for the involvement of a community to be effective. This work introduces a new concept: community-shared decision making. Although it is under the frame of SDM it is an unexplored topic. The medical decision presented is the Human Papillomavirus vaccination in men, the objective of the thesis is to assist the community of patients to communicate among themselves regarding this topic. When facing a decision where different aspects matter, a multicriteria decision analysis method is required. This method follows a socio-technical approach. The social component aims to capture the points of views of participants, the technical one builds a model to help elicit a decision taking into account all the criteria that matters and at which level.

Male university students were invited to an online 2 round Delphi process. They were presented with the highlights of HPV and vaccine’s implications and, later, asked to assess importance of them. The community SDM was given at this point, while presented with the views of the colleagues and having to assess importance again.

The results showed a remarkably low awareness of HPV. The community also presented a high concern for being protected against the infection. For the other implications, a high dispersion of results was obtained, therefore, the medical society could not be informed about male’s community decision regarding the vaccine. Future work needs to be done and the medical community needs to raise awareness regarding HPV.

Key words: Welphi, MACBETH, Human Papillomavirus, shared decision making.

1. INTRODUCTION

Traditionally, “shared decision making” is the procedure by which patients and their respective clinicians, discuss and concur to an agreement about an alternative treatment and/or option. There are however medical situations which go beyond the clinician-patient dyad and have effects in the community. A clear example is the individual decision to get vaccinated that will ultimately affect the immunological status of an all community.

A prominent medical subject being discussed in Portugal at the moment is the inclusion in the national vaccination plan of the vaccine towards Human Papillomavirus (HPV) for males. Since approval a HPV vaccine for females in 2006 interest in expanding HPV vaccination coverage to males has steadily increased. [1]

HPV infected men are at risk of developing HPV related diseases and they increase the risk of infection in women.
Human Papillomavirus (HPV) is the most common sexually transmitted disease among students worldwide. The fact that it constitutes a good case study to explore a new method that can be applied for enhancing patient community-shared decision making, made the primary motivation of the thesis. The lack of knowledge shown by university students in this important health care problem and the use of the discussion’s results to inform the clinicians on which strategies should be put in place to promote a given vaccination plan made the final motivation for the thesis. Considering we are exploring a new approach and there is also a great lack of information regarding the HPV vaccination in male university students, this study can be considered exploratory. It will collect information regarding the applicability of the method being developed and make a first survey at the male university students’ beliefs and values, that will later set the basis for future studies. The new approach follows a socio-technical approach since it involves a technical component, as the modelling of male’ views in a multicriteria model, and a social component to obtain the information to be used in the modelling. To promote communication among participants and to encourage the active discussion, the application of the Delphi as participatory methods will be carried out. Once the information is collected, the multicriteria model can be built. The MACBETH (Measuring Attractiveness by a Categorical Based Evaluation Technique) approach will be followed.

2. LITERATURE REVIEW

Shared decision making

Shared decision making (SDM) is a relative new approach in the clinical field. It has been defined as “the involvement of both patient and doctor with a sharing of information by both parties taking steps to build a consensus about preferred treatment and reaching an agreement about which treatment to implement”. SDM promotes the selection of a choice based on evidence and patient’s preferences. The stages of SDM include a two-way exchange of information between physician and patient, clinicians provide technical information on options, outcomes and probabilities; and the patients adjudicate the value of good and bad outcomes. Later, they together discuss and deliberate about these possible outcomes and values and preferences. The process finishes with the selection of an option that is consistent with the values and preferences of the patient. Shared decision-making maximizes the likelihood that patient as well as physician will be respected and content in the outcome. Bearing in mind the community concept, the concepts are the same as in any other SDM process, but here, focusing in the patient side, the deliberation is made by the individuals of the community.

Patient decision aids

Patients and clinicians need to discuss the options by using precise, objective, up to date evidence and make mutual decisions taking into account the patients’ context, values and preferences. Hence, implementing shared decision-making is not an easy task. Doctors need the aptitudes and tools to do it in a trustable environment and patients need information and support. Patient decision aids (PDA) are tools designed to help people join in decision making about health care options. These tools help patients to personalize the information, to understand that they can choose among various options, to appreciate the scientific uncertainties inherent in that choice, to clarify the personal value or desirability of potential benefits relative to potential harms, to communicate their values to their practitioners, and to gain skills in the steps of collaborative decision making. There are a lot of different types of patient decision aids with different formats and to be used at different time or in different situations. Some PDA include personal stories because the opinion of family, friends and other patients that went thought the same health problem has been proven to influence the patient’s decision. This is essential for community-shared decision making to happen. However, these tools do not allow for interaction between participants, which is the main point of this new method.
Participatory methods. Delphi

A participatory approach has the main objective of involve all participants in the process of gathering information and decision making in order to reach a compromise when there are a wide variety of opinions. Delphi is an example of participatory method. It focuses “on a systematic collection and aggregation of informed judgement from a group of experts on specific questions and issues” with the aim of “to obtain the most reliable consensus of opinion of a group of experts.” Its four main key features are anonymity, iteration, controlled feedback and statistical aggregation of group response. The Delphi method is an iterative survey of experts. Each participant must complete a questionnaire, assuring the anonymity and allowing to be held it on-line, which facilitates the dissemination among a big community.

The method consists of different rounds, at least two, of a questionnaire and, at the beginning of the following round it gives the feedback of the previous round’s results. With this information, the questionnaire must be filled again and the participants can alter their original assessment or stick to it after knowing and evaluating the viewpoints of the other participants. So, the iteration and controlled feedback are the features allowing for communication among male students. This process is repeated as many times as is useful. In most Delphi processes the level of agreement increases from round to round. The statistical aggregation of group response can be used to inform the medical community about the opinions and beliefs of males as a community.

Multicriteria decision analysis. MACBETH

Multi Criteria Decision Analysis methods are techniques designed to help people make better choices (that are consonant with their preferences and values) and they are especially useful in situations that involve tangible and intangible considerations.

It is viewed as a socio-technical approach. The social component aims to capture the points of views of participants, creating a “shared understanding of the issue”. The way to obtain the social aspects is the participatory methods, presented in the previous chapter.

Technical elements allude to the techniques to support the different steps of the development of an evaluation model, the MCDA methods. MACBETH (Measuring Attractiveness by a Categorical Based Evaluation Technique) differs from MCDA approaches because it only requires qualitative judgements about differences of attractiveness between to options at a time, in order to generate numerical scores for the options in each criterion and to weight the criteria. It has seven possible semantic categories: no, very weak, weak, moderate, strong, very strong and extreme.

It can be firstly seen as 3-main steps process: Structuring, Evaluation and Recommending:

- Structuring: define the options and establish the criteria together with its descriptor of performance.
- Evaluating: The performance of the different options for each criterion is transformed into value and the weights for each criterion are defined by the decision maker. The value of each alternative in each of the criteria is aggregated together with the weight of each criterion in order to obtain its overall value (additive value).
- Interpretation and final decision: A sensitivity and robustness analyzes are performed on the results and will lead to the more attractive decision.

The use of this easy comprehensive questioning protocol has been the reason why this is the MCDA technique used in this thesis, given that an online platform will be implemented and therefore something that is very clear to be understood by all the participants is needed.

For a community shared decision making.

The communication among participants is done by a participatory approach, where they will discuss the assessment of weights to obtain a final decision of the problem.

Once a consensus is obtained, it just has to follow a usual MCDA procedure, the difference here is the way that weights were assessed.

The challenge of using it among a community is to try to elicit all the possible criteria of all of them and implement them in the participatory method.
Human Papillomavirus in men

Human papillomavirus (HPV) is the most common sexually transmitted infection worldwide. It is really common, nearly all sexual active people are infected in some point of their lives. It is transmitted skin-to-skin. Exist more than 150 types of HPV, 40 of them can affect the genital area as well as the mouth and throat, but 9 of them are known to cause the majority of HPV-related cancer and diseases. The problems these 9 types caused can be divided into two types: low risk types, the ones causing genital warts, and high-risk types, which may lead, for men, to cancers of the penis cancers, of the anus and back of the throat, including the base of the tongue and tonsils (oropharynx). There are no symptoms of an HPV infection. Having multiple sexual partners, smoke, a weakened immune system or to be non-circumcised or being with one are some of the risk factors. The only way to be 100% prevented is the sexual abstinence. However, the use of condoms protects a 70 % and there’s a vaccine, that if given before any contact can help get prevented. \[^{18}\]

The vaccine is targeted against the most dangerous HPV types. The vaccine indicated for both males and females 9 through 26 years. It is administered in 3 doses (0, 2 and 6 months). The vaccine is safe, the side effects are no different from other vaccines, including pain, redness, swelling or fever. Most people who get vaccinated don’t have any problems with it, except for who is allergic to the ingredients of the vaccine. \[^{18}\]

Studies estimate that the use of the nonavalent vaccine offers a 90% of protection against vaccine and a 74% HPV- associated cancers. It costs approximately 300 euros. \[^{19}\]

3. PREPARATION, DESIGN AND IMPLEMENTATION OF A NEW METHOD FOR COMMUNITY-SHARED DECISION MAKING. CASE STUDY: HPV VACCINATION IN MEN

There are two possible options: vaccine or not vaccine.

After a large revision of different studies about the male views in HPV, the criteria of the model together with their descriptors of performance were stablished and validated for an expert in the field.

The criteria used in the model include the cost, side effects, efficacy for warts, efficacy for cancer and time.

It is important to mention that there are some aspects related with each patient that may influence the decision, such as their religion or cultural beliefs (the personal opinion about vaccines, fear of needles...) or their lifestyle (including sexual activity or sexual orientation).

These aspects have not been taken into account to build the model because they are not equal for all the population nor objective and this method is pretended to be launch on a large, unknown population. It would be important however to ask for the personal features, called variables of control, outside the model to see how and at which degree they affect the decision.

EVALUATION.

The model is formed by two options (vaccine or not) which means the value function would not be needed. The options are compared directly. The method should ask for weighting only. People should weight the five criteria (cost, efficacy for warts, efficacy for all HPV related cancers, side effects and time). For these criteria, each one is better under one option (scoring 100) and for the other option is just the opposite (scoring 0).

At this point, one of the most important parts of the thesis as well as one of the most difficult is faced: The questioning protocol for weighting criteria needs to be established

The question should not fall into “the most common critical mistake”. This is weighing criteria based only on the notion of importance. The question should be based on improvements, not only in the criteria. As this problematic affects all the community and this thesis is treated under the basis of a community-shared decision making, this question should be implemented in the Welphi platform, based on the Delphi process.
Welphi requires the insertion of the emails before launching the process. The first step was to collect the emails, while doing it, the problematic of gathering some of them from Portuguese students was presented. Núcleo de Engenharia Biomédica, as the entity who has a mailing list with all the biomedical students was contacted. They send a catchy email presenting the topic, the aim of the study and to whom is addressed, with a link to a google form attached where students could introduce their emails.

In the google form they were asked to introduce the emails as well as some personal questions to use as a value of control while analyzing the results. Once the emails were collected, they were invited to a two closed rounds Welphi process, requiring registration. They were first presented with the information of what they were going to be faced as well as the main ideas of HPV and the vaccine to make an informed decision.

Secondly, they were faced 5 criteria regarding the different implications that taking or not the vaccine has and asked how much they value them, according to their willingness to be prevented of HPV infection. The criteria were presented alphabetically in order to no introduce any kind of preference or bias.

The scale used to qualitative judge the criteria is the same on as the MACBETH uses with 7 different levels from “not” to “extreme”. There might be some questions to which the respondents may not know to answer or not want to. As a way of preventing the abandonment of the process or answering randomly, the option “do not know/do not want to answer” was also included. The reason of selecting this option can vary largely is this is why they can also provide comments.

The Welphi questionnaire round 1 was send to 107 participants, 46 of them (43%) went through round 1 between 18th of October and 24th of October. The participants who completed the first round were invited to continue the process and complete the second and last round. They were informed of what did the second round consist of. They were faced with the same question together with the views of their fellow colleagues and were invited to either keep or change your previous judgments. It started the 24th of October and was available up until 31st of October 27 of them completed the second round (60% of the ones who passed the first round).

At the end of round 2, an email was sent to the participants showing gratitude for the collaboration presenting the final feedback.

### 4. RESULTS AND DISCUSSION

The statistic characterization of those who completed both rounds were:
- The mean age is 22,9 years old.
- 60 % of respondents Spanish, followed by Portuguese, Italian and Argentinian, in this order.
- 67% of them don’t have a stable relationship.
- The 90% are heterosexual.
- Most of them (95%) don’t have any issue with vaccines.
- Regarding if they have a family doctor, half of them have it and the other half don’t.
- Only 15 % have been vaccinated against HPV.
- 71% stated to know nothing about how HPV affects man.

#### Round 1
Considering a level of agreement above 51 %, as might be seen, the results are quite dispersed. Only in efficacy for all HPV related cancers this agreement is reached among participants. The criteria that is most dispersed is time. Some of them found it very important and almost at the same level for others it is not important.

#### Round 2
Considering a level of agreement of 51%, in this round the answers showed a higher level of agreement. Now both efficacies have reached and surpassed this level. Cost is seen as an important fact but an agreement is not reached. For time, participants changed from being important to not important. In side effects, there are also
some changes but they cannot lead to any conclusion.

Comparing rounds and final discussion

Results say the agreement of at least 51% has not been reached for three criteria: cost, side effects and time. So, results are not conclusive. This means, that what has been done is not sufficient to build the model. The following step would be to put in the model the ranking of the indicators to then assign weights. But, what the community wants regarding the weights is still not known. The ones valuing poorly the efficacy just disappeared in the second round, this might be because they either changed the opinion or the ones who follow up the process were the ones for whom it was really important. The correlation of both questionnaires might be useful to state some hypothesis, for example the one of homosexuals and bisexuals being more willing to get vaccinated. [20] Only 25% of all the participants invited completed the process. Need of an action plan to engage participants.

It is feasible to think that probably, if the information about HPV was the first thing given they might have been more willing to participate. The fact of having so many different questionnaires facilitates the abandonment of the process. Having to register in a website to participate in the process has reported to be seen negatively. All these creates an environment where males have to be really interested to keep up all the steps.

5. CONCLUSIONS AND FUTURE WORK

The primary objective was to assist the community, communicating among themselves. It is possible to see that people changed their opinions, they had communicated, and, therefore, it is possible to see an evolution.

However, the results were more dispersed than what was expected. With this dispersion, it was not possible to see what the community thought. The medical doctors could not be informed about the thought of the community regarding the ultimate decision of being, or not, vaccinated but some clues can be provided: as they value highly the efficacy against warts and cancers but they also value highly the cost, even though the level of agreement was not reached, it is plausible to think that if the cost reduced, males would get vaccinated.

It is important that the medical community know that population is not aware of this health issue so there is a lot to do in terms of public health to reach this people and make them understand the importance of the vaccine. This was a preliminary study which goal was to explore the Delphi method in a way to engage a community in a shared decision context where the community can say something. The ideal, of course, would have been to see the model (the final decision) and then inform medical community. Given the potential and importance of this context, some future work suggestions are presented.

Eventually, there are two options to finish the model:

- Conduct a third round of the process looking for a higher level of agreement.
- The opinions of the enlarged group would be taken into consideration, seat in a decision conferring process in which this information will be used to inform a strategic group of students that will help to build the model.

In both cases, something should be done to raise the awareness of the community, before following up with the process. This can be done in different ways. For example, a face to face session in the campus and invite a doctor.

Some of panelists stated that they could not express their real feelings and opinions while weighting the implications. Criteria have to enable to build a requisite model to represent all the situations and feelings, the structuring part might need to be revised.

To have robust information more people answering is needed, which is translated into more data. The questionnaire needs to be spread. If this future work actually takes place,
given the difficulties of managing the different platforms where the information was (google form, Wephi…) it is very important for all the information to be in the same place and accessible, with a link for example. This would facilitate the dissemination of the questionnaire.

The population is not aware of this health issue so there is a lot to do in terms of public health to reach this people and make them understand the importance of the vaccine.

6. BIBLIOGRAPHY