A Matter of Life or Death

Designing a Decision Support Tool for Neurosurgeons

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ABSTRACT

Decisions can range from trivial to critical. In the studied MDT meetings at St.Olavs Hospital, decision making have a huge impact in a patient's life. To better ensure that the right decisions are made, different perspectives relevant to the topic is considered. Ethics, economics, quality of life as well as the inevitable clinical factors all contribute with pros and cons that should be considered when designing a decision support tool. By using the decision-centered design framework, the demanding tasks that the user group face are identified. Suggestions are then made for what to include in a design for those tasks. The main emphasis should be on improving the understanding of the already existing information, focusing on excluding the irrelevant factors, and highlighting the most important ones. This can be done by visualizing and structuring what is presented verbally today.

KEYWORDS: decision making, decision-centered design, glioblastoma, ethics, information visualization

1. INTRODUCTION

Decision making is part of our everyday life. Some decisions can be perceived as small and trivial whilst some can be of a quite more serious character. In some cases, the right way to act can seem obvious, and in other it might be more unclear. When making medical decisions, professional knowledge and experience will help a long way, but is not always enough to make the "good" decisions. What might actually promote quality of life and the best outcome for the patient can depend on the person and his or her situation, and not only standardized knowledge. High quality of the medical service is therefore not only about high level of knowledge, but also how one manages this knowledge (Hov & Seljeskog, 2013).

1.1 MDT Meetings

This article is written based on a design project in collaboration with SINTEF Technology and Society, department of Health, and St. Olavs Hospital in Trondheim. The aim is to design a decision support tool for neurologists to be used during multidisciplinary teams (MDT) meetings

Patients diagnosed with deadly brain cancer can be discussed in a MDT meeting to reach an agreement of which treatment, if any, to take. During the MDT meetings at St. Olavs, each patient is briefly presented to the rest of the team by the respective operating neurologist. This presentation is done verbally, combined with MR images showing the tumor.

The team assesses various criteria like the patient's age, medical history and size and growth pattern of the tumor to reach a decision.

Decisions are today based mainly on clinical information about the patient and the tumor itself, and does not explicitly include other perspectives. When dealing with such high-risk decisions that directly affects someone's life, how can one make the right decision?

2. THEORY

2.1 Ethics

Ethics can be defined as the doctrine of moral, and its purpose is to study how one *should* act. Often terms like "right" and "wrong", "good" and "bad" reappear (Sagdahl, 2017). One of the main questions of ethics is "How can I justify that one action or decision is better than the other?". Ethical reflection therefore engages the conscious mind, all our knowledge and insight, feelings, values and norms. Even our intuition and our impulses should be brought into consideration when reflecting on our choice of actions (Hov & Seljeskog, 2013). The field of the study of cancer - oncology, or neuro-oncology in particular, is often complicated by ethical dilemmas. This field stands alone in medical specialties when it comes to the large number of seriously ill patients, in which their day-to-day care involves decision on life and death (Newton & Malkin, 1997).

2.2 Glioblastoma

Glioblastoma, a grade IV astrocytoma, is the most aggressive and lethal form for brain cancer (Klepp, 2016). About 300 new cases are registered each year in Norway, and frequency and worsened prognosis are linear with age. The overall prognosis for patients with glioblastoma is poor - only about 1 out of 4 patients live beyond two years after being diagnosed (Parsons et al., 2008).

MRI scanning and ultimately a biopsy is used to diagnose glioblastoma. Due to its seriousness and complicity, a patient's medical case can be brought up and discussed amongst a board of medical professionals within the neurological field. For patients diagnosed with glioblastoma a curative treatment is almost always certain to not be the case (Storstein et al., 2011). Therefore, the main objective is often to prolong the patient's life as much as possible, but not at every cost. Operation is usually not preferred if this may lead to loss, or significant reduction, of the patient's quality of life. However, what can be categorized as perfect health is difficult, or even impossible, to define.

2.3 Quality of Life

Quality of life is a personal and individual measurement that lends itself to a philosophical approach rather than a scientific one (Slevin, Plant, Lynch, Drinkwater & Gregory, 1988). QALY – quality-adjusted life years, is a health economic term that can be used for evaluating cost-effects of medical interventions. It presumes that a life year of pain, illness or disability of a certain degree has reduced quality compared to a life year without the equivalent problems (Braut, 2017). The meaning and usefulness of the QALY is however debated, partly because some argue that determining the level of health places more importance on physical pain or disability over mental health (Dolan, 2008).

To quantitate subjective parameters such as quality of life, several instruments have been developed. One of these is the Karnofsky performance scale index. The index, ranging from 0 to 100, is a tool that can be used to assess disability (Karnofsky & Burchenal, 1949). The index can also be used to compare the efficiency of different treatment options and to evaluate the patient's prognosis. The lower the Karnofsky score, the lower the probability of survival. It will therefore be reasonable to evaluate a patient's KPS when considering treatment options, as this gives a somewhat objective assessment of the patient's state (Christensen, 2014). However, it has been shown that clinicians might assess the patient quite differently than the patient would assess himself, suggesting that clinicians can not

always accurately determine how the patient feels (Slevin et al., 1988).

A study conducted at St.Olavs Hospital in Trondheim, Norway between 2004 and 2009 looks into the correlation between operation and Karnofsky performance status (KPS). The study looked into the state of patients with brain cancer after surgery. Out of a total of 141 operations, a decrease in KPS was observed in 39% of the patients after 6 weeks. The KPS was measured both before and after surgery, and a significant decrease between the two measurements was found (Gulati, Jakola, Nerland, Weber & Solheim, 2011). It is also shown that early deterioration in quality of life following surgery is related to impaired survival (Sagberg, Solheim & Jakola, 2015). Of this one might conclude that surgery is not the best option for every patient.

2.4 Health Economics

As with many other areas in health care, oncology is under constant pressure to control costs while at the same time maintaining or even improving the patient outcomes as well as the quality of the care given to enhance the value of oncology. Unlike many other areas in health care however, the practice of oncology represents some challenges that makes improving and assessing this value quite intricate.

To start with, both professionals and patients want to treat for cure. This might not always be possible, and in that case, the goal is to extend life and reduce pain and burden of disease.
Second, while treatments are often life sparing, they might also be extremely toxic, and in some cases life threatening.
Third, payment structures for medicine are connected with practice.
Fourth, there is often an enormous pressure on the providers to apply the newest technology to patients who have failed to respond to the already established treatment. This can happen even if there is incomplete or uncertain evidence supporting this new technology. Providers might hesitate to stop toxic treatments or to move to palliation, even when the patient is at the end of life. Lastly, the newest treatments within oncology are also among the costliest (IOM, 2009).

2.5 Clinical Decision-Support System (CDSS)

A clinical decision-support system (CDSS) is any computer program designed to help healthcare professionals to make clinical decisions by generating advice for the specific case (Musen, Middleton & Greenes, 2014). It provides support before, during, or after the clinical decision is made, and it can vary from performing decision making to rather supporting it (Berner & La Lande, 2016). CDSS are usually divided into two categories: assisting health-care professionals in finding out what a patient's diagnosis is, and assisting with decisions about what to do for the patient. Some systems assist with both, but the advice on what to do for a patient can not be formulated without considering the balance between cost and risk. The implementation of such a system requires that patient data is captured accurately and completely, which in turn calls for a standardized way of expressing clinical situations (Musen et al., 2014).

2.6 Decision-Centered Design

Decision-centered design (DCD) is a framework that focuses on designing solutions that support challenging decision making. It focuses on key decisions and translates these into design requirements rather than trying to document all possible cognitive requirements (Militello & Klein, 2013).

2.7 Semi-Structured Interviews

To examine the topic further, interviews were conducted. Due to the nature of the topic, semi-structured interviews were found most relevant. This type of interview method is characterized by its unique flexibility. It is structured enough to address specific elements of the research question, and yet it leaves space for the

interviewee to offer new meanings to the topic that is being studied (Galletta, 2013). The questions are rather open, so that the person being interviewed can broaden his/her answers. The focus is on the interviewee and what that person says and means, so the interviewer must try to speak as little as possible (Langdridge, 2004).

3. METHOD

3.1 Literature Review

The basis of this article is a literature review presenting literature and publications that are found relevant for suggesting perspectives to include in the decision support tool. The theory relevant to this case had been found to include ethics, patient autonomy, clinical data, economy and information visualization. To support the literature, semi-structured interviews with experts within different professions relevant to the design has been performed. These interviews have been conducted to be able to suggest to which extent these perspectives should be included in a decision support tool. Second-hand observation has also been used to gather insight as support.

3.1.1 Decision-Centered Design

Including DCD is relevant for understanding what areas should be highlighted in designing a tool that will help neurosurgeons make "better" decisions. The framework helps to identify the demanding tasks that the surgeons face, and hence come up with suggestions designing for those tasks.

The DCD framework consists of five phases; preparation, knowledge elicitation, analysis and representation, application of design and evaluation. This article will focus on the first three of these, as they are perceived as most relevant for the topic.

1- Preparation
   - **a. The user group**
   - **b. Goal is to identify cognitively demanding tasks**

2- Knowledge elicitation

3- Analysis and presentation

4- Application of design

5- Evaluation

Preparation:

In this stage the goal is to gather background material and to identify tasks that are cognitively demanding for the user group. The user group are here defined as neurosurgeons and other clinicians who make challenging decisions during these meetings at St.Olavs Hospital. In these meetings, the same patients are often brought up several times due to a relapse of the tumor. The reoccurring patient's situation is not always clear or remembered by the whole team, mostly because the composition of these teams vary. The information is presented verbally, and the way this information is presented varies accordingly from clinician to clinician. Some are more thorough, whilst others give more of a brief introduction.

The cognitively demanding tasks have been identified based on semi-structured interviews and second-hand observation. First, understanding the environment of the tumor just hearing about it, and not seeing it visually is sometimes challenging for the clinicians present at the MDT meetings. This lack of visualization of neuro-anatomic relations means that they have to make a mental model of the tumor's environment to understand the situation, and to be able to forecast a prognosis (Downs & Stea, 1973).

Visualizations are an increasingly important part of cognitive systems, and until recently, the term described the construction of a visual image in the mind (Little, Fowler & Coulson, 1972). Now it has come to mean more of a graphical representation of data or information and thus evolving from something internal to an external support tool to making decisions (Ware, 2000).

Visualizing information is no trivial task. On one hand, the graphics must be easy to comprehend and not too much information should be inaccessible, but on the other hand, it is also important to exclude irrelevant information (Miettinen, 2014).

Second, some of the information given at the MDT meetings is hard to objectify. Information that is presented verbally will vary from clinician to clinician in terms of conviction, structure and interpretation, making each presentation different from the other.

Knowledge elicitation:
This stage is the elicitation of critical incidents and key components of the decision making, often done by interviews and observation. This is done to be able to do a cognitive task analysis. The knowledge elicitation is based mainly on second-hand observation as well as a semi-structured interview with a surgeon in order to identify both the key information itself and how it is used during problem solving. The focus of the interview was the cognitive task of evaluating the character of the tumor based on verbally presented information. As a result of the interview, it shows that some clinicians feel that the information they are presented to might be subjected to bias. This is due to the subjective way of presenting and interpreting the patient's illness.

Analysis and presentation:
During this stage, qualitative data are organized, and key elements that will drive design are highlighted. Situation awareness is knowledge about where they are, what they have done, what is about to happen and where to go (Endsley, 2012). This can be thought of as an internalized mental model of the current state of the operator's environment – and all incoming data from the surroundings such as fellow team members and systems must be integrated into a whole. The neurosurgeons' situation awareness depends on understanding and interpreting MR images so that they can tell which area is afflicted by the tumor, and which areas that are in danger of becoming afflicted, as well as determining where to gain access if an operation is to be performed.

3.2 Interviews

As a common denominator for the semi-structured interviews conducted in relation to this article, the interview objects in each respective field were asked what they perceive to be the most important aspects to include in a decision support tool. The project and its goals were presented, and the interview objects were asked to give their statement and thoughts upon this. Following is a summary of these statements.

3.2.1 Surgeon at one of Norway's biggest hospitals

The interviewed surgeon was asked about opinions on what are the most important factors to include when designing a decision support tool for use in MDT meeting. To summarize, the surgeon explained that the tool should definitely show the focus areas of surgeons, such as the patient's key information. Further, the surgeon stated that this could, and should, include the patient's age, Karnofsky index, medical history as well as comorbid disorders.

The surgeon would then explain that the meetings can become very subjective and unstructured, and often anecdotes and stories might lead the clinicians off track. This lead the interviewee to pinpoint the desire for a more structured and defined system.

When asked about the importance of economics within treatment of glioblastoma, the surgeon interviewed stated that although one doctor in each department is responsible for keeping the budget in mind, this budget is not really considered within this domain. While expensive drugs are not distributed to absolutely everyone who needs it (Bordvik, 2017), treatment is usually always performed if it is perceived as useful for a patient diagnosed with glioblastoma. Perceived quality of life will after a while reset itself,

meaning that with time the patient can reconcile with the situation as it is. The physical and psychological consequences related to performing an operation might be easier for the patient to cope with as time passes by, but it is a prerequisite that the survival prognosis is of such a character that this restructuring process might take place.

3.2.2 Designer at a Norwegian research company

When asked on a designer's point of view of the decision support tool, the designer stated that it is important to satisfy the clinician's goals, which is to make the decisions more objective and obvious. Further, the interviewee suggests that this can be done by visualizing the data that they already have available, and that are now presented verbally at the MDT meetings. The designer would emphasize making a system that is built on structure, so that the meetings can take place more efficiently. It will therefore be important to find the balance between a rigid and a completely free structure. Also, the designer would focus on using design that cannot be misinterpreted when making a decision. In other words, it has to be clear, concise and intuitive.

4. DISCUSSION

Based on the literature review and the supporting interviews, the economic perspective is perhaps not appropriate to include in the decision support system. Although the cost/benefit of each treatment is subtly considered mentally, there is no need to state this explicitly in a system. The consequences of declining treatment on the basis of cost will be fatal in this domain. Usually there are many factors that will speak against treatment much sooner than the cost, such as Karnofsky and prediction. If the topic was of a more common character, priorities would have to be done as the hospital's budget is not indefinite.

The decision support system can be designed to implement CDSS on the lowest level, where doctors are merely supported in the decision by having it presented. It is thought that the level of the CDSS can increase as more research is conducted, as machine learning is now being used to make a database of cases. In the support tool, it is imagined that the system can suggest similar previous cases to show what decision was made, and what the outcome was. This requires that patient data is captured accurately and completely so that it can be expressed as standardized information. If this is done, comparing and sharing across hospitals will contribute to a much larger database, which in turn leads to a better CDSS.

The main focus in such a support tool will be to present the existing data visually, rather than adding more information. That being said, the tool will seek to also include a more in-depth understanding of the tumor and its location. This can be done by including a 3D model to more accurately show the surroundings of the tumor. This will hopefully help strengthen the surgeon's situation awareness.

It is not always desirable to treat for the sake of treatment itself. As well as being costly, the treatment can also harm the patient, as it can dramatically affect the QALY. This can suggest that the tool should include some prognosis alternatives, as different outcomes for different decisions. This can be supported by an increased focus on standardizing the existing information.

As mentioned by the interviewed surgeon, there is a wish for objective, quantitative data presented as numbers and facts. This may well lead to more efficient meetings with less guesswork, but at the same time it removes a bit of the human factors involved.

When discussing quality of life, there is a question of who should assess this. As mentioned there can be a poor correlation the reported quality of life assessed by the clinician versus the

patient. This might raise a question of whether measurement tools like the Karnofsky index should be incorporated in the decision tool. However, studies have shown that the doctor's assessment of the patient's quality of life measured in terms of the Karnofsky index is correlated with survival. Karnofsky index should therefore be included in the decision support tool.

5. CONCLUSION

Designing a tool to support such high-risk decisions is an intricate process. Not only should it consider clinical information provided and analyzed, but it should also take into account the patient himself. The patient's quality of life both before and after surgery is something that is difficult to measure objectively, but this can at least be a matter of discussion within the team responsible for the decision making.

Based on the findings, the decision support tool should include all information that is already present today, presented in a visually comprehensible manner. The key information, like the patient's age, Karnofsky index, medical history as well as comorbid disorders should, alongside describing images of the tumor, be the core of the tool.

There should be an increased emphasis on visualization of the data that is already available today. This visualization should be done comprehendible and intuitive. It should include all information that is needed to reach a decision, whilst it at the same time excludes any information perceived as irrelevant.

The system should function as a CDSS on a low level, that is to support which action to take. It should therefore be a system that assists in giving advice on what to do, showing the costs and risks in a non-economic matter, and rather showing it in consequences for the patient's perceived quality of life.

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