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Decision support systems in oncology: Are we there yet?

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There is a long history of applications of decision support systems to oncology. Almost from the birth of the so-called "expert systems", programs dedicated to helping practitioners in establishing diagnostic, treatment or monitoring of cancers have been developed. Among the first to explore this area was ONCOCIN [Shortliffe, 1986] in the mid 80's. Like many other systems, ONCOCIN was based on a set of rules, encoding the actions to trigger in specific situations. More generally, a clinical decision support system such as ONCOCIN is a computer program that takes as input the description of a medical situation, and provides as a result information supporting the practitioner in making the appropriate decisions concerning this situation [Musen, 1997]. Such a program intends to capture, to encode, medical knowledge and to apply problem-solving method to automatically "reason" upon this knowledge.

While there have been a lot of research, prototypes and experiments on applying decision support systems in medicine and specifically in oncology, they have never been really adopted to support the daily practice of oncology. Expert systems, after having generating so much enthusiasm, have appeared disappointing and acquired a bad reputation. They where blamed not to be adaptive enough to particular situations, not to be helpful enough as they were not able to explain their results, and also not to be dynamic enough as they were hard to evolve together with the advances in medicine. However, the underlying technologies for decision support systems have evolved a lot since the early expert systems. Research in knowledge management has produced adequate methods for handling the difficulty of capturing and maintaining computerized expertise, and to provide the appropriate level of interaction between the system and the practitioner. Therefore, this might be the time to consider once again the question of decision support systems in oncology: Is their bad reputation still justified and what are the obstacles to their widespread adoption?

To derive elements of answer to these questions, we consider our concrete experience in building a modern decision support system in oncology: the Kasimir project.

The Kasimir project was born in 1997. It gathered specialists in oncology and researchers in psycho-ergonomics and in computer science. Its goal is decision knowledge management in oncology in the framework of Lorraine (a region of East of France). Such knowledge can be found in decision protocols, that are documents explaining the standard decision to be applied to some decision problems (standard, according to the medical state of the art, following the principle of evidence-based medicine). For example, the breast cancer treatment protocol describes the standard treatments, function of the description of a patient ill with breast cancer and of its cancer. Other decision protocols were considered in this project, e.g., prostate decision protocol, breast cancer surveillance, inclusion of patients in clinical trials, etc.

Two types of decision support have been studied in the Kasimir project: protocol application and protocol adaptation. The study of protocol application has led to computer programs within the Kasimir system that are nowadays stable and are based on standard methods and

tools of the domain of knowledge-based systems (which is a subfield of computer science). Such a program has a friendly user-interface for describing a patient and its cancer and for displaying the associated standard decision (d'Aquin *et al.* 2005). Some studies carried on by physicians have shown a statistically significant improvement of the observance of a decision protocol when the physicians use the Kasimir system, compared to their observance when they use the decision protocol in the form of a paper document (Rios *et al.* 2003).

For a majority of patients, the standard decision given by protocol application can be applied as such. The specialists in psycho-ergonomics involved in the project have shown that for the other patients (one third? 40%?), the oncologists *adapt* the decision protocol, i.e., actually use it, but with a critical eye and not in a straightforward way. There are many reasons why a protocol has to be adapted, e.g., drug contraindications, closeness to a decision threshold, psychological problems of the patient, cancer of a pregnant woman, breast cancer of a man, etc. The complex and rich domain of decision protocol adaptation has been deeply studied in the Kasimir project (Lieber *et al.* 2008) but still requires some research and development in order to obtain tools that could be used with benefit by physicians in their daily practice. Therefore, we have concentrated our effort for transfering this research to the medical community mainly on protocol application.

The key issue for having a tool for protocol application is the implementation of a *computerized protocol*, i.e., the translation of the decision protocol document into a machine-understandable file expressed in a standard knowledge representation formalism. The translation process is not straightforward: it requires from the knowledge engineer in charge of this task to interact with physicians, in particular to better understand the medical notions used in the protocol and to point out some implicit pieces of knowledge (that are to be made explicit for computers). It also requires to be tested by an oncology specialist before being given to any physician. This entails some effort of oncology experts and of knowledge engineers for the first version of the computerized protocol as well as maintenance efforts for its next versions (in particular, a new version of the breast cancer treatment protocol is published every 6 months).

The end-users of the Kasimir system are physicians that are not highly specialized in oncology. The end-users we have met have tested the system for several weeks, and are willing to use it in their daily practice, which involves up-to-date computerized protocols. However, as mentioned above, this implementation of protocols and their maintenance require time of oncology experts. Unfortunately, because of the low demography of these specialists, at least in Western Europe, and because of the growing number of cancers, the time that the specialists can spend on tasks that are not in the center of their medical activity is getting lower and lower. Moreover, their benefit from this work is not obvious: as specialists in oncology, they do not need the help of such a decision support system.

Now, what is the future of the Kasimir system? At first glance, it seems that it is confronted to the so-called knowledge acquisition and maintenance bottleneck. Now, it can be remarked that oncology experts *do* spend a lot of time for acquisition and maintenance of decision protocols in the form of paper documents. Once these documents are published, it is understandable that the experts are reluctant to do an additional effort for validating the computerized protocol implemented by knowledge engineers. But must this effort be *additional*? The job of knowledge engineers is the management of knowledge acquisition and maintenance. Thus, would it be possible to settle an efficient synergy between oncology specialists and knowledge engineers that would lead to protocol in two forms (paper

documents and computerized forms)? From our experience in the Kasimir project, our opinion is that such a synergy is possible and that it should lead to:

- A benefit in time for the oncology specialists (for the acquisition and the maintenance of the protocols and because simple cases–that do not require adaptation—can be managed by less specialized physicians);
- A benefit in competence to less specialized physicians (able to solve at least simple cases);
- A benefit in healthcare quality for the patients (having the level of speciality in oncology fitting the complexity of her/his case).

Such a shift in organization requires a political decision and an acceptance from the medical community. Our message from a computer science viewpoint is that this shift is technologically possible and should be beneficial.

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