Shared Decision-Making Ontology for a Healthcare Team Executing a Workflow, an Instantiation for Metastatic Spinal Cord Compression Management

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Abstract

Regardless of potential benefits and better outcomes, adoption of shared decision-making between a patient and providers involved in his/her care is still in its infancy. This paper intends to fill this gap by formalizing shared decision-making, situating it as part of team-based care delivery, and incorporating workflow concepts allowing for identification of shared decision-making tasks. We accomplish that by creating novel shared decision-making ontology which constitutes the first step required in the development of a decision support system for shared decision-making. The proposed ontology formally defines and describes the key concepts and relations in the shared decision-making domain and lays the foundation for the formalization and support of the patient management process. We illustrate the applicability of the proposed ontology by creating its instantiation for the complex patient management scenario involving shared decision-making about the treatment of metastatic spinal cord compression

Introduction

In the early 2000s, former AMIA president C. Safran stated that "the patient is the most underutilized resource in healthcare" (Safran C. Quote from testimony to the US House, Committee on Ways and Means, Subcommittee on Health, Health Care Information Technology Hearing, 17 June 2004). Addressing this underutilization needs to start with the medical encounter when decisions about treatment strategies are discussed and explored. In 1990, writing about clinical practice guidelines, Eddy argued that a treatment can be "standard" only if "there is virtual unanimity among the patients about overall desirability… of the outcomes"[1]. This implies that optimal treatment decisions not only need to consider clinical outcomes but should be aligned with patient values and preferences and therefore have to be developed in a "shared" manner. Thus, the process of reaching such a decision has to be "shared" between a patient and all providers involved in his/her care. It was demonstrated that such shared decision-making leads to better care and better outcomes. Therefore, shared decision-making has been advocated as the most suitable model for decision-making during medical encounters when more than one treatment option is available to the patient. Evidence-based recommendations for physicians have also followed this paradigm by increasingly stressing the pivotal role that patients should play in medical decisions and stress the potential positive impact of shared decision-making on patient outcomes, cost of treatment, and satisfaction with care[2,3].

In most cases shared decision-making is ad hoc, not embedded in clinical workflows, and its enactment is often left to the initiative of the single medical practitioner leading the encounter. One of the reasons for such a situation is lack of formalization of shared decision-making processes and lack of the integration with the realities of team-based and evidence-based care delivery. In the last few decades a number of efforts to formalize shared decision-making have been made[4–6]. Some approaches, developed around a patient-physician talk model, have been proposed to partition shared decision-making in three or four analytical steps[7], and a number of decision aids have been developed to provide patients with the required support to effectively participate in decisions about their health[8]. However, despite involvement of the implementation community[9,10], a wider adoption of shared decision-making is still lacking. Researchers have identified several barriers to the adoption of shared decision-making[11,12]. One barrier is the lack of effective models and tools that consider the shared decision-making process in a holistic and integrative manner. At the same time, patients are increasingly demanding a move away from a paternalistic approach to the patient-provider relationship[13], expecting higher quality and better transfer of information and desiring an active participation in the management of their health[14].

There is an opportunity for the medical informatics community to create the needed support tools for shared decision-making. However, considerable challenges related to the creation of these tools persist. Obstacles to creation include the fact that shared decisions have to involve a team, including the most responsible physician, for the final decision about treatment (e.g. surgery vs radiotherapy), one or more consulting practitioners with different specialties, nursing and support staff, and patient and/or his/her family members. On the other hand, most research on shared decision-making has been confined to an ideal situation where patient interacts with a single physician/provider during a single (or a limited set of) encounter.

Another challenge is related to the integration of shared decision-making with clinical workflows, the identification of tasks that can be "shared", and defining how to incorporate patient's values and preferences into treatment decisions. Thus, operationalization of shared decision principles is often left to the single physician leading the encounter, leaving the process unstructured.

As a result, comprehensive decision support to facilitate shared decision-making is difficult to develop and such initiatives are often limited to providing decision aids and educational material to patients, which have proven to be only partially effective[15]. More effective ways of supporting shared decision-making should be based on the formalization of the decision-making process and its integration with the clinical workflows.

This paper intends to address the challenges of providing decision support to shared decision-making by 1) formalizing the process, situating it as part of team-based care delivery, and 2) incorporating workflow concepts allowing for identification of shared decision-making tasks. The present paper contributes to these objectives by creating a novel shared decision-making ontology (SDMO) that represents the necessary first step, according to the principles of ontology-driven system and software engineering[16,17], for the future development of decision support tools. The proposed ontology formally defines and describes the key concepts and relations in the shared decision-making domain and lays the foundation for the formalization and support of the patient management process.

The paper is organized as follows. We start by describing the SDMO and its organization, concepts and relations. We illustrate use of the SDMO to formalize shared decision-making by creating its instance to support the complex management of a patient with metastatic spinal cord compression (MSCC). Finally, we report on the technical implementation of SDMO in Protégé and consistency checking of our ontology using OWL and the HermiT reasoner.

Methods

The ontology has been organized using concepts and relations coming from four main subdomains: workflow subdomain, patient subdomain, team subdomain, and decision-making subdomain. Figure 1 shows a graphical representation of the SDMO.

Workflow subdomain concepts and relations are used to formalize the clinical workflows of team-based patient management. In developing the ontology for this subdomain we relied on earlier research[18,19] using the Business Process Modeling Notation (BPMN) standard[20] to represent clinical workflows. In the proposed ontology, workflows are represented using the BPMN-derived concepts of *node* and its subclasses *activity*, *gateway* and *event*, *arc* and *task collection*. However, because of the high cohesion and low coupling principles that drove structuring of the SDMO, it is possible to use other process representations for this set of concepts without need to revise the overall model, providing that *workflow*, *non-decision task* and *decision task* concepts are not changed. This is because these concepts act as an interface with other subdomains of the SDMO and ensure the coherent integration of the workflow subdomain in the general SDMO.

Patient subdomain concepts mainly represent patient-related data in terms of clinical *observation*s (what is being observed) and their *value* (what is the value of the observation for the specific patient), patient *preference model* (what is the formalism chosen to represent preferences), and specific *preference* (the actual instantiation of the preference for this patient). Both *observation* and *preference model* play the role of *input data* for the decision-related concepts. The *patient* is managed by the team according to a *presentation*-specific *workflow,* which also defines the requirements for the *team* in terms of *members*, as well as their *specialtie*s.

The core of the team subdomain has been developed in our earlier research and has been described in detail elsewhere[21]. A *practitioner*'s *specialty* defines which workflows he/she is able to execute and lead. On the other hand, task assignment is not done just according to practitioner specialties, but incorporates practitioner *capabilities.* Specific *non-decision tasks* in the workflow require certain c*apabilities* in order to be appropriately *assigned* to a team member for execution.

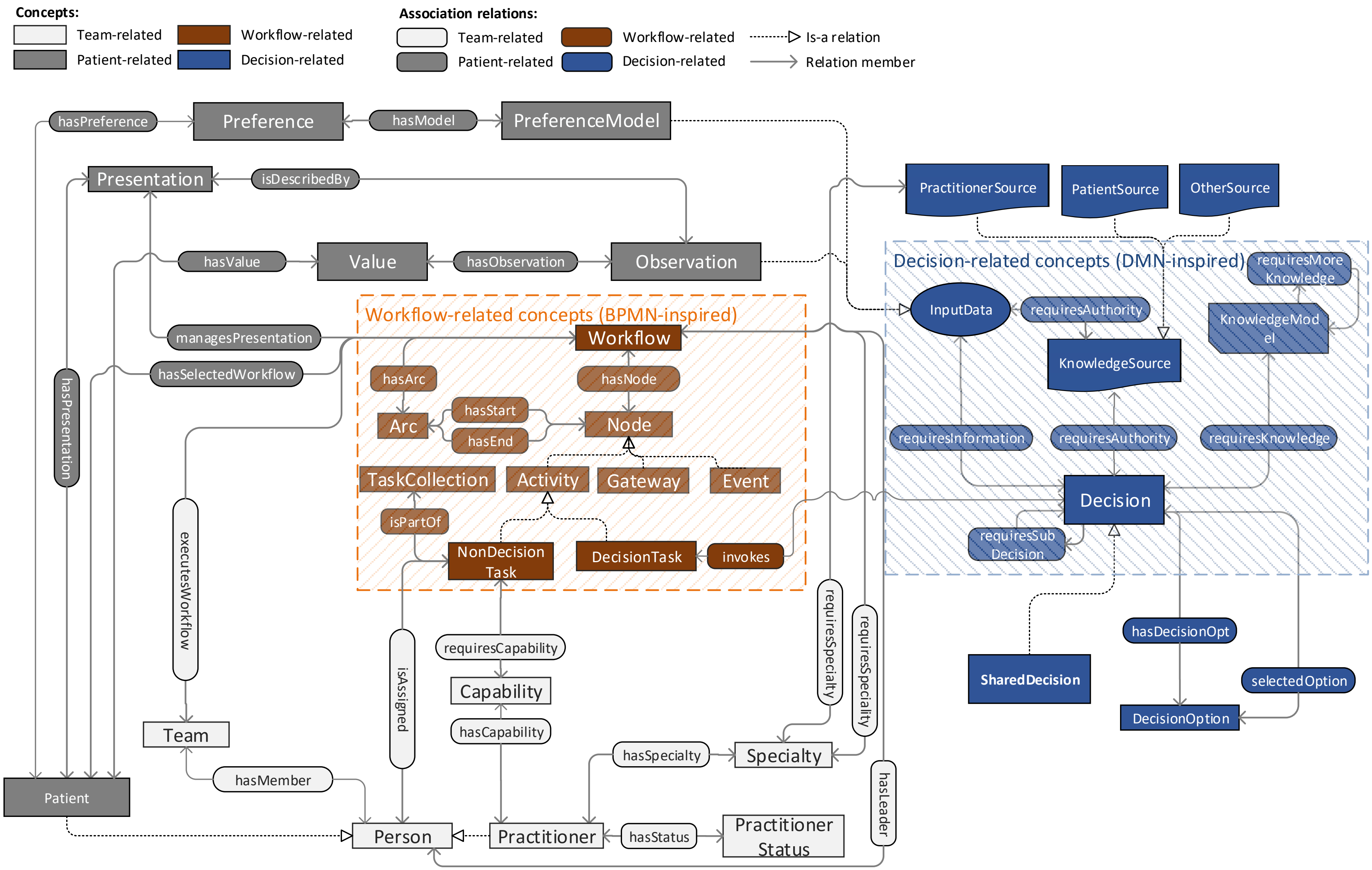

Figure 1. Shared decision-making ontology.

Some changes in the team subdomain, like the new relation *has member* (which now allows both *practitioner*s and *patient* to be considered team members) have been introduced in order to link team-related concepts to the decision-making subdomain.

The decision-making subdomain concepts and relations constitute the core of the SDMO and are instrumental to model situations where patient values and preferences are an integral part of the decision. These concepts are linked to workflow subdomain by the means of the *decision task* concept, that represents a special type of *activity* that requires to receive the output of a *decision* in order to be completed (for example, an activity "prescribe treatment" needs to receive the output of a decision "select treatment option" in order to be completed). In this context, a *shared decision* is a special type of *decision* where both *patient* and *practitioner* are involved as *knowledge sources* (see *practitioner source* and *patient source* in Figure 1). The output of a *decision* is a *selected option* chosen by the patient and relevant members of his/her healthcare team from the *decision option*s (e.g. surgical intervention vs radiotherapy) that are available for that specific *decision.* The *decision* concept also models the specific sub-decisions that have to be taken to establish final *selected option*. Indeed, there might be more than one *decision* involved in a decision problem and usually those decisions are structured in a hierarchical manner where results of lower level decisions (e.g. those that limit the number of viable options that should be discussed with the patient) feed into higher-level ones (see the *requires subdecision* recursive relation in Figure 1). In the SDMO the decision subdomain concepts have been modeled following the Decision Modeling Notation (DMN) standard[22]. Use of this standard is aligned with the use of BPMN-derived concepts for representing workflows (both standards originate from the Object Management Group) and follows the ontology engineering best practice of concept reuse[23]. DMN-derived concepts needed to model decisions are *knowledge model, knowledge source,* and *input*. *Decision*s use *knowledge model*s to specify how to process certain information (e.g. how to calculate a risk score based on patient clinical data) and require a number of *knowledge source*s being participants of the shared decision-making process and providers of *input data*. In our context, *knowledge source*s correspond to members of the healthcare team (including the *patient*). Similarly, *observation*s and *preference model*, are specifications of the more general concept of *input*, and represent the connection between the decision-making and patient subdomains of the SDMO.

Results

SDMO instantiation: Metastatic spinal cord compression scenario

In order to demonstrate how SDMO can be used in practice we created its instantiation using a scenario describing the management of a patient with metastatic spinal cord compression (MSCC). The scenario itself has been developed together with spinal surgeons at The Ottawa Hospital. The scenario mimics a complex and realistic case where a team-based approach is essential to the proper management of the patient and shared decision-making is highly desirable. In the following, we discuss how instantiating concepts from SDMO supports shared decision-making involving MSCC management.

Sarah, a 71 year old female patient with a known diagnosis of breast cancer presents to the emergency department (ED) with a chief complaint of increasing nocturnal back pain and progressive difficulty ambulating due to mild leg weakness and numbness. MRI imaging shows the presence of a spinal metastasis and soft tissue epidural compression. Sarah is started in the ED on non-steroidal anti-inflammatories and dexamethasone to control pain. The oncologist on call is consulted and her assessment of Sarah's condition indicates a potentially unstable spine (SINS score of 7). The history and physical exam confirms that the patient has mild proximal leg weakness and sensory impairment in the lower extremities. There has been no incontinence and sphincter function is preserved. The results of blood tests indicate hypercalcemia and Sarah is started on bisphosphonates. A surgical consult is requested in order to develop a multidisciplinary care plan to be presented to the patient. The care team agrees on two options for Sarah, both with a goal of pain reduction and optimization of her mobility. A third option not to undergo any treatment is also available for Sarah:

Option 1: Palliative surgery (tumor debulking/decompression and spinal stabilization) followed by radiotherapy;

Option 2: Radiotherapy alone.

Option 3: No treatment.

Considering that Sarah's life expectancy is assessed to be approximately 12 months, both options are feasible and, at this stage, a meeting is arranged with the patient, the spine surgeon, and the oncologist to discuss the viable options.

The spine surgeon informs Sarah that Option 1 entails a minimum of 3 months of recovery and is associated with surgical risks (surgical complications such as hardware failure, surgical site infection or neurological deterioration in addition to medical complications) but with the potential to improve mobility, reduce pain and halt neurological deterioration. In turn, the oncologist discusses Option 2, which may halt or slow neurological deterioration, improve pain, avoid associated surgical risks and allow for quicker recovery period. However, pre-operative radiation would increase the risk of wound complications if surgery is eventually required and radiation may be less efficacious than surgery at restoring neurological function[24]. The no treatment option implies no risk of side effects but it would also not change Sarah's current state, with a significant possibility of rapid deterioration over time.

Thus, Sarah's decision hinges on her attitude towards an estimated 3 month recovery period and population derived risk of surgical complications as compared to a less invasive and relatively known path associated with radiotherapy. In the past Sarah showed a tendency to minimize (or even avoid, if possible) uncertainty while making her choices, so she is clearly a risk averse person. A formal assessment of Sarah's preferences is conducted using the standard gamble method for utility elicitation. After taking into account Sarah's risk-averseness, spine surgeon, oncologist and Sarah (the team) agree that Option 2 is the preferred one.

The following sub-sections provide more details on the instantiation of each of the ontology subdomains and walk the reader through the structured approach that the SDMO supports. Figures 3, 4 and 6 summarize the instances of the SDMO concepts and relations needed to support the MSCC scenario.

Workflow subdomain

The management of Sarah (breast cancer with evidence of MSCC and neurological symptoms) demands that a specific clinical workflow has to be followed to provide evidence-based care. We chose to implement the National Institute for Clinical Excellence (NICE) workflow to manage patients with/at risk of MSCC[25]. Interestingly this workflow recommends, "enabling patients to actively participate in their care" and explicitly suggests shared decision-making in cases where MSCC is present. However, it does not specify how this recommendation should be operationalized and the enactment of shared decision-making is left to the physicians involved. In addition, team-based care is mentioned as an essential aspect of the management of MSCC suggesting that "treatment for pain or preventing paralysis caused by MSCC should be made by relevant spinal specialists in consultation with primary tumor site clinicians and with the full involvement of the patient". Figure 2 shows a portion of the NICE interactive workflow "Treating painful spinal metastases and preventing metastatic spinal cord compression" formalized using BPMN, while Figure 3 details the instances from the SDMO needed to represent this workflow.

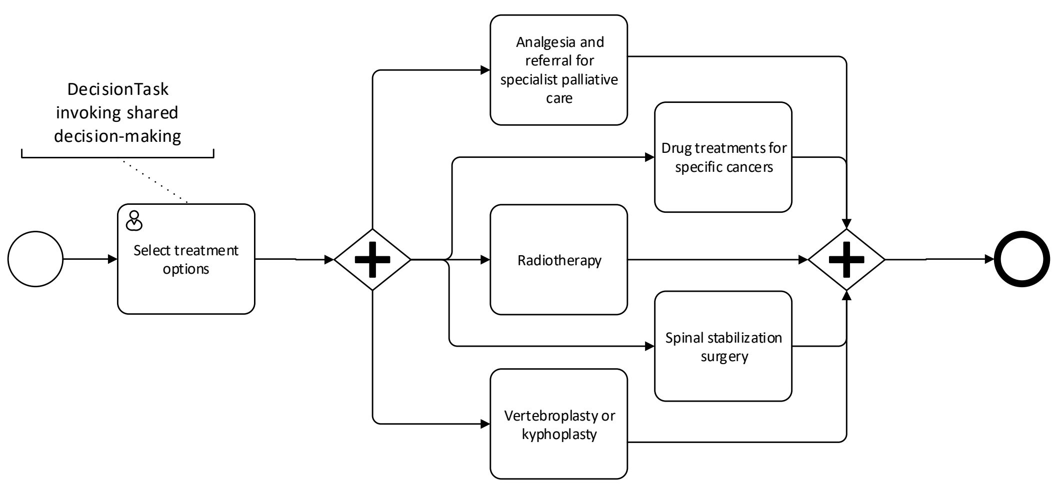

Figure 2. BPMN formalization of NICE metastatic spinal cord compression workflow[26], - treating painful spinal metastases section. A special activity *select treatment options* invoking shared decision-making (instance of *decision task* ontology concept) is used to formalize the need of selecting the most beneficial treatment options to control pain and to slow neurological deterioration.

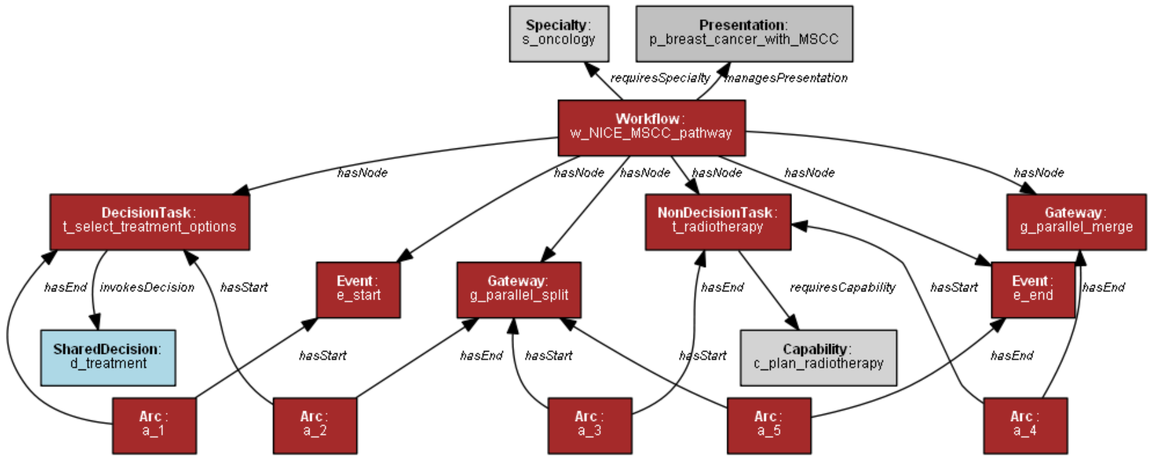

Figure 3. Graphical representation of the instances of SDMO workflow subdomain concepts (rectangles) and relations (arrows) needed to represent the portion of the NICE workflow depicted in Figure 3. Color coding of concepts is in accordance to the one used in Figure 1. Just one (t_radiotherapy) of the five *NonDecisionTask*s has been represented in order not to overload the graphical representation.

Team subdomain

Two medical specialties are needed to effectively manage the MSCC patient Sarah: spinal surgery and oncology. The specialists, together with the patient, collaborate in shared decision-making process to establish a multidisciplinary care plan that takes into consideration Sarah's preferences. Team-related and workflow-related concepts are instrumental to the execution of the workflow and establishment of team composition and task assignment. These have been described in detail in our earlier research[21] and are not discussed here. Figure 4 summarizes the SDMO instances needed to support MSCC scenario.

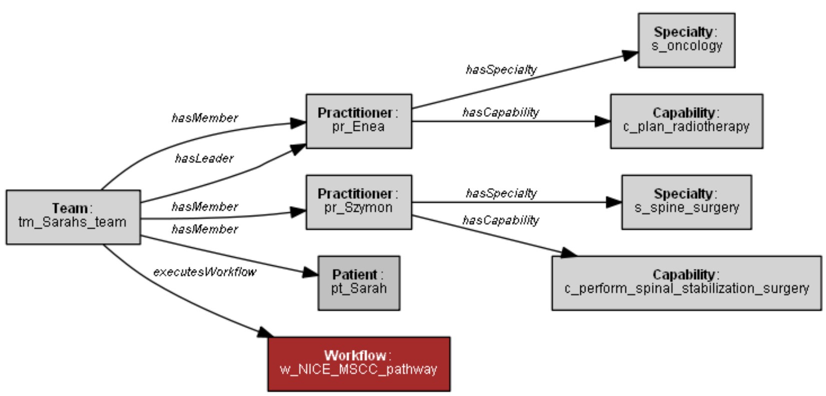

Figure 4. Graphical representation of the instances of SDMO team subdomain concepts (rectangles) and relations (arrows) needed support the scenario. Color coding of concepts is in accordance to the one used in Figure 1.

Patient and decision-making subdomains

The shared decision-making in our scenario involves selection of treatment options for Sarah. We model the decision problem instantiating decision-making subdomain concepts of the SDMO. Figure 5 shows a Decision Requirement Diagram (part of the DMN standard) modeling the *shared decision* about treatment, while Figure 6 summarizes the instances of the concepts from SDMO needed to support the MSCC scenario. The decision-making process starts with the development by the oncologist and the spine surgeon of a multidisciplinary consensus care plan that restricts the available range of treatment options only to the ones that are viable for Sarah's situation. The establishment of the multidisciplinary care plan is already a decision (i.e. instance of the *decision* concept) whose output informs the shared decision by limiting the range of *decision option*s to be considered as the candidates for the *selected option*s. Both medical specialists rely on several sources of medical knowledge, such as clinical practice guidelines, risk scores (e.g. SINS, revised Tokuhashi, Tomita and Baur scores) while considering treatment benefits in terms of life expectancy and quality of life that every option should bring to the patient. All of this information acts as *inputs* and *knowledge models* to the multidisciplinary care plan decision (Figure 2), which in turn, serves as an input to the shared decision-making about the treatment. The multidisciplinary care plan, in addition to the no treatment option, restricts Sarah's options to palliative surgery followed by radiotherapy, or radiotherapy alone. The actual *shared decision* regarding which option to select involves both medical specialists and Sarah. The main factors that are being considered include the primary tumor site (this heavily influences prognosis, life expectancy and success rates of treatments) and Sarah's preferences. Different preferences models can be adopted to assess preferences in the SDMO but here in order to establish Sarah's risk attitude we relied on utility coefficients[27]. Our earlier research produced a tool that implements several utility elicitation methods for use in shared decision-making[28,29]. Sarah's risk aversion is formally assessed using the standard gamble method[30], in which she refuses to undergo an hypothetical surgical intervention that might significantly mitigate her symptoms but also involves a risk of death. Sarah refuses to even consider this gamble and is therefore assessed as a zero-trader (i.e. her utility coefficient is 1) characterized by a very strong risk aversion. Her risk-averse attitude together with the fact that MSCC originating from breast cancer is sensitive to radiation therapy make *Option 2: radiotherapy alone* the preferred treatment for Sarah.

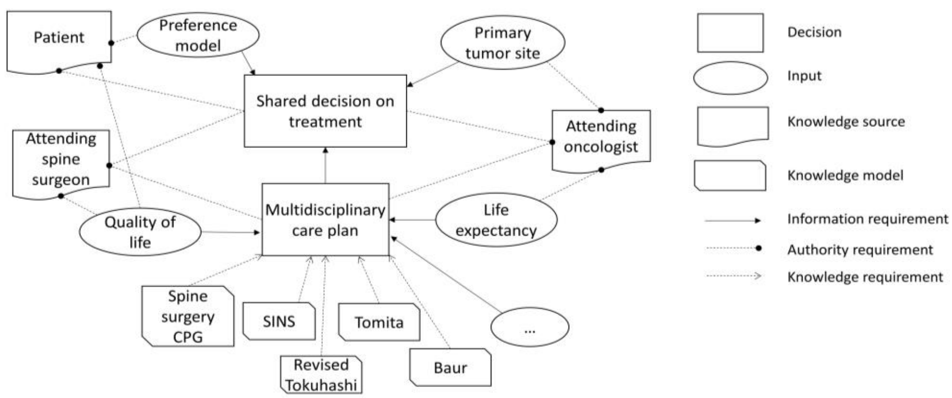

Figure 5. DRD representation of the *treatment option selection* shared decision task. The inputs that model data required by the different scoring systems are omitted to allow a more compact graphical representation.

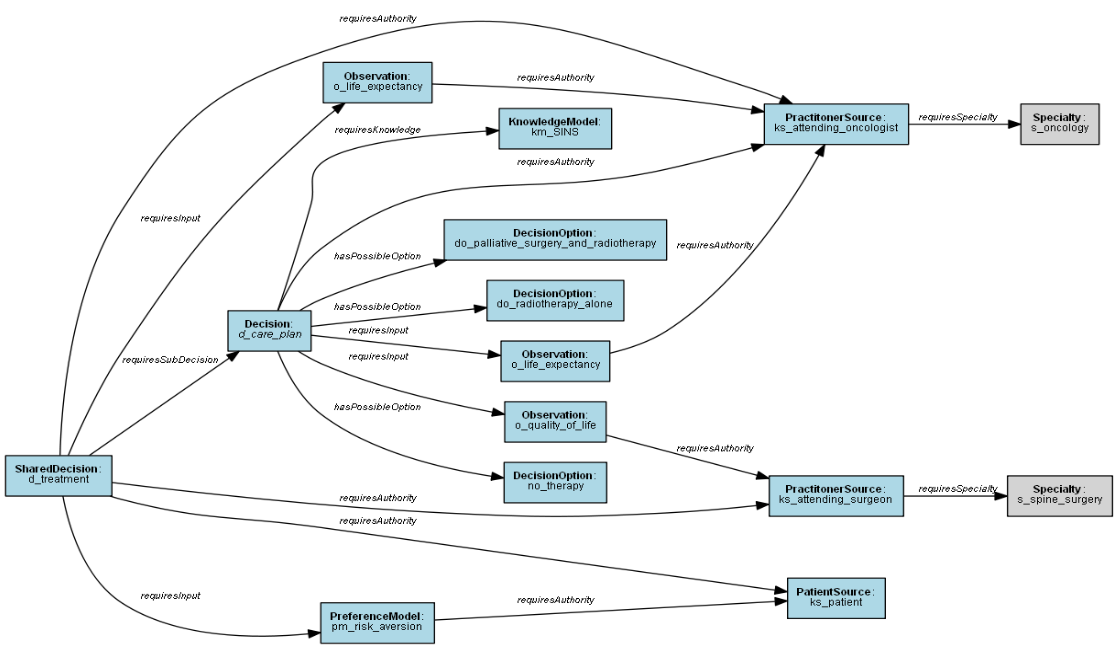

Figure 6. Graphical representation of the instances of SDMO decision subdomain concepts (rectangles) and relations (arrows) needed to support the MSCC scenario. Color coding of concepts is in accordance to the one used in Figure 1. Only one (SINS) of the *knowledge models* has been represented in order not to overload the graphical representation.

Ontology technical implementation and consistency checking

The SDMO presented in this paper has been implemented using Protégé 5.2.0[31] and is available to the readers, together with the instance base we created to support our MSCC scenario, at: http://www.mobiledss.uottawa.ca/sdmo/sdmo.owl. Availability of the SDMO in a standard OWL formalism enables researchers to build upon SDMO and represents first step required for its use in the development of computer-based decision support system for shared decision-making. Incremental consistency checking using the HermiT reasoner has been conducted during the ontology implementation. Several refinements were iteratively introduced until no formal defects in the ontology structure and in the corresponding instance base were found by the reasoner. The final version of the instance base has been directly used to produce the graphical representations reported in Figure 3,4, and 6 using the Graphviz library.

Discussion

Shared decision-making fosters active involvement of a patient in a process where physician presents evidence-based treatment information and options while openly eliciting and incorporating patient values and preferences. Research so far has focused mostly on empowering patients with some form of decision aids that help better understand the clinical context and how patient's values and preferences play in that context. Elwyn et al.[32] argue that focusing just on patient empowerment is too narrow and a number of different potential effects should be considered. However, in order to do so, one needs to develop support tools that span the entire shared decision-making process and support multiple actors participating in it. However, implementation of patient-centered decision support, and especially shared decision-making, is still in an early stage of maturity[33,34]. In this paper, we argue that development of these tools is possible only if the shared decision-making is formalized and integrated with the realities of modern care delivery – the presence of the interdisciplinary healthcare teams and workflow-driven and evidence-based patient management. The first step in the proposed formalization is to systemize what shared decision-making is about, and this can be accomplished with creation of a SDMO. Such ontology should include concepts and relations that are associated with a decision-making process (by all team members, including the patient), workflow and its execution, patient, and team. Similar integration into clinician workflow and computerization are advocated by Kawamoto[35] as two of the critical features of successful clinical decision support systems.

In this paper, we leveraged the previous experience of our group in supporting shared decision-making[29,36,37] and management of the complex dynamics of an interdisciplinary healthcare team[21] in order to develop a shared decision-making ontology. The SDMO proposed in the paper draws from the BPMN and DMN standards for better portability. It formalizes the intertwined character of shared decision-making process by bringing together patient's preferences and values elicitation and use, physician's evidence-based approach to patient management, and collaborative and team-based decision process. Therefore, SDMO is composed of four subdomain ontologies each representing relatively homogenous set of concepts and relations associated with each of the aspects of disease management and diagnostic processes. Such proposed representation facilitates SDMO re-use in different clinical context and for different standards.

We operationalized SDMO by its instantiation for managing a complex case of the MSCC patient. The presented instantiation can be used as a foundation for creating an architectural framework for a computer-based decision support that helps an interdisciplinary team to include patient in their decision-making process and at the same time helps the patient to learn about his/her values and preferences. The proposed ontology can be reused in other medical domains that need a blueprint on how to effectively integrate these aspects.

The main limitation of our study consists in the fact that only a limited formal validation of our ontology was conducted using the specific case of MSCC scenario and well-formed ontology principles checked via the HermiT reasoner. Further evaluation of the SDMO using ontology engineering principles such as competency questions[38] is planned for future work. To facilitate dissemination and re-use of our SDMO, we also plan to adopt BFO as a general framework[39] for the future versions of or ontology, and possibly submit it for inclusion in the OBO foundry[40]. The next step in our research is to develop the architectural framework to create MSCC decision support system, and to retrospectively evaluate this system in a simulated clinical setting.

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