SpirOnto: Semantically Enhanced Patient Records for Reflective Learning on Spiritual Care in Palliative Care

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Abstract. Ontologies as shared understanding of a domain of interest can support reflective processes in spiritual care. Such an ontology has been extracted from an empirical analysis of historic patient records, which has identified a key structure. This ontology is supposed to support the reflective learning process of the palliative care team, which is interdisciplinary. A first prototype for a semantically enhanced patient care documentation system has been developed which embeds links to spiritual care into practice and helps to create awareness among other disciplines about the systematic nature of spiritual care.

Keywords: ontologies, spiritual care, patient documentation, reflection

1 Introduction

Palliative care is a challenging multidisciplinary field where different perspectives need to complement each other, including nurses, doctors, social workers but also the frequently neglected aspect of spiritual care. Particularly this aspect has become more complex as a consequence for an increasingly multi-cultural society with a myriad of religious and spiritual ideas and beliefs.

Currently there is little awareness about spiritual aspects in palliative care in adjacent professions (such as physicians or nurses), and the perceived significance of this part of palliative lags behind other professions. This is due to spiritual care not being explicitly represented in boundary objects between the professions, most notably in patient records, but also due to lack of evidence about the effectiveness of spiritual interventions beyond anecdotal evidence.

An analysis of their work and learning practices has revealed that due to the demanding nature of palliative care, reflective practice can already be identified on a regular basis, particularly as regular, but informal group meetings, and as institutionalized "supervision" in larger time intervals. This is an important element of coping strategies. In these reflection sessions, narratives about patients (from varying timeframes) are used to deepen the understanding about individual cases, but also to discover patterns across cases, to rationalise encounters of everyday practice. Team members have developed a remarkably rich understanding of their work through these practices.

To promote the understanding of spiritual care, building upon those reflective practices seems to be a very promising approach. Therefore the work presented in this paper has concentrated on identifying and designing artefacts that can act as boundary objects and support the reflective learning process and that can promote the maturing of knowledge, especially through two activities: getting an overview about individual cases and discovering patterns across cases.

The key idea of the approach is a spiritual care ontology, which represents a shared understanding of the domain accessible to all involved professions. This ontology is used to enhance patient records, represents a scaffold for reflection sessions, and captures evidence about relationship between patient situations and effective interventions.

In the following sections, we present the ontology and how it was developed (section 2) and the concept of how it is designed to support the (collective) learning process (section 3) before we present a first prototype in section 4.

2 Spiritual Care Ontology

In order to come up with a meaningful and relevant ontology, an empirical approach has been chosen to develop the ontology (more details on the process are described in Stiehl et al. (2011)). As a first step, a qualitative empirical analysis of 143 records of patients between 2004 and 2010 has been conducted. The concepts found were iteratively integrated into an (informal) ontology using concept maps. This ontology was discussed with practitioners in workshops for relevance and comprehensibility to align the empirical results with the needs in everyday practice.

The structure of the resulting ontology can be decomposed into the following key elements:

- **Facts about a patient or its social environment** including relatives and friends (expressed as direct properties). This includes demographic data, information about course of disease and care status, but also the cultural background (e.g., religion, migration background, or whether an individual has been raised in rural or more urban areas).
- **Observations** that led to the identification of the facts (having a timestamp and a possibly rich description of the observation.
- **Spiritual concepts** that interpret facts (and thus also observations). This includes a large set of concepts, such as eternity and finiteness, eternal love,

love, guilt, purity, powerlessness vs. almightiness, or autonomy. The links to observable behaviour or facts are context-dependent interpretations – different individuals link the same "facts" to different concepts, depending on their background and personal expectations. The spiritual concepts originate from spiritual traditions, but are not limited to a single religion, which is particularly important with the increasing diversity in religion and culture within society.

- **Spiritual interventions** are possible spiritual care activities. These can include active spiritual support, meaningful silence, pastoral interviews, practical consultancy, or rituals.

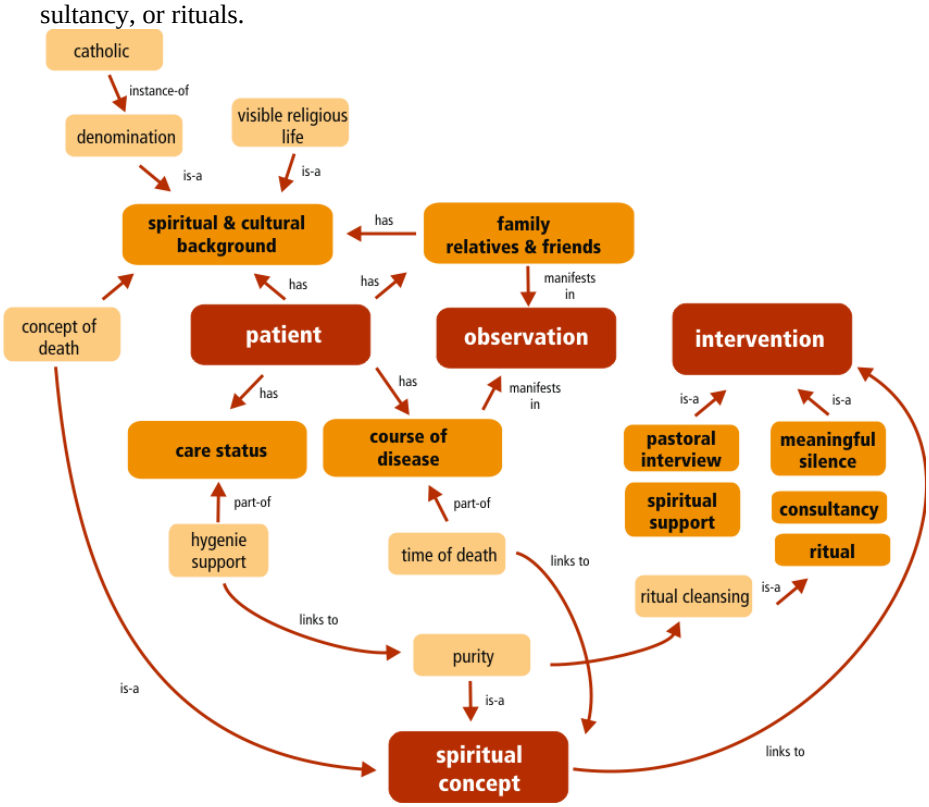

Figure 1: Small subset of the ontology for spiritual care

It is important that there is a connection between these key concepts. Observations lead to facts about a patient (or their relatives). These can be linked to spiritual concepts, such as concepts of death, purity, or forgiveness. These links show needs and unresolved spiritual conflicts that are particularly important in palliative care processes. It should be noted that spiritual care is necessary for the patient, but also for the relatives, and even for the palliative care team. Finally, the spiritual care interventions link to spiritual concepts so that the identification of concepts can help to identify appropriate interventions (and their contextualization). Such interventions could be anointing in a catholic tradition, but also ritual cleansing in other cultures. But it could

also identify topics for pastoral interviews. A small example of the ontology is shown in figure 2 (the whole ontology consists of more than a hundred elements).

This ontology does not only allow for representing the knowledge about a patient and their social environment in a systematic way; it also represents to a certain degree the knowledge about appropriate spiritual care by providing the relevant concepts and identifying the possible interventions, which is an analogy to diagnosis and treatment in medical care.

3 Ontology & the Loops of Learning

The ontology is not only intended to act as a boundary object (together with the patient record) between the disciplines, but also as a bridge between operational and reflective processes, which is common in reflective learning:

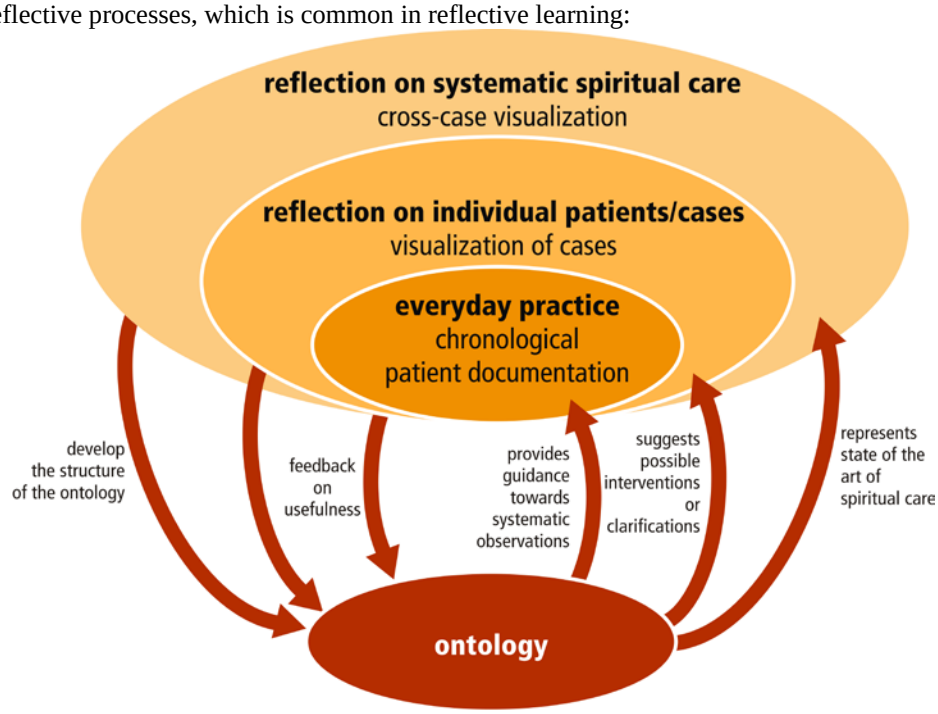

Figure 2: Levels of reflective learning and the role of the ontology

- On the **operational level**, carers document their activities as well as any observations on the state or other aspects deemed to be potentially relevant. This usually takes place in a chronological way. Palliative care processes, however, often extend over long periods of time (it also has to be taken into account that not only the patient, but also relatives are to be cared for). The key idea is that by annotating these incrementally collected notes with concepts from the ontology, a system can tie together distant observations about (possibly) the same aspect. Also the ontology can guide towards possibly neglected aspects.

- This forms then the basis for **reflection about individual cases**. Reflection is already institutionalized as regular meetings. The ontology can help as a structure to have a systematic look at aspects that might be relevant for spiritual care. It is important to note that these observations are typically made by the various disciplines and need to be put together to have a reasonably complete overview. The structure of the ontology can show gaps of information and its use promotes awareness and understanding of relevant spiritual care aspects.
- On a longer timescale, **multiple cases** can be analysed to enhance the body of evidence about effectiveness of spiritual care interventions in certain contexts. Patterns can be discovered, such as differences in age with respect to dealing with the prospect of dying (such as asking why). Such patterns can be then used to further enhance the ontology and can feed into targeted research activities.

4 The System

A first prototype for a novel patient documentation system that is guided by the ontology has been developed in a participatory design approach. The resulting system is based on a flexible backend implemented in Java ontop of Sesame RDF store and Lucene for fulltext search. The front-end is has been implemented for Windows Tablets and laptops in C# using the Windows Presentation Framework. The front-end is designed to support offline operation so that the application does not depend on network coverage at all times.

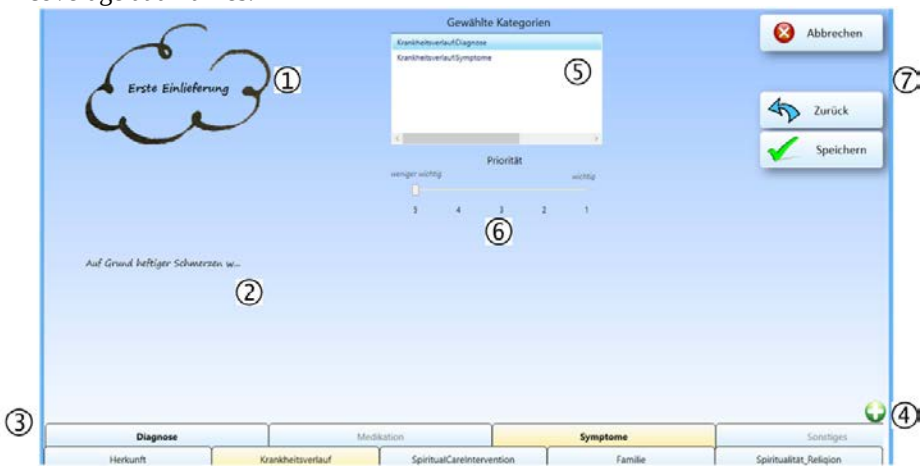

Figure 3: Screenshot showing an observation annotated with concepts from the ontology (tabs at the bottom)

The prototype allows for entering notes about patients in a chronological way. In a simple interface, the user can assign concepts from the ontology to the note. Only a small part of the ontology is static (in the sense that it can only be changed by an administrator); apart from that, users can extend the concepts in the ontology if they find

that something relevant is missing (or rename concepts introduced by others, e.g., after a discussion in a meeting). This supports the gradual maturing of the ontology, not only as part of the reflective sessions, but also as part of everyday practice by capturing aspects that are not yet covered by the ontology.

5 Outlook

While spiritual care is often belittled as lacking evidence of its effectiveness compared to other disciplines in palliative care, the development of the ontology has already shown that spiritual care follows a systematic approach. This systematic approach is made visible through the general structure of the ontology that has been derived from historic patient records: observations/facts, spiritual concepts as interpretations, and spiritual care interventions. Workshops with physicians, social workers, and carers have shown that the ontology can act as a boundary object between the disciplines and can create awareness about spiritual care and its relevance for holistic care.

A first prototype has been built that demonstrates a novel approach to care documentations where observations can be associated with spiritual care concepts in a lightweight way. This opens the possibility for enhancing the reflection on the individual patient (that already takes place) with a structured representation about individual cases (e.g., to more easily discover gaps), and for developing spiritual care knowledge further (by analysing across cases and collecting the experiences).

We are aiming at trialling the prototype and gaining additional evidence about how such an ontology can enhance both practice and associated learning processes.

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References

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