NAOMI platform optimizes communication with relatives of patients

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***Abstract*—Relatives of patients admitted to the Intensive Care Unit (ICU), Burn Unit, heart monitoring and stroke care, or other units where patients are monitored and treated for acute, life-threatening disorders, experience a lot of stress. Despite medical staff trying to comfort and support relatives as much as possible and offering all needed information about the patient's situation, relatives tend to misinterpret and forget most of the given information. Whenever available, the relatives are given brochures where they can read the given information again. However, as these brochures need to be generally applicable, they contain a lot of information that is not directly relevant for the patient's relatives. In order to gain as much information as possible, the relatives often turn to the Internet, which also contains a plethora of information that is not applicable to the particular patient's condition. This often leads to misconceptions, more worry. confusion or unneeded concern and stress. To counter these issues, we designed the NAOMI platform, a patient information system that supports communication between the medical staff and patient's relatives about the patient's condition through a digital platform. NAOMI automatically retrieves the patient's pathologies and/or symptoms from the electronic patient record and uses this data to automatically generate, using semantic technologies and natural language processing, a digital brochure that only contains relevant information, avoiding misconceptions and providing a source of information that is personalized to the patient's current condition.**

Keywords—component, formatting, style, styling, insert (*key words****)***

I. Introduction

The Intensive Care Unit (ICU) of Ghent University Hospital is responsible for the treatment of patients with acute, life-threatening disorders. The patient is constantly monitored by a team of doctors and nurses. During the hospitalization, the patient's relatives experience a lot of stress. The medical staff of the Ghent University Hospital tries to comfort and support the family members by offering specific information about the patient's situation. However, during this stressful period the family members tend to forget the given information, and up to 70 percent of the given information is lost. Dynamic care plans and the involvement of numerous clinicians complicate the information-sharing even more. Currently, this information sharing is being performed verbally, supported by paper brochures whenever available. The few available brochures are created for broad categories of pathologies, to ensure usability for a large group of patients. Consequently, they contain a lot of information that is not applicable to the particular patient's condition. As such, the family members tend to be drowned in non-specific and detailed information. To enrich their knowledge about the patient's pathology, they then tend to search the Web for more information, e.g., using Symptom Checker[1]. This leads to misconceptions and more worry because the found material is not personalized and contains too much information that does not apply to the specific situation or treatment of the patient. The study of Verhaeghe et al. showed clearly that adult patients and family members have needs in 4 different areas: cognitive, social, emotional and practical. The cognitive need, i.e. need for information and knowledge is the most prominent, and communication is seen as the central mechanism for information processing and knowledge sharing.

To counter these issues, we have designed a patient information system, called NAOMI, to support communication between the medical staff and the patient's relatives about the patient's condition. NAOMI allows the medical staff to upload brochures. These are semi-automatically annotated according to pre-defined, fine-grained categories. When a patient is admitted to the ICU or his/her condition is updated in the electronic patient record (EPD) of the hospital, his/her pathology and/or symptoms are automatically mapped on these annotations. As such, only relevant brochures are provided as information to the relatives. In this way, NAOMI provides a source of information that is personalized to the patient's current condition. Moreover, to support verbal communication, NAOMI also contains a question-and-answer service, allowing the medical staff to inquire about the (medical) history and lifestyle of the patient, and a diary, enabling the patient and relatives to share text and pictures with each other.

II. Related work

The medical world is currently lacking an application that offers dedicated, personalized information based on the situation of a patient at the ICU. Tools exist that try to offer information based on specified symptoms. These tools like 'Symptom Checker' are readily accessible on the World Wide Web. However, they can lead to misconceptions, as the patient's symptoms are often not described according to the correct medical terms.

The ICUSmart Care application is an application designed for the Pediatric Intensive Care Unit (PICU) at the Great Ormond Street Hospital for Children in London and meets mainly the cognitive needs of the user. In this application

[1] https://patient.info/symptom-checker

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information can be shared about the medical equipment, treating staff and patient data via a real-time visualization. In addition, this provides a large improvement in cooperation with family members, through increased access, presence and interaction with both the patient and his/her family[2]. A major shortcoming of this latter application is however the absence of emotional support for patients and their relatives. The FamiliaresHUCI Fuenlabrada application does meet this requirement by adding an intensive care diary. The application was specifically developed to support patients suffering from the post- intensive care syndrome, which is a syndrome affecting especially the most critically ill patients and which is a collection of physical, mental and emotional symptoms that continue to persist after a patient leaves the intensive care unit. Patients and family members can submit their concerns on a daily basis. and record experiences, stories during the patient's stay in intensive care.

Another development that is in line with the idea behind the NAOMI platform, is the website of a hospital in the Netherlands. This hospital, called Ziekenhuis Gelderse Vallei (ZGV)[3], offers information categorized according to the possible diseases and disorders of a patient. The information that is available is represented in a clear and intuitive way. In addition, the brochures consist of reliable information, as they are written by medical experts. The difference with the aforementioned website is that the NAOMI platform offers dedicated information about the patient's situation, in a timeline. This way, family members don't have to look up additional brochures themselves, and are able to have an overview on the different catheters, tubes and pathologies of their family members. On top, the NAOMI platform is an interactive web application that's available on every device with an internet connection. It supports interaction by being able to consult dedicated brochures and by communicating with the medical staff about the Quality of Life (QOL) of the patient.

III. NAOMI Architecture and Details

A. Architecture

In general there are three main components in the development of the platform, as shown in Figure 1. Two web applications have been developed: one for the patient and his family members and one for the medical staff. Both applications communicate with the NAOMI server. This server contains the backend mechanisms and is connected to the NAOMI database.

The database of the NAOMI project only contains data needed for the operation of the platform. In this database, information about the brochures and accounts are stored. For the mechanism that links a brochure to the disease of a patient, extra information about the patient is necessary. This data can be retrieved from the existing databases in the Ghent University Hospital. The platform can access this data through the use of a data virtualization system, called jBoss Teiid[4]. The integration of the NAOMI components in the existing environment of the Ghent University Hospital is illustrated in Figure 2.

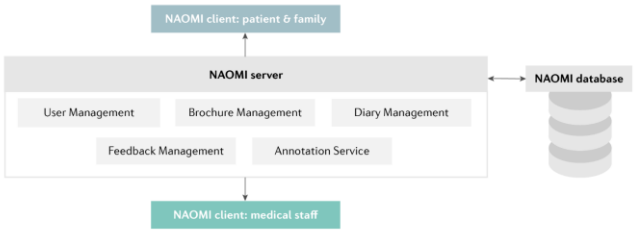

Figure 1: High-level architecture of the NAOMI platform

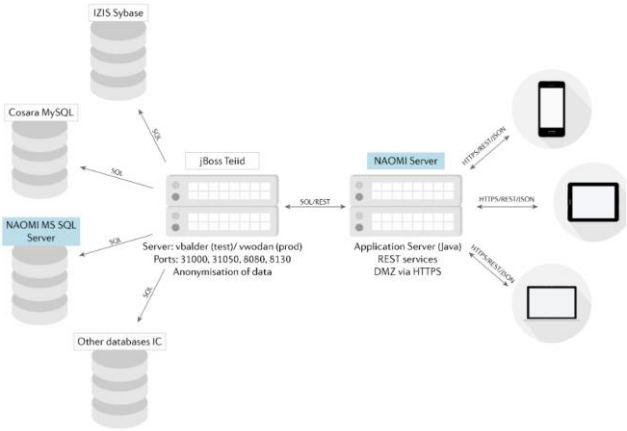

Figure 2: The NAOMI platform integrated with the Ghent University Hospital architecture

As mentioned earlier, the NAOMI server includes the techniques to represent dedicated information for the patient. To do so, the development of the server comprises 3 main functionalities:

- An annotation system to categorize brochures by predefined categories
- A rule-based system to retrieve the pathology of a patient and link this with the correct brochure information
- An API for communication between the server and the client

B. Annotation system

A semi-automatic annotation system was developed to find out which brochure is associated with the specific pathology of the patient. This system annotates each paragraph of a brochure with one or more medical terms/categories, this way categories can be linked to the medical texts.

The system fundamentally relies on the use of a medical ontology, more specifically the SNOMED CT (Systematized Nomenclature of Medicine – Clinical Terms) ontology[5]. This ontology represents a collection of medical concepts where each one of them is described by fixed medical terms. The advantage of an ontology is that every term or token can be represented by a set of agreed concepts. In this way knowledge can be shared within the medical domain in a uniform way. To retrieve data from the ontology, the database platform Stardog[6] makes it possible to query, search and analyze graph data with the use of SPARQL queries[7].

Using SNOMED CT, brochures can be classified into predetermined categories. Kirsten Colpaert, MD, compiled the relevant categories herself. For each paragraph in a brochure, the annotation system extracts matching SNOMED CT labels. Then, the mapping of the categories is obtained by

[2] https://patient.info/symptom-checker
[3] https://www.geldersevallei.nl/patient/
[4] https://docs.jboss.org/author/display/teiidexamples/What+is+Teiid
[5] https://www.snomed.org/snomed-ct
[6] https://www.stardog.com/
[7] https://www.w3.org/TR/rdf-sparql-query/

checking the found SNOMED CT labels with the fixed set of predefined categories. An example of the mapping can be found in Table I.

To extract the matching SNOMED CT labels from the brochure, the annotation algorithm first identifies the different paragraphs in the brochure. Next, tokenization is performed that splits up the paragraph in single tokens consisting of 1 or more words that have joint meaning. For example the sentence 'The patient has non-invasive ventilation' would result in five different words: 'The', 'patient', 'has', 'no' and 'ventilation'. With the use of tokenization it is possible to maintain the negation in the sentence, namely 'non-invasive ventilation'. Next, the text is normalized to remove capitalization and superfluous characters, e.g., punctuation and numbers. Each word is then reduced to its stem through lemmatization and stop words are removed. Lemmatization reduces each word to its base or dictionary form, thus increasing the chance of matching with a SNOMED CT label. The application of lemmatization was possible by integrating the annotator of the Stanford CoreNLP toolkit[8]. A list of frequent stop words is maintained. This list contains words that do not contribute to meaningful information like 'a', 'the', etc. Finally the remaining words are translated to English such that they can be matched with the English SNOMED CT labels.

The brochure and its labels are stored in the database in a tree-based manner. The root is the title of the brochure. Each child of this root represents either a paragraph or a subtitle. Paragraphs below a subtitle are added as children of this subtitle node. As such the structure of the document is reflected in the shape of the tree, i.e. the more subtitles, the deeper the tree. A parent node also receives the labels of its children and the most frequent ones are used to label this parent (i.e. title). As such, the root contains all the most important labels that categorize this brochure and all the relevant paragraphs and titles can easily be identified that are linked to a particular term.

Table I: Mapping between predefined categories and SNOMED CT concepts

Fixed category name	SNOMED CT id	SNOMED CT label
Coma	id/371632003	Coma (disorder)
Delirium	id/2776000	Delirium (disorder)

C. Rule-based brochure suggestion

The second part of the methodology to deliver dedicated brochures is the rule-based system. This system retrieves the pathology of a patient and determines which brochures need to be shown.

The rule-based system, implemented with the Easy Rules system[9], uses patient data from the ICU database of the Ghent University Hospital. This data or 'facts' function as the input of the rule-based system. Next to the facts, the system also needs 'rules'. They describe which action must be executed under which condition. Each rule has been created by a medical expert and encompasses the mapping between the patient's condition and a fixed category.

The core of the rule-based system is the inference engine. This engine compares rules and facts. When a certain fact matches a condition or rule, an action is being fired. This way, each patient can be linked to a predefined category as shown in Table II. The link between a patient and a category ensures that only paragraphs from brochures related to this category are shown in the platform.

Table II: Example of a fact and rule in the rule-based system

Fact	Endotracheal tube present for more than five days
Rule	Add category 'Swallowing disorder' to patient

D. Web application

The NAOMI client is an Angular web application that is available through a URL. The choice for developing a web application relies on providing easy access on each device. The only requirement being the presence of an internet connection. In total two web applications have been developed.

The first application was designed for use by patients and their relatives. In this web application, the user can consult and review content that is fitted to the patient's situation. This content is displayed both in a timeline and in alphabetical order. An example of the timeline can be viewed in Figure 3. In addition, this application provides a way to communicate with the medical staff about the Quality of Life (QOL) and medical history of the patient. This communication is available as a question-and-answer service and complements the verbal communication. Overall, the user experience for the patient and his family members are very similar. The only difference is the management functionality. For example, the patient can view and edit linked family members and, if desired, even delete a family member from his account.

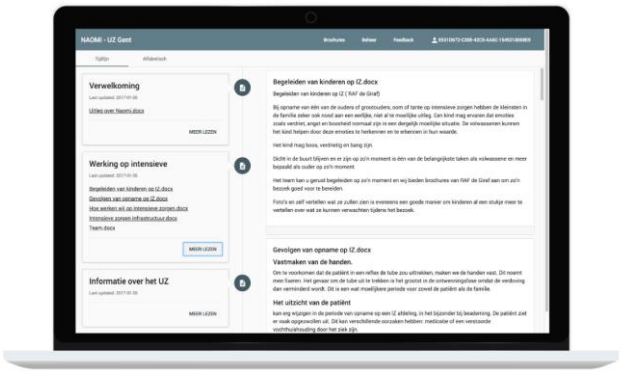

Figure3: Timeline in the patient web application

The second web application is the one created for managing the NAOMI platform. This application is only available for the medical staff. The main functionality is the possibility to upload new brochures. When a new brochure is being uploaded, it passes through the annotation system. The result is a set of SNOMED CT labels that can be viewed in the browser. An example of the semi-automatic annotation process is visible in Figure 4. Next, a medical expert can evaluate the proposed labels for each brochure. The next step is to decide whether or not the paragraphs have been labeled correctly. If there are wrong or unnecessary labels, the medical expert can decline them. Finally, the annotation system categorizes this newly added brochure and attaches it

[8] https://stanfordnlp.github.io/CoreNLP

[9] https://github.com/j-easy/easy-rules

to the collection in the NAOMI database. Now this brochure can be linked to the patients, depending on their condition.

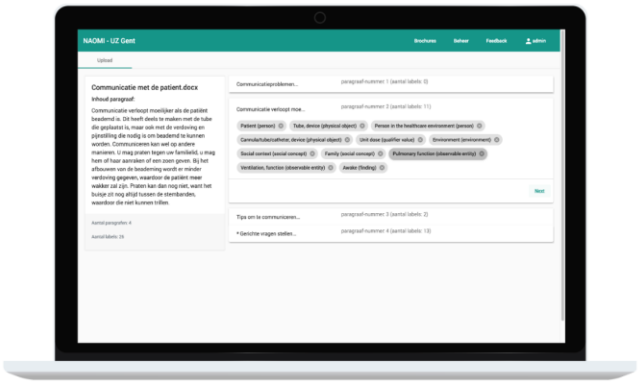

Figure 4: The UI for semi-automatic annotation in the web application for the medical staff

In addition, the application allows the administrator to manage the QOL part of the communication between family members and medical staff. The administrator has access to all available accounts and is capable of linking family members to a patient. This is illustrated in Figure 5.

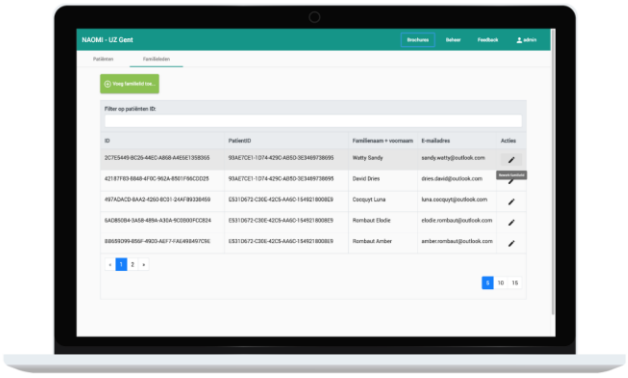

Figure 5: Management page in the medical staff web application

Finally, a Diary service is foreseen allowing the patient and the relatives to write texts and upload pictures chronicling his/her stay at the ICU as well as events happening in the lives of the relatives. An example is shown in Figure 6.
A video of the web applications can be found at: https://www.youtube.com/playlist?list=PLFnSuWuVj0rFwVYp4o1d0bekLVYaq8n9J.

Figure 6: The UI for the diary application

IV. Evaluation

Some tests were performed to evaluate the semi-automatic annotation system of the NAOMI platform. The first test was the evaluation of the total amount of labels that were retrieved using various versions of the annotation technique as shown in Figure 7. For 86% of the tested brochures, the annotation with the one word label extraction (including paragraph extraction, optimized normalization and stop word list for the ICU, lemmatization, and translation, excluding tokenization and identifying negations) showed an increase in the number of labels that were found in relation to the baseline method (excluding lemmatization, with a standard stop word list not optimized for the medical ICU setting and standard normalization which was sometimes prone to removing too much symbols, e.g. hyphens combining words such as non-invasive). The two word label extraction (including additional tokenization of up to two words) showed an increase of 93% of the total amount found in comparison to the one word label extraction. The last method, the advanced label extraction (including additional tokenization of up to three words and improved detection of negation), only showed an increase for 43% of the tested brochures. This is due to the reformation of labels such as 'Oxygen (substance)' and 'Mask (physical object)' into one label namely 'Oxygen mask (physical object)'.

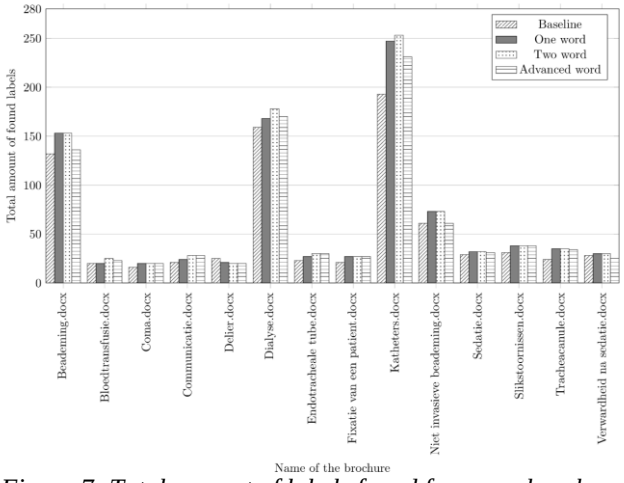

Figure 7: Total amount of labels found for every brochure, tested with each one of the annotation methods

As a complementary test, it has been evaluated what labels the annotation system returns for a sample text. This accuracy test gives more insight into what labels had been assigned correctly or not. This sample text was compiled with medical terms from the different brochures, provided by the Ghent University Hospital. This way, it was possible to set the ground truth for what SNOMED CT labels to expect. Depending on this ground truth, labels are assigned 'correct' or 'incorrect'. In total, the sample text consists of 248 words. Because the originally found labels often contained too many synonyms, a filtering of these synonyms was done for each one of the annotation method results. Next, each label was reviewed and was criticized whether or not it was correct. The results of this test are available in Figure 7. In this Figure, it is clear that the number of correctly labeled words, via the one word label extraction, has increased 3.26% compared to the baseline method. It is also noticeable that the amount of correctly labeled words has further increased with the two word label extraction. The advanced word method finally shows a small decrease of 1.42%. Every time this method is executed, it takes three consecutive words into account. This way, the annotation system is inclined to find more labels as well as more synonyms. However, these synonyms do not occur with every method, so they were not first removed in the filter process of this test. In this test, the small decrease in the total amount of correct labels is the result of this event.

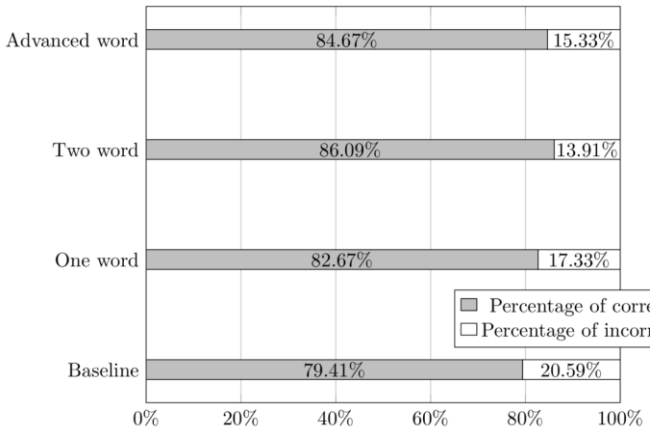

Figure 8: The accuracy of the annotation method, tested with a sample text (%)

Besides the technical evaluation, a qualitative explorative study was performed by 2 master thesis students, evaluating the needs of ICU patients and their relatives about this informative application. In total 10 patients and 12 relatives were interviewed. Both patients and family members have a need for information, and the brochures and diary were seen as the most supportive functions, with a great emphasis on the timeline, in combination with the communicative aspect of the diary. They believe that too much technical jargon is used in standard brochures, and Naomi solves this. They expect that the given information will be scalable and accessible to everyone. They advised us to keep the brochures short and concise. Many perceived that a medical diary would be of great mental support and have decreased stress levels substantially.

V. NAOMI NEXT STEPS

The Naomi application is a means for improving the literacy of family members and patients. In that sense, it fills in a knowledge gap, and decreases the stress that is accompanied with the admission of a family member to the ICU. But besides giving information about the disease status, Naomi could also be upgraded in order to provide information about services that are potentially useful for the relatives. These offerings of services by means of an app in app service, could be adapted to the needs of the family members according to the timeline of the patient's admission. Here are some examples for services provision: at admission of a patient to a hospital, it is required to fill in the administration for work absenteeism. Not doing so in a timely manner could have financial implications for a longer term. A second example could be that the application of the social security company to which the patient is affiliated will be shown, along with the recommended brochures applicable to this patient journey. These recommended brochures could change in the course of the patient's admission to the hospital. At a certain moment this could also be accompanied with the offering of a rental service for needed aids and furniture (e.g. crutches, wheelchair, bed,...), depending on the course of the hospital admission. Other service providers such as meal deliverers, day-care for children, and shelter for pets could be made available if wanted. Information on transportation could be made available with an app in app feature. Another feature that is very useful for the family members is the availability of a notification showing by a specific color code if a family member is still in the operating room or not. This can be very valuable since timings of operations are not always fixed: they can be delayed, changed in time, or operations can take longer than expected, which can create many stressful moments for family members.

Currently, a human-centered design thinking process is taking place, where all stakeholders will be interviewed regarding these potential services, and as such will be able to give their ideas and comments regarding the given solutions. Engaging with patients and family members reveals the way they think and which values they hold, which is not always obvious to the people who own them. Through a process of observing, engaging and watchful listening, all information can be gathered to go to a designing process. This will improve the potential usefulness of the application substantially.

VI. CONCLUSION

Naomi is an application that can be of great additional value in the care of the patient and the support of the family and will contribute to the humanization of care of the hospitalized patient and their family members. By performing a design thinking process the usefulness of the application could be substantially improved.

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