

Towards a Comprehensive Cohort Visualization of Patients with Inflammatory Bowel Disease

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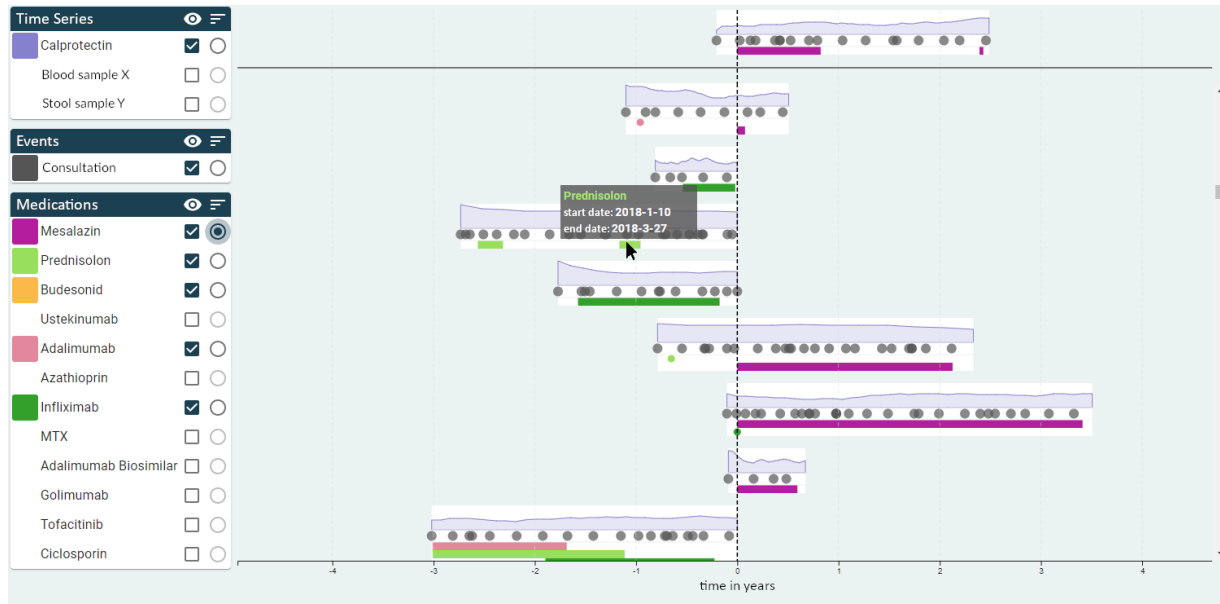


Figure 1: Visualization of a cohort of patients with inflammatory bowel disease with implemented feedback from the evaluations. Users can select data through the menu on the left. On the right side, this data is visualized for each patient in the cohort, with the focal patient at the top. Time series of blood or stool values, important events and prescribed medications are displayed in each patient’s row. A tooltip shows additional information while hovering over an element. A timeline displays disease progression in years and can be synchronised to a specific element, in this case Mesalazin.

ABSTRACT

This paper reports on a joint project with medical experts on inflammatory bowel disease (IBD). Patients suffering from IBD, e.g. Crohn’s disease or ulcerative colitis, do not have a reduced life expectancy and disease progressions easily span several decades. We designed a visualization to highlight information that is vital for comparing patients and progressions, especially with respect to the treatments administered over the years. Medical experts can interactively determine the amount of information displayed and can synchronize the progressions to the beginning of certain treatments and medications. While the visualization was designed in close collaboration with IBD experts, we additionally evaluated our approach with 35 participants to ensure good usability and accessibility. The paper also highlights the future work on similarity definition and additional visual features in this on-going project.

1 INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic, costly disease characterised by relapsing-remitting symptoms, causing inflammation of

the gastro-intestinal tract [2, 14]. Well-known varieties of IBD are Crohn’s disease or ulcerative colitis with clinical features including diarrhea, abdominal pain, and, in the case of ulcerative colitis, perianal bleeding. The disease progression of IBD often spans several decades and its prevalence is increasing globally [6]. Managing this disease can be complex, since physicians usually only have access to written patient records of individual patients, which leads to a great amount of manual work if the complete medical history is to be considered. Collecting and visualizing this patient data can help physicians gain a quick overview of the patient and other similar patients. The IBD specialists in our collaboration explained to us that understanding the effects of biologic (protein-based) drugs that stimulate the body’s response as part of an immunotherapy against IBD are of particular interest. The first biologic drug that is given to a patient seems to have a larger than expected impact on the disease progression, which makes the decision for a certain compound one of the most vital steps in the treatment of an IBD patient. Comparing patients and their disease progressions in relation to the chosen treatments is therefore an important IBD-specific analysis that our experts requested to help raise the standard of care and quality of life for their IBD patients.

Based on collaboration with IBD specialists we designed a visualization to clearly display multimodal information of patients of a cohort regarding disease progression and prior treatments. During development, we periodically carried out expert interviews to ensure that the visualization is moving in the appropriate direction. This included evaluation sessions with IBD specialists, an external evalu-

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ation, and a usability study with university students. Fig. 1 shows the state of the application after implementing feedback gathered in all these evaluations.

2 RELATED WORK

In recent years, visualization in healthcare has become more widely used and prevalent. While analyses of IBD treatments and cohorts are a ubiquitous topic of research [16, 19], medical data pertaining this disease is rarely summarized in a comprehensive visualization. Instead, data tables and independent visualizations are still predominantly used [17]. The workshop on visual analytics in healthcare has established itself as an important event showcasing new approaches in the visualization and analysis of medical data. Patient cohorts are an important mechanism for analyzing similar disease trajectories and drawing new conclusions about treatments.

Maftools by Mayaconda et al. [13] is a tool that focuses on visualizing a large cohort of the Mutation Annotation Format (MAF) data. Zhang et al. [20] developed a platform for Cohort Analysis via Visual Analytics (CAVA). This tool is designed to accelerate domain experts’ cohort studies. Their visualization approach includes an interactive Sankey diagram to easily display complex analysis pathways that were chained together. Bernard et al. [3] have developed a visual-interactive system that enables physicians to define and analyze cohorts of prostate cancer patients. This system focuses on defining and visualizing patient cohorts and helping physicians and researchers increasing their analytical workflow. A visualization by Antweiler et al. [1] focuses on identifying, assessing and visualizing clusters in COVID-19 contact tracing networks. Their visualization displays multimodal data of events (contact, first symptoms, test results) and time periods (infectious periods, quarantine) in a single row per person. Events are displayed as colored circles and time spans as colored bars. Their approach is used in our visualization in a modified form. However, none of the previous work targeted IBD or the visualization of similarly long disease progressions.

3 VISUAL COHORT ANALYSIS

The goal of our visualization is to provide a quick overview of a disease progression over a long period of time. Fig. 1 shows our visualization filled with example data. The user can select relevant information through a menu on the left side. The selected information is displayed in multiple rows in the resulting visualization on the right side. A selected focal patient is always displayed at the top of the page and will stay there while the user may scroll through other patients of the cohort to ensure a good comparability to this focal patient. On the bottom of the page, a timeline shows the relative duration of the treatment history for all patients within the cohort. Additionally, a tooltip is shown on mouseover with further information on the corresponding event, e.g. the start and end date of a prescribed medication. Time series of blood or stool samples are displayed as a line chart at the top of each row. Below this, different events, e.g. consultations or surgeries can be displayed as icons on the timeline. Prescribed medications are shown in the bottom part of each patient row. Each medication is represented by a colored bar, corresponding to the color chosen in the menu on the left. Collecting ideas on how to visualize overlapping prescriptions and events was one part of the usability evaluation. In the current state of the visualization, overlapping prescriptions are stacked vertically and overlapping events are transparent. Different design ideas were collected and evaluated and will be implemented in subsequent iterations of the tool. These ideas are further elaborated in Sect. 4.3.

Furthermore, users are able to set the focus of the timeline at the bottom of the page to the peak in a time series of a measurement, a specific event or the start of a medication by pressing a button in the menu. In this case, the visualization will shift the timeline to the selected element. In Fig. 1 this alignment is shown for the medication Mesalazin. The user can now compare for example how

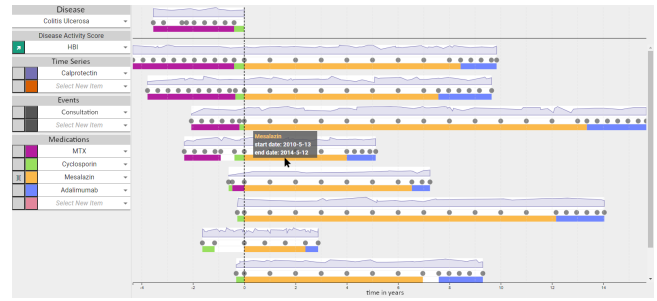


Figure 2: Our visualization in a previous iteration, which was used in the evaluations.

a specific blood level changed after prescribing a specific medication. Another example is examining disease progression after a surgery. By selecting and deselecting elements in the visualization, physicians can easily individualize patient care, after examining how treatments worked for other patients.

3.1 Technical Implementation

The basis for our visual-interactive system is data from the University Hospital Frankfurt [11]. A complete real-world data set was not yet available at the time of the evaluations. For this reason, we took the data of approx. 500 patients provided by our partners in Frankfurt and constructed a realistic, but simulated data set containing all relevant attributes for the evaluations. The department that specializes in treatment of IBD provided the data from their hospital information system (ORBIS) after technical, ethical, and GDPR approval. Our tool was developed as part of a larger project to advance cost-intelligence, data-driven medicine. Our cohort visualization is one module within a software framework that uses the data from Frankfurt to support decision making by IBD experts. Together with other modules our cohort analysis tool will be integrated into a dashboard providing the physicians with a powerful analysis tool set. To ensure the accessibility for all modules of the dashboard and to make the database easily extensible with data from additional sources, the ORBIS data was mapped into a knowledge graph by the data experts from our consortium. Our tool accesses this data via a secure connection to the database using SPARQL [18] as query language. The processing of the data to match the requirements of our visualization is performed on a Java backend. Here, we select a group of appropriate patients based on their similarity to the focal patient, thus creating a cohort that can be explored using our visualization. The visual-interactive tool is implemented as a web application. Notable frameworks we use are React.js [15] for the basis of the application, d3.js [4] for the event-based patient cohort visualization, and Material-UI [12] for the GUI components.

4 EVALUATION

During development expert interviews were held periodically. Since physicians usually have a very busy schedule, we scheduled feedback sessions as rare as possible and as often as needed. We were able to schedule five sessions with a senior expert at our partner clinic in Frankfurt and two meetings with the external advisory board to gather this expert advice. The functionality and user-friendliness of our tool was evaluated by an external company specialized in evaluating software solutions in the health sector. We also conducted a quantitative user evaluation with university students to collect feedback on the usability where domain expertise was not required. All evaluations were conducted with the state of the application as shown in Fig. 2.

Data The data set used in all evaluations contained a virtual

patient cohort with simulated multimodal data. It includes blood samples of Calprotectin, medical consultations as events and the medications MTX, Cyclosporin, Mesalazin and Adalimumab. This data was chosen in accordance to feedback from IBD specialists, in order to not distract from the visualization during the interviews. It was also constructed to be able to show all relevant features of the visualization.

4.1 Expert Feedback

Feedback sessions with domain experts were conducted as an online video meeting, where IBD specialists were shown a live demonstration of the tool via screensharing. While it would have been preferable to have in-person meetings, we had to schedule online meetings due to the pandemic, which caused a more complex technical infrastructure in letting the experts use our application directly. The experts were able to ask questions about the tool at any time. After a demonstration of the features of the tool, we asked the domain experts about further features they may want to see in the tool (implemented as mock-ups). This approach allowed us to collect feedback on several design ideas before implementing them into the tool. In general, the feedback was positive. Physicians appreciated the clear and easy-to-read layout and the ability to quickly compare several patients. It was also noted that our tool could be used in teaching in order to explore long disease progressions and the impact of different treatments on the patient's wellbeing.

4.2 Functional Evaluation

As part of an evaluation of all modules of the complete dashboard, our module was functionally evaluated by an external company specialized on evaluation in the health sector. First, we presented all current features of our tool with an outlook into future work. Afterwards, the evaluator asked specific questions about the future integration of the tool into the dashboard and assessed functionality and usability of the current state of the application. After the live interview, the application was made available to the evaluator for further testing. In general, the assessment of our tool was positive. There were no technical problems in using the application and especially the clear overview over a large patient cohort was commended.

4.3 Usability Evaluation

We conducted a usability evaluation with 35 students on our tool. The students who participated in this evaluation were all taking the course on "user-centered design" at the time and they all study subjects related to computer science. Since the goal of the evaluation was to collect feedback and determine usability flaws in addition to the domain expert feedbacks, a medical background of the participating students was not required. Students were instructed to interact with the visualization with no prior knowledge about its features and only a short introduction to IBD and patient cohorts. While exploring the visualization we asked them to comment on perceived appealing and disruptive design elements and assess this using the AttrakDiff [10] and System Usability Scale [5] questionnaires. Using this evaluation approach helped us to understand which design elements worked well in guiding users without domain expertise. Further, participants were instructed to examine the visualization with respect to consistency, Gestalt laws [8] and reduction of memory load. Complementary to the AttrakDiff questionnaire and in preparation for creating new design ideas, participants also were asked to find specific pragmatic and hedonic qualities of the visualization. Almost all participants were in the age range of 20-30 years old with only one participant in the range of 30-40 years old. Of the 35 participants, 25 were male and 10 female. 62.9% of the participants have stated to have prior knowledge in information visualization. Feedback in general included improvements on visual aspects of the tool to create an intuitive workflow, impressions of

Type	Feedback	Impl.
E	Highlight important events like infections in a distinctive way.	●
E	Visualize when blood or stool values cross a threshold value.	○
E	Sort medications into a hierarchy to identify problematic administrations.	●
E	Visualize co-existing diseases and concomitant medications to ensure no harmful interactions during treatments.	●
E, F	Visualize concurrent prescriptions and events.	●
E, F	Save the current view as a screenshot.	○
F	The overall design should match the dashboard for future integration.	●
F	Manually arrange patients to provide a better overview.	○
F, U	Provide panning and zooming functionality.	●
F, U	Selected elements do not disappear from the drop-down menu.	●
F, U	A more prominent highlighting to further distinguish the focal patient from the other patients.	●
U	Add a higher contrast between the background color and the patient's color.	●
U	Indicate the mouse position to help reading the chart.	●
U	Add icons to the buttons.	●
U	Add an additional button to select custom colors for each element.	●
U	Permanently display all patients' IDs to be able to quickly locate patients again.	○
U	The menu bar should be expandable and collapsible.	○

Table 1: Most common feedback from the domain experts (E), the functional evaluation (F) and the usability evaluation (U). The circles indicate whether the feedback is implemented in the current iteration (●), being currently worked on (◐) or not yet implemented (○).

the usability while working with the tool and new design ideas to improve on perceived flaws.

4.4 Results

The most common feedbacks and feature suggestions from all evaluations are collected in Table 1. Table 1 also shows which feedback is already implemented and being worked on in the current iteration as seen in Fig. 1.

The results of the AttrakDiff evaluation can be seen in Fig. 3. This scale is used to measure pragmatic and hedonic qualities [7] of a product. Pragmatic qualities describe how comprehensible, ergonomic and task-oriented a product is perceived. Hedonic qualities describe the innovativeness, enjoyment and general "appealingness" of a product [9]. On average, participants rated the pragmatic and hedonic quality as well as the attractiveness of the tool as neutral (PQ=3.96, HQI=4.25, HQS=4.1, ATT=3.8, on a likert scale from 1 (disagree) to 7 (agree)). As the participants of the usability evaluation had no expertise in the domain, these results were to be expected. Still, neutral values provide insight as this means that the application is not badly designed, but at the same time has room for improvement, which the students described in the feedback they provided. Participants commented positively on the clean interface of the visualization with no superfluous components. At the same time, some participants noted that the empty interface with no selected data felt "challenging" since they thought it would be demanding to find the data to display, but were pleasantly surprised

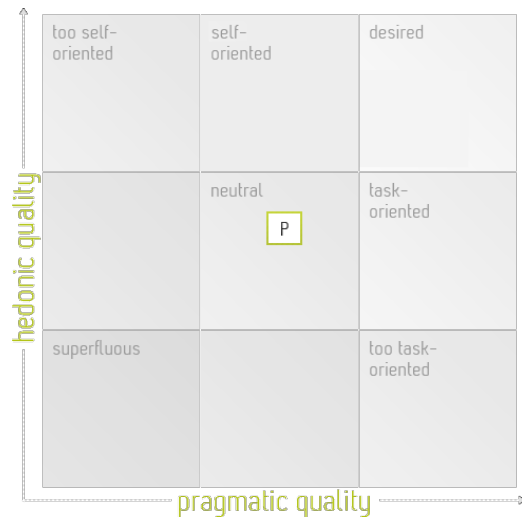


Figure 3: Results of the AttrakDiff evaluation with medium value of the dimension with prototype P [10].

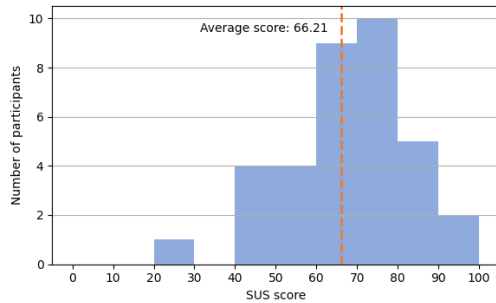


Figure 4: System Usability Scale scores. The average score (orange line) is 66.2 [5].

at the ease of displaying relevant data. The System Usability Score averaged at 66.2, with the lowest score of 22.5 and the highest of 97.5 (cf. Fig. 4). The large variance of SUS scores could be a result of the foreign domain of IBD for computer science students. While most participants placed importance on considering the tool from a physician's point of view, some did not see value in using the tool themselves and scored accordingly.

Fig. 5 shows different design ideas by participants for overlapping medications, concurrent events and improvements on the menu. Participants were directed to pay special attention to the limitation imposed by the limited screen space. For medications, a popular approach was to have the bars interlock. This way, two medications are easily distinguishable while keeping required space to a minimum. For more than two medications, many participants proposed decreasing the bar height or using texture to indicate further information to be accessed via tooltip. Icons were the most popular visualization technique proposed for events. Combined with color and transparency, two to three simultaneous events can comfortably be distinguished. For more than three events, displaying them vertically with smaller icons was often proposed. Since one frequent feedback was the inadequate depiction of the buttons, many design ideas featured improved menu elements. The button to remove an element from the visualization was often suggested as a bucket or "X". Another frequent suggestion included permanently displaying the icon for setting the focus of the timeline on all relevant buttons and

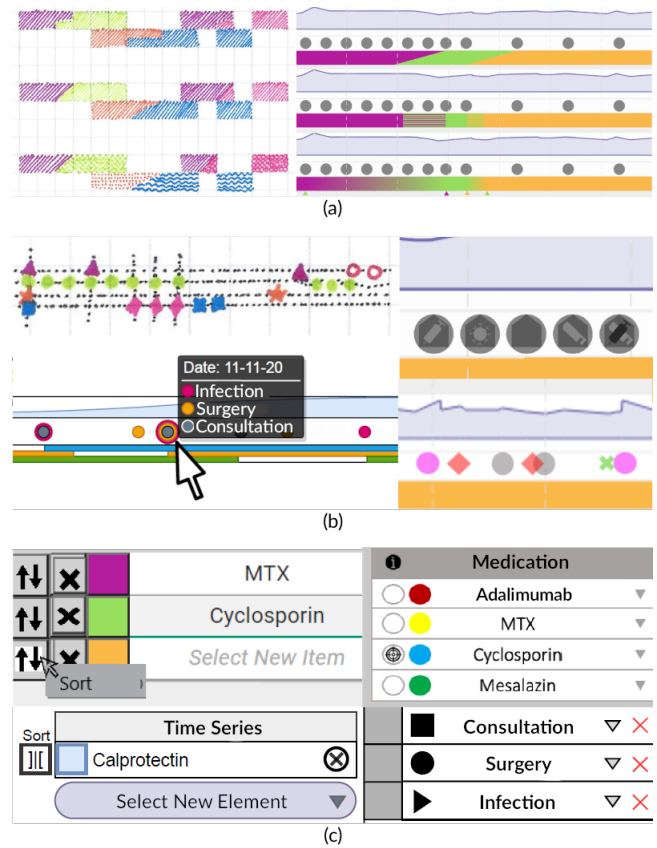


Figure 5: Different design ideas for overlapping medications (a), overlapping events (b) and menu improvements (c).

highlighting the element that is currently selected. Displaying icons on the buttons was commonly referenced in the task of reducing memory load for the user.

5 CONCLUSION AND FUTURE WORK

We presented a comprehensive visualization for cohorts of patients with IBD with the ability to display multimodal data. Domain experts gave quite positive feedback on the visualization and appreciated the ability to quickly gain an overview of the disease progression over a long period of time. Our visualization can help increase the standard of care by presenting complex information in a concise and easy to understand manner, allowing specialists to focus their expertise on patient care instead of manually browsing through patient records. We conducted a usability evaluation with university students to gain insight on aspects, where domain expertise was not a requirement. The usability evaluation showed that our visualization can be used without the need for an in-depth introduction.

Feedback from both domain experts and university students will be implemented in subsequent iterations of our tool. The collected design ideas for improvements and new features gave important impulses for future developments and will be evaluated again by our collaborating domain experts. Furthermore, in our future work we will work on the similarity definition for long disease progression coupled with an interactive filtering approach to allow our experts to quickly define a specific cohort of interest.

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