Interactive Visual Analysis of Patient-Reported Outcomes for Improved Cancer Aftercare

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Abstract

The monitoring and planning of cancer aftercare are commonly based on clinical, physiological and caregiver-reported outcome measures. More recently, patient-reported outcome (PRO) measures, capturing social, psychological, and financial aspects, are gaining attention in the course of establishing a patient-centered healthcare system. PROs are acquired during regular aftercare consultations where patients are asked to fill in questionnaires.

We present an interactive visual analysis (IVA) approach to investigating PROs. The approach is applied in clinical routine during the aftercare consultation to assess the development of the particular patient, to compare this development to those of similar patients, and to detect trends that may require an adaptation of the aftercare strategy. Furthermore, the approach is employed in clinical research to identify groups of similarly developing patients and risk factors for poor outcomes, as well as to visually compare patient groups. We demonstrate the IVA approach in analyzing PROs of 1025 head and neck cancer patients. In an evaluation with 20 clinicians, we assessed the usefulness and usability of a prototypical implementation.

CCS Concepts
• *Applied computing → Health care information systems; Health informatics;*

1. Introduction

Commonly, the monitoring and planning of cancer aftercare are based on clinical, physiological, and caregiver-reported outcome measures, such as disease recurrence [DRSN11]. However, there is growing recognition of *patient-reported outcome (PRO)* measures as complements conveying crucial information about *functional aspects* in patients' lives, such as social, psychological, and financial aspects [LGS07]. Studies have shown that considering patient feedback on cancer aftercare leads to improved outcomes.

The treatment of cancer patients with radiation therapy, for instance, may yield multiple impairments of functional aspects, e.g., reduced social functioning and increased fatigue [LDdL*08]. Data about these factors can be gathered in aftercare by questionnaire-based systems, such as OncoFunction [ZPS*16]. This tablet app is used by the patient at each consultation before seeing the physician to answer multiple questions on a Likert scale [LDdL*08,ZPS*16]. During the conversation with the patient, the PROs are then evaluated by the physician using a web interface. In-depth discussions with collaborating physicians revealed multiple shortcomings of this interface including a missing overview of the patient's development over all consultations and a visual comparison with the development of similar patients over time.

We propose an *interactive visual analysis (IVA)* approach for investigating PROs of a single patient and a patient cohort over time. In clinical routine, the approach supports a quick detection of anomalous answers, such as a bad condition, a study of the patient's development, and a prediction of the future development based on those of similar patients who have progressed further in aftercare. In clinical research, the approach facilitates the detection and comparison of patient groups with similar aftercare developments and the identification of risk factors for poor aftercare outcomes. We demonstrate the approach for the analysis of PROs from *head and neck cancer (HNC)* patients. This paper extends the work of Müller et al. [MZWOJ17] and Zebralla et al. [ZMW*17] by:

- a presentation of a patient's development over all consultations,
- a visual comparison of this development with the developments of similar patients,
- a comparative visualization for finding similarities and differences between groups of patients, and
- an extensive clinical evaluation study with 20 clinical experts.

2. Related Work

Most work focuses on the design and formal interpretation of PRO measures [LCL*16,NMC17,ZPS*16] and only little work has been dedicated to PRO visualization [GFMMC18, SBS*18]. Grossman et al. [GFMMC18] identified the design requirements for an in-

terface assisting patients with PRO survey completion and found visualization to be a key factor in engaging patients. Snyder et al. [SBS*18] compared multiple visualization techniques for investigating PRO development over time in individual patients and patient cohorts and concluded that line graphs outperform pie charts, bar graphs, and icon charts. However, the visualization of many functional aspects in one line graph yields a cluttered visualization and displaying one line graph per aspect is space-consuming.

2.1. Visualization of Longitudinal Categorical Data

In evaluating PROs, the numerical values of functional aspects, i.e. the original Likert values, are often categorized [HSJT*13]. Since the functional aspects are surveyed at multiple consultations, the corresponding categorized values can be viewed as longitudinal data. Glyphs are particularly suited to visualize multi-variate categorical data [BKC*13]. Tueller et al. [TVDB16] introduced horizontal line plots for visualizing longitudinal categorical data and compared them to existing techniques such as stacked bar charts and growth curve plots. Horizontal line plots performed best. In visualizing patient cohorts however, they fail to explicitly convey the temporal changes in the condition of each individual patient. Parallel sets [KBH06], are well suited to represent suchlike *transitions* by arcs connecting corresponding elements. In the medical field, parallel sets in combination with Sankey diagrams were used to analyze Electronic Medical Records [WLM*14, WG11]. We combine parallel sets with a glyph-based visualization of functional aspects.

2.2. Interactive Visual Analysis of Cohort Study Data

The PROs of a patient cohort represent a special instance of cohort study data. In an *interactive visual analyis (IVA)* of those data, the user may define and compare sub-cohorts through linking and brushing in coordinated multiple view systems. By drilling down into the multivariate relations between variables (over time), the user can not only verify an a priori hypothesis but also generate new hypotheses. Turkay et al. [TLLH13] have demonstrated hypotheses generation using IVA in the context of cognitive aging. Klemm et al. [KOJL*14] proposed the integration of a coordinated multiple views framework into the workflow of epidemiologists. Their approach allows for the direct comparison of aggregated subcohorts within a mosaic plot and tabular view inspired presentation. Both works focus on the analysis of a single time step of longitudinal data. Bernard et al. [BSM*15] developed a visual system to analyze prostate cancer cohorts. List view inspired visualizations present an individual's transition over time. However, only the transition from good to bad is conveyed. We aim at presenting all transitions.

3. Requirement Analysis

Physicians pursue multiple goals (**G**) in investigating PROs. In clinical routine, they are interested in an overview of the patient's current condition and in finding anomalies (anomalous answers) that may require a review of the aftercare strategy (**G1**). Furthermore, they want to inspect the patient development over consultations to assess the appropriateness of the current aftercare strategy (**G2**) and forecast a patient's condition by analyzing a cohort of similar patients that have progressed further in aftercare (**G3**). In clinical
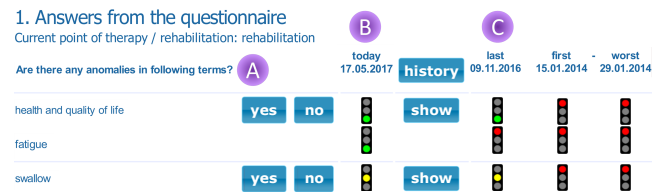

Figure 1: *Original PRO visualization. Traffic lights and text encode the patient's condition for each functional aspect [ZPS*16].*

research, physicians want to identify and compare groups of patients that benefit from a certain aftercare strategy (**G4**). Moreover, they want to process the identified groups using dedicated statistical analysis software (**G5**).

Currently, the PROs are presented to the physician through a web interface using traffic lights (Fig. 1) [ZPS*16]. Instead of showing each original patient answer, i.e. numerical value on a Likert scale, the answers are grouped according to the functional aspects, the values in each group are summed up, and the sums are categorized according to a thresholding-scheme by Harréus et al. [HSJT*13] into the three conditions: good, moderate, and bad. The web interface is divided into three parts: Part (A) lists the functional aspects and the physician can mark anomalies. Part (B) depicts the current condition of the patient regarding these aspects. Part (C) either conveys the condition at particular previous consultations or shows the underlying answers of an aspect for the current consultation.

The current web interface supports only goal **G1** and partially **G2**. In in-depth discussions with collaborating otolaryngologists and multiple site visits, we identified the following requirements on an improved approach that addresses all goals.

R1 **Patient's Current Condition.** The patient's condition represented by the most recent PRO needs to be conveyed (**G1**).

R2 **Patient's Development Over Consultations.** Since only predefined consultations are shown in the original interface and inferring the time interval between consultations is tedious, a development presentation over all consultations is requested (**G2**).

R3 **Trend Detection.** The visual order of consultations in the original tool hampers a temporal trend detection. Hence, a consistent arrangement of all consultations is required (**G2, G3, G4**).

R4 **Underlying Answers.** In the original presentation, the underlying answers leading to a threshold-based category are only presented for the current consultation. However, their analysis and comparison over multiple consultations is required in finding detailed information leading to the conditions (**G1, G2**).

R5 **Interactive Cohort Development Over Time.** Since neither comparisons of the current patient with similar patients nor subcohort discovery are provided in the original tool, an interactive graphical presentation of all patients over time including filter mechanisms is requested. This feature is not required on a regular basis, but for predicting a patient's most likely forecast by investigating patients having similar developments (**G3, G4**).

R6 **Tabular Presentation and Export.** To get more insight into and to allow for deep statistical analysis of a patient's as well as a selected subcohort's development in all functional aspects, a tabular presentation and export method are required (**G5**).

4. Data Compilation and Cleansing

A PRO database including 1025 HNC patients with multiple after-care consultations in between July 2013 and February 2019 was used. For each patient and consultation, 43 answers related to 11 functional aspects as well as the corresponding threshold-based categories were recorded. Because of the unassisted completion of the questionnaire, the voluntary participation, and varying time intervals between consultations, not all questions for each patient at every consultation or year of aftercare were answered. To still consider these incomplete datasets in the analysis, data imputation was conducted. This is common practice in epidemiological and clinical research [BF14, BHF15]. We employ the widely used deterministic hot deck imputation since it avoids strong parametric assumptions. Each missing value is replaced with an observed value from the most similar record (donor) [KK86, AL10]. Here, the donor is characterized as the record having the most similar development of the selected functional aspect over years of follow-up. In the frequent case of multiple records with an equally similar development, the one with the most similar development of all other functional aspects is chosen. To provide comparability across patients with a different number of consultations per year, only the closest consultation to full years after therapy was considered.

5. Interactive Visual Analysis Approach

The approach is implemented in D3 [BOH11] as a web-based framework comprising four linked views (Fig. 2, 3).

(A) Patient Status. The patient's current condition in each functional aspect is shown in a list-inspired view (Fig. 2, A) (R1). Since traffic light glyphs have a poor data-to-ink ratio and human beings are experienced in abstracting and interpreting facial expressions, face-like icons are used to encode the three categorical values *good*,
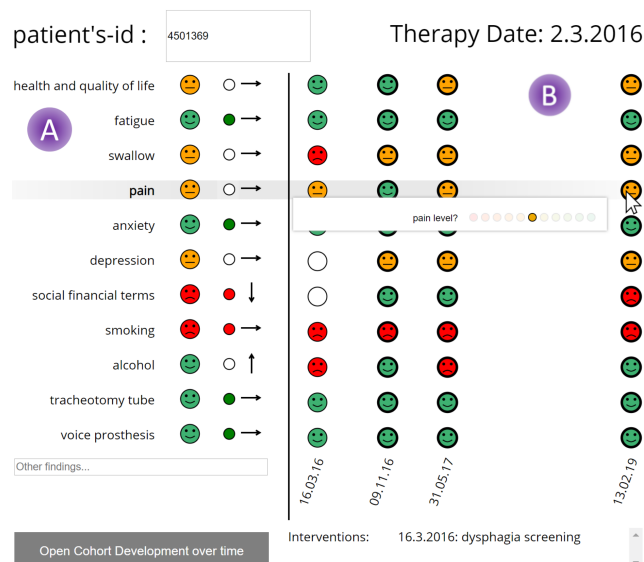
Figure 2: *Patient Status (A) and Development (B) views. Icons depict the patient's condition for each functional aspect. Through hovering, the underlying questions and their answers are shown.*
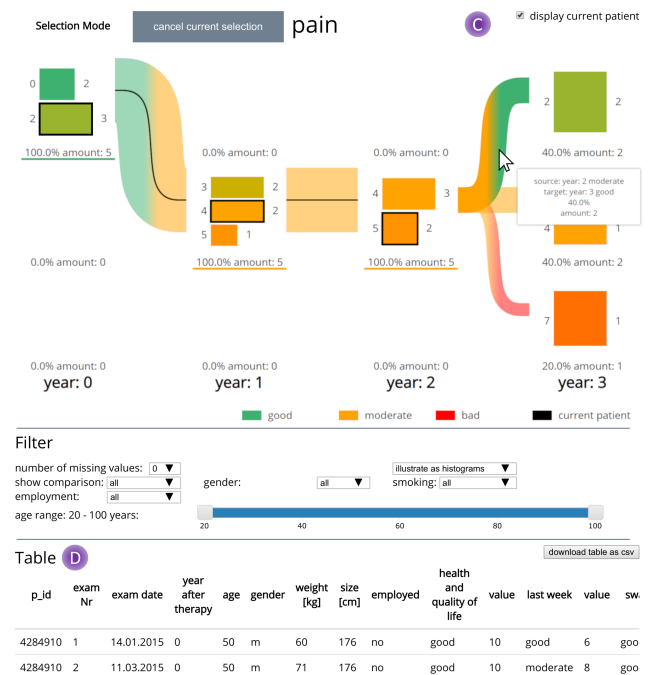
Figure 3: *Cohort development visualization (C) of the functional aspect "pain" and tabular presentation (D) of patient data. Horizontal bar charts provide details on each functional aspect and arcs indicate the development of patient groups. Through filtering, patients with a development equal to the one of the patient under investigation (indicated by black arcs and borders) are shown.*

moderate, and *bad*. An empty circle represents a missing values. Next to each icon are a round checkbox, which can be used to tag an anomaly, and an arrow indicating the development from the previous to the current self-assessment (R3).

(B) Patient Development. The patient's development over consultations (R2) is shown in a time line view (Fig. 2, B) (R2, R3). Through hovering methods, the underlying questions and related answers on a Likert scale are shown (R4). Underneath the time-line view, the patient's history of clinical interventions is provided. While line graphs instead of face-like icons would further simplify a temporal trend analysis, they consume more screen space.

(C) Cohort Development. Since the cohort development presentation is rarely used in clinical routine but mostly in research, it becomes visible by clicking on the *Open Cohort Development* button (R5). Currently, three years after therapy are presented since this time span is available for most patients in the growing database. The cohort development visualization (Fig. 3, C and 4) is inspired by Sankey Diagrams [WLM*14] and Parallel Sets [KBH06] to convey the transition of each functional aspect over years of aftercare. The user can choose between three graphical presentations:

1. **Face-like icons** represent the threshold-based categories (Fig. 4).
2. **Horizontal bar charts** display the distribution of the patient answers underlying the categories (Fig. 3, C).
3. **Comparative presentation view** opposes two groups of patients, e.g., employed and unemployed patients (Fig. 4).
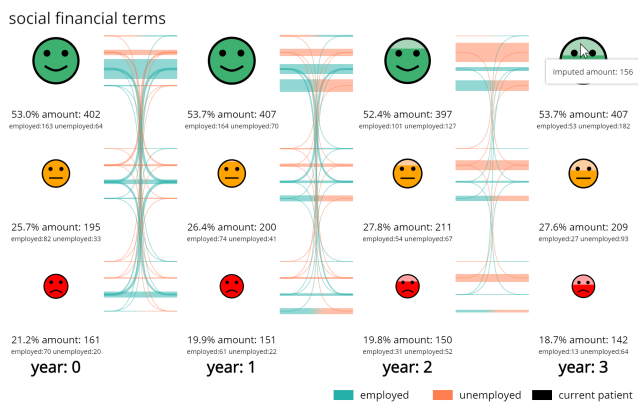
social financial terms

Figure 4: *Comparative presentation of employed and unemployed patients in the functional aspect "social and financial terms" illustrated as icons. Imputed values are emphasized having a brighter color within the icons and hovering allows for their investigation.*

The number and percentage of patients per year and threshold-based category are given through text labels underneath the icons / bar charts. The percentage of imputed values is encoded by an icon part rendered with less saturation and the number of imputed values is provided through hovering (Fig. 4). The development of patients over consultations is conveyed through arcs, where the arc thickness corresponds to the percentage of patients showing a certain transition. Associated tooltips depict the amount and percentage of patients with a certain transition (Fig. 3, C). The development of a selected patient in the context of the cohort is represented by black arcs and borders of icons / bars (Fig. 2, B and Fig. 3, C). Filtering methods can be applied to patient attributes, e.g., gender, in order to define a sub-cohort and clickable icons refine a cohort according to the corresponding functional aspect and year of aftercare.

(D) Tabular Presentation and Export. A table view displays all patient attributes and self-assessments as well as the ordered interventions of the currently selected group of patients and a *.csv* export enables further analyses with external tools (Fig. 3, D) (R6).

6. Evaluation

The IVA approach shall be applied during aftercare consultation. Here, the physician is seated towards the patient, investigates the recorded PROs and in case of anomalous answers, asks the patient for reasons to get a closer insight. It was decided to first evaluate the approach in a dry run to limit interruptions of clinical routine.

6.1. User Study

In a user study, the approach was evaluated by 6 otolaryngologists from the Ear-, Nose- and Throat (ENT) department, 9 radiotherapists / radio-oncologists, 4 medical researchers, and 1 nurse (11 females, 9 males). Among them, 4 and 16 participants were familiar and unfamiliar with the original presentation (Fig. 1), respectively.

Participants were asked to perform the same tasks using alternatingly the original PRO visualization (Fig. 1) and the new approach (Fig. 2 and Fig. 3) and the timings were recorded. These

tasks included the investigation of the patient's current condition, trend analysis, detection of anomalous answers, forecasting based on similar patients, and cohort comparison. In this context, a statistically significant time saving (~37%) and improved answer accuracy using the proposed approach have been observed.

Additionally, a survey consisting of 26 closed-ended answered on a six-point Likert scale and five open-ended questions was designed to gather insights into the usability and potential clinical relevance of the approach. Further details regarding the questionnaire, detailed answers, procedure, and statistical analysis are provided in the supplemental material. The most important insights are summarized in the following.

All participants confirmed that the proposed approach fulfills their demands on quickly detecting anomalous patient conditions while simultaneously investigating the patient's development over aftercare. They appreciated the self-descriptiveness, controllability, and conformity with user expectations of the patient status and development presentation. All participants emphasized the importance of the cohort development view however, one participant claimed its insufficient self-descriptiveness.

6.2. Case Study

By investigating the development of an exemplary patient (black) in the context of similar patients that progressed further in therapy (color), one can see that the patient most probably has a good / moderate forecast in the functional aspect *pain* within the third year after therapy (Fig. 3, C). By focusing on those patients with a good forecast, one can reason about their improved situation and, e.g., prescribe their ordered interventions to the exemplary patient.

The comparative presentation assists in getting an overview of the different patient groups over time of aftercare. While investigating the database, the clinical experts observed a drop in employment rate one and two years after therapy (Fig. 4). One reason could be that patients are not on sick leave anymore but also not yet fully rehabilitated. This hypothesis has to be validated in a future study.

7. Conclusion and Future Work

This work presents an IVA approach for the investigation of PROs in cancer aftercare. It supports the comprehension of the rehabilitation process of an individual patient and of a patient cohort over years of aftercare. Using the approach, anomalous patient answers quickly become apparent. An interactive comparative presentation assists in finding similarities and differences between sub-cohorts. Filtering methods support a definition of the desired sub-cohort.

To evaluate the approach, a user study has been conducted. It is concluded, that on average the approach performed well in all technical evaluation aspects. Furthermore, most participants preferred the approach and a mentionable time saving with respect to the old presentation could be reported. In a case study, forecasting patient development and hypothesis generation were demonstrated.

In the future, several improvements, e.g., in depth statistical analysis, intervention grouping and comparison, as well as clustering of similar patients over all functional aspects, are planned. The approach will be integrated and evaluated in clinical routine this year.

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