# MedStory: unlocking the qualitative power of medical narratives

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## **ABSTRACT**

Medical narratives are a qualitatively-rich component of medical records with limited visualization support. In this work we propose a text-centered approach for medical narrative visualization to better support their complexity, based on design goals derived from the literature and a formative study.

**Index Terms:** H.5.2 [Information Interfaces and Presentation(e.g., HCI)]: User Interfaces—User-centered design; J.3 [Computer Applications]: Life and Medical Sciences—Medical Information Systems;

#### 1 Introduction

Medicine is a highly interpretive activity that relies heavily on freetext narratives present in clinical notes, which collectively describe the medical trajectory of a patient [1]. The temporal presentation of events as a coherent narrative is an efficient way to encompass the complexity of a patient's illness by seamlessly integrating medical problems and context, and is a rich rhetorical tool to register physicians' views of a medical case [1]. However, given the constant time pressure and the potentially large number of clinical notes in a medical record (*e.g.*, in cases of chronic illness), unstructured text quickly becomes unwieldy. Data visualization has been proposed as a solution to summarize medical records (in particular medical text) [4], but focus has been placed mostly on "strictly medical" aspects such as symptoms and medications, with little attention given to contextual aspects such as family situation, occupation, and how patients are coping with their disease.

In this paper we share some of our early explorations to bridge the immediateness of visualization and the qualitative richness of text with a concept of *text-oriented* visualization, which is built on a principled set of design goals informed by a review of the literature and findings from a field study that investigated clinical practices around medical narratives. We present an early prototype, *MedStory*, and point to important directions that future development should take in order to support qualitative interpretation in medical practice.

## 2 BACKGROUND

To better characterize the problem of conveying the qualitative aspects of medical narratives, we sought complementary perspectives from the literature and from real world practice to inform our design.

# 2.1 Literature Highlights

On qualitative complexity and visualization. The power of medical narratives lies in their ability to reconcile various perspectives of a patient illness trajectory in a concise and flexible manner, *i.e.*, interconnecting co-occurring medical events, progression, psychosocial factors and rhetoric as one entity [1]. This freedom and power makes it virtually impossible to structure every single aspect of the narrative, which in turn makes it difficult to create an all-encompassing

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visual vocabulary. Thus, to preserve qualitative complexity, we need to leverage original texts alongside visualization.

On structure and granularity. Medical narratives are *multi-layered*, featuring different levels of content granularity and structural formats. There is, however, a trade-off between structure and flexibility [6] which calls for *hybrid approaches to medical narratives*, and has been discussed from various perspectives, including the varying levels of engagement of clinical reading employed by physicians [3] and how balanced levels of structural granularity can help speed up information retrieval [8].

**On facets.** The "point-in-time" nature of clinical notes makes it difficult to extract comprehensive sub-stories (that is, stories about specific medical problems), a process which physicians must engage in before every consultation [2]. Faceting should be facilitated to mitigate the effects of fragmentation.

**On time.** Supporting temporal awareness is essential, as understanding patterns of illness progression is an integral part of medical practice. Its relevance is supported by the various medical visualization systems created up to date [4,5], which all feature some form of timelines or time-varying representation.

## 2.2 Formative Study

We recruited 8 physicians with diverse backgrounds, from 4 different Canadian health institutions (including hospitals and private clinics) and 4 areas of specialization (general practitioners, pediatricians, a gastroenterologist and an orthopedic surgeon) for a formative study. We conducted semi-structured interviews with all participants, and full-day observations of clinical practice for 5 participants. Research questions encompassed how medical narratives are stored (*embodiments*), expressed (*representation*), used (*high-level goals*) and transformed (*low-level tasks*). A summary of our findings follows.

Importance of text and interpretation: Text was the prevalent form of storage for clinical data, and took up significant time and attention from physicians, who had little visualization support beyond standard charts for quantitative data (e.g., weight and bloodwork measurements). In addition, the importance of contextual information was observed in very concrete ways, for instance in the impact that employment and socio-economic status had in medical decisions and how it affected options for differential diagnosis (e.g., accounting for extreme stress at work), what kind of treatments could be offered (e.g., if patient can access private therapies) and how compliant they could expect patients to be to one treatment or another (e.g., vitamin supplements versus changes in the diet).

**Structure of text:** Levels of structure varied from loosely structured free-text (text snippets organized under a SOAP outline (Subjective, Objective, Assessment and Plan) to a mix of structured fields (*e.g.*, enumerated lists) and free-text (to complement or override default values). More specialized disciplines leveraged more rigid structures, whereas general practitioners tended to work with less constrained SOAP-based formats; overall, they all fell somewhere in the middle of the spectrum, indicating a general need (with varying levels) for flexible structures.

**Fragmentation:** We found content fragmentation to be one of the most significant challenges related to medical record usage. Narrative components were scattered across different documents, making it difficult to piece together the story of a particular medical facet (*e.g.*, all episodes related to hypertension in a record that

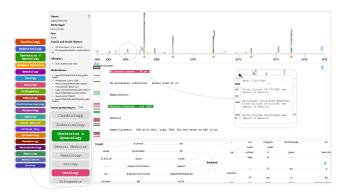


Figure 1: *MedStory*'s interface consists of: (1) an *overview panel*, featuring (1.a) medical specialty filters; (2) a *temporal view* of medical events; (3) a *document view*, containing all notes for a patient, with a linked (3.a) navigation bar for overview, tag highlighting and quick text navigation; and (4) a *word tree view* for custom faceting.

contains a number of other medical problems). This problem is pervasive and was also identified in past studies [2].

**Time-saving strategies:** With limited preparation time and the need to establish treatment continuity, physicians often focus on the most recent note in a patient record, which generally helps recall the most pressing issues and pending tasks since the last visit. This strategy can lead to recency bias of the medical history, as there might be older events relevant to the issues at hand and that were not brought up recently in the records nor by the patient herself. An alternative solution consisted of manually curated summaries that encompassed some of the most relevant aspects of the medical record, but which required conscious effort and precious time.

# 2.3 Design Goals

We distill past work and findings into four design goals:

(D1) Design for and around text, to preserve qualitative richness by providing access to the original text, and leveraging links between text and corresponding visual abstractions.

(D2) Support temporal awareness, by conveying how medical problems, treatments and patient attitudes progressed over time.

(D3) Support levels of granularity, to facilitate overview + details navigation and information retrieval for quicker insight.

(D4) Support multiple facets, to mitigate record fragmentation and connecting related topics for easier understanding.

### 3 MEDSTORY

We focused our efforts to create a visual prototype to embody the four design goals, including supporting unstructured text. We used clinical notes obtained from the Informatics for Integrating Biology and the Bedside (i2b2) project <sup>1</sup>, a collection of anonymized clinical texts compiled into a corpus for research purposes. For this preliminary exploration, we aggregated information layers by manually annotating text snippets with timestamps and a number of semantic tags, including: *document sections, document details* (e.g., record date), *clinical measurements, treatments, medical events, clinical observations*, and *medical specialty*. We opted for a tag-based approach to allow for easier compatibility with automated information extraction algorithms, to be explored in future iterations.

MedStory is organized as 4 synchronized views: an overview panel, a temporal view, a document view, and a word tree view. The overview panel provides summarized information (D3), consisting of standard fields (e.g., medications, allergies and family history) populated with the patients most recent clinical details, and was

motivated by the various summarization strategies we observed in our studies. Below the summary, a list of *medical specialty filters* can be used to activate various medical facets (*D4*) (*e.g.*, Cardiology), highlighting text and timeline events with its associated color.

The document view contains all the clinical notes for that patient organized in chronological order, as a scrollable journal (D1, D2). It features a navigation bar on the left (D3), showing the location of highlighted snippets (i.e., text segments associated to an active filter) within the overall text structure. This view can be potentially revealing not only for structural but also for temporal patterns of medical issues (D2), indicating for instance whether a certain class of medical problems is recent or chronic. It also helps to locate related snippets for quicker navigation and to compare facets (D4).

The *temporal view* conveys time-relevant snippets of text on a distorted timeline [7] (D2, D4); more distortion is applied to clusters of events, allowing for better space usage when the medical history is sparse. Events are shown as solid circles for exact dates (e.g., "two days ago") or transparent circles for "fuzzy" dates (e.g., "recently"). When hovered over, event snippets are revealed, and when clicked, the document view shows snippets in context (D1, D3).

Finally, the *word tree view* can be used for contextual text search, and offers a more customizable faceting option than the medical specialty filters (D4). It displays sentence segments before and after occurrences of a searched term, and also redirects to the document view when a snippet is selected (D1).

#### 4 CONCLUSION AND FUTURE WORK

In this work, we presented our explorations for a more qualitative and text-centered approach for medical narrative visualization, including findings from a formative study and an interactive prototype.

At this stage, we have completed a solid minimal foundation covering all four design goals, which we hope to improve and refine with feedback from physicians in follow-up evaluations. Future technical additions will include *automation support*, from integrating automatic information extraction algorithms to supporting curation and validation mechanisms for users to fix and improve automated results; *integrating other non-narrative elements of the medical record*, such as quantitative datasets and images; and *providing users with the ability to customize their own filters*.

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<sup>1</sup>http://www.i2b2.org/