Health Forums

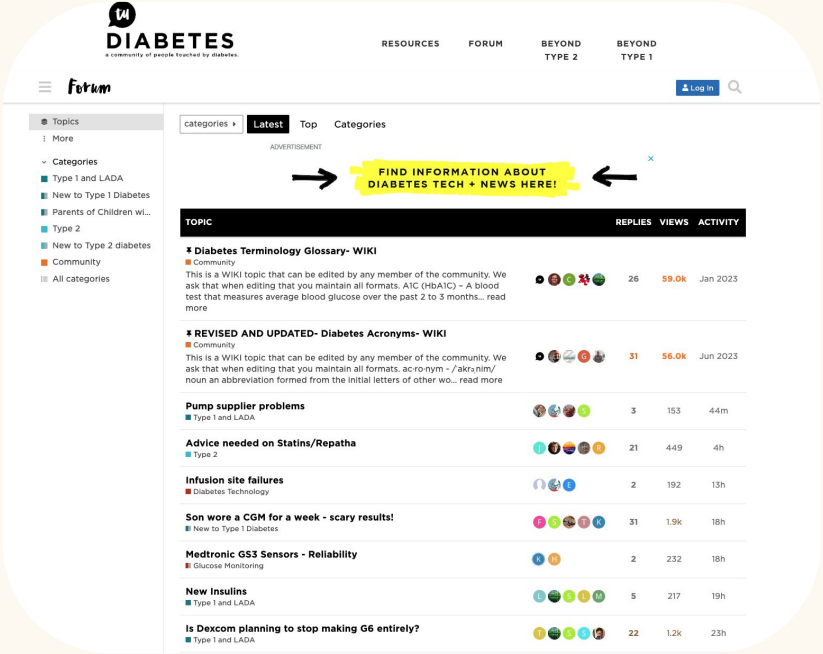
IN4MATX 251
Di Hu

Today's Goals

- Articulate how members of online health communities engage in collective sensemaking; what are the attributes of, contribution to, and triggers of this collective sensemaking.
- Explain why and how individuals seek peer support in online health communities, and what type of supports can be found in these communities.
- Discuss design implications for better collective sensemaking and peer support in online health communities.

Have you ever been a member of any health forums or online communities?

If not, have you searched about your health online? How was your experience?



Collective Sensemaking in Online Health Forums

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(2015 CHI)

About this paper

Problem:
Online health communities collect vast amounts of information and opinions in regards to health and wellness management. **However**, these opinions are usually stored within lengthy and loosely structured discussion threads; synthesizing information in these threads can be challenging.

Objective:
To examine how individuals in online health communities share information and learn from each other.

Method:

- An mix-methods approach grounded in the theoretical perspective of collective sensemaking,
- Interviews with 9 members of the TuDiabetes community,
- Quantitative analysis of patterns of interactions within 20,000 discussion threads,
- Thematic analysis of 30 of the most popular discussion threads,
- Discourse analysis of 2 of the most popular threads.

Discuss: What is collective sensemaking?

How do individual experiences contribute to this process in online health communities?

Definition of Collective Sensemaking

Collective sensemaking: It is the process by which community members construct shared knowledge structures and build meaning together.

- **Participation**: social experience of membership in social communities and active involvement in social enterprise.
- **Reification**: the "process of giving form to our experience by producing objects that congeal our experience into "thingness".

Compared to **sensemaking**: It shifts focus from an individual to communities of peers.
Compared to **collaborative sensemaking**: individuals use each other to collectively make sense of new information, rather than work towards a common goal.

Findings

Attributes of Collective Sensemaking

- Lateral engagement between participants.
- Reaction to previous perspectives
- Transformation of ideas

Contributions to Collective Sensemaking

- Agreement/disagreement with previously stated position
- Presenting argument for/against previously stated position
- Further developing previously stated position
- Personal reconciliation
- Synthesis of previously stated perspectives

Findings

Triggers of Collective Sensemaking

- Reference to a contentious topic
- Contentious or strongly expressed opinion
- Statement of a personal question in generic terms
- Involvement of core members of the community

Dimensions to Collective Sensemaking

- Information-driven
- Experience-driven

Compare with Wikipedia and Stack Overflow

“In contrast with Wikipedia authors and participants of Stack Overflow who usually seek consensus, members of TuDiabetes often value multiplicity and diversity of perspectives, rather than agreement among contributors.”

Discuss: Why different?

Limitations with “Current” Platforms

Information Overload

The structure of traditional discussion boards often results in redundant posts and makes it difficult for users to synthesize and comprehend the wealth of information.

Fragmented Reading Strategies

No metadata and effective search function. Common practices like random sampling of posts lead to a fragmented/skewed understanding of discussions.

Recap: What are the design implications of this paper?

Design Implications

Explicit Collective Production of Shared Artifacts:
Tools that facilitate the creation of shared content collections, similar to Pinterest, to reinforce collective sensemaking.

Tagging Contributions:
Allowing users to tag their posts with specific types (e.g., new perspective, agreement, resource suggestion) to clarify their role in the discussion.

Computational Text Analysis and Visualization:
Using natural language processing and data visualization to create summaries of discussion threads, highlighting key points and areas of debate.

Discuss: What do you think about these implications? Do you see these ideas implemented in today's forums? Any examples?

https://forum.tudiabetes.org/

Discuss: How can the hottest technology today (aka LLM) be used to realize design ideas that facilitate collective sensemaking in online health communities?

Recent studies...

Scope of Large Language Models for Mining Emerging Opinions in Online Health Discourse

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Abstract

In this paper, we develop an LLM-powered framework for the curation and evaluation of emerging opinion mining in online health communities. We formulate emerging opinion mining as a pairwise stance detection problem between (title, comment) pairs sourced from Reddit, where post titles contain emerging health-related claims on a topic that is not predefined. The claims are either explicitly or implicitly expressed by the user. We detail (i) a method of *claim identification* — the task of identifying if a post title contains a claim and (ii) an opinion mining-driven evaluation framework for stance detection using LLMs.

We facilitate our exploration by releasing a novel test dataset, Long COVID-Stance, or LC-stance, which can be used to evaluate LLMs on the tasks of claim identification and stance detection in online health communities. Long Covid is an emerging post-COVID disorder with uncertain and complex treatment guidelines, thus making it a suitable use case for our task. LC-Stance contains long COVID treatment related discourse sourced from a Reddit community. Our evaluation shows that GPT-4 significantly outperforms prior works on zero-shot stance detection. We then perform thorough LLM model diagnostics, identifying the role of claim type (i.e. implicit vs explicit claims) and comment length as sources of model error.

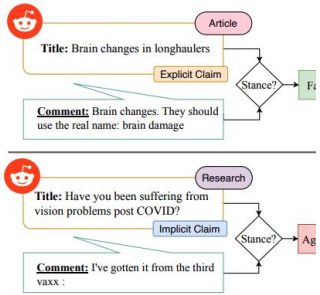

Figure 1: Example post title and comment pairs r/covidlonghaulers displaying flairs (Article/Rese claim type (Implicit/Explicit), and stance label Favor/Against/None). In the "Favor" sample (top), the ment supports the claim in the title that long COVID c

Indicative Summarization of Long Discussions

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Abstract

Online forums encourage the exchange and discussion of different stances on many topics. Not only do they provide an opportunity to present one's own arguments, but may also gather a broad cross-section of others' arguments. However, the resulting long discussions are difficult to overview. This paper presents a novel unsupervised approach using large language models (LLMs) to generating indicative summaries for long discussions that basically serve as tables of contents. Our approach first clusters argument sentences, generates cluster labels as abstractive summaries, and classifies the generated cluster labels into argumentation frames resulting in a two-level summary. Based on an extensively optimized prompt engineering approach, we evaluate 19 LLMs for generative cluster labeling and frame classification. To evaluate the usefulness of our indicative exchanged, so it is still necessary to read most of them for a comprehensive overview. In this paper, we depart from previous approaches to summarizing long discussions by using *indicative* summaries instead of *informative* summaries.[3] Figure 1 illustrates our three-step approach: first, the sentences of the arguments are clustered according to their latent subtopics. Then, a large language model generates a concise abstractive summary for each cluster as its label. Finally, the argument frame (Chong and Druckman, 2007; Boydstun et al., 2014) of each cluster label is predicted as a generalizable operationalization of perspectives on a discussion's topic. From this, a hierarchical summary is created in the style of a table of contents, where frames act as headings and cluster labels as subheadings. To our knowledge, indicative summaries of this type have not been explored before (see Section 2).

Investigating Support Seeking from Peers for Pregnancy in Online Health Communities

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(2017 CSCW)

Sharing a Lucky Story

New mother*, 25 years old*, 30 days post-delivery, developed a blurred vision.

Visited the first hospital on a Friday morning; Notified that no CT results would be out over the weekends*.

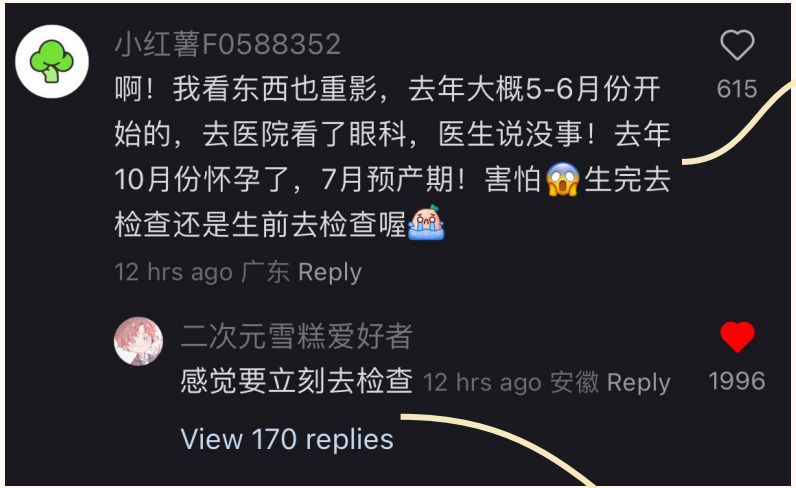
Because the patient's vision is impaired (which was a obvious symptoms and was affecting her activities*), so they decided not to wait any longer,

They went to another hospital because they were told by their friends* that instant CT results were available there.

They saw an eye doctor* there. Nothing wrong with the eyes. The eye doctor recommended* them to check with a neurologist to see if the issue was about her head instead of her eyes.

They caught a brian tumor?, and the patient was hospitalized on that day.

This patient survived.



Oh! I **also had a double vision**. It started around May or June last year. I went to the hospital to see an eye doctor. The doctor said it was fine! I got **pregnant** in October last year and my due date is July! I'm afraid, **should I go for a check-up after or before delivery**

I think you need to get checked immediately

About this paper

Problem:
Existing work focuses on pregnancy as a homogenous period and does not examine the specific support seeking needs and behaviors that characterize the different temporal stages of pregnancy.

Objective:
Our study aims to fill this gap by studying pregnant women's support seeking motivations, activities, and the responses they received from peers over the course of pregnancy, a time that can present different needs at different stages.

Method:
Qualitative content analysis

- Grounded theory approach
- 600 posts (200 for each trimester) and their associated comments were analyzed

Findings

Motivations for Seeking Support Online

- Limited access to healthcare professionals
- Frustration with healthcare providers
- Limited offline support
- Mismatch between information and actual experiences

Type of Supports Sought

- Advice
- Formal and informal knowledge about pregnancy
- Reassurance
- Emotional support

Findings

Topics in different stages

Trimester 1			Trimester 2			Trimester 3		
Topics	**N**	**%**	**Topics**	**N**	**%**	**Topics**	**N**	**%**
symptoms	64	32.0	symptoms	65	32.5	labor related	58	29.0
miscarriage-related concern	36	18.0	baby movement	25	12.5	symptoms	55	27.5
confirmation of pregnant	24	12.0	emotional stress	22	11.0	emotional stress	24	12.0
emotional stress	19	9.5	gender prediction	20	10.0	baby measurement & movement	17	8.5
lifestyle	12	6.0	shopping	14	7.0	delivery related	14	7.0
family relationship	11	5.5	lifestyle	13	6.5	lifestyle	11	5.5
ultrasound results	10	5.0	other test results	11	5.5	general advice	5	2.5
medication	7	3.5	ultrasound results	7	3.5	shopping	5	2.5
date of conception	6	3.0	body shape	6	3.0	family relationships	4	2.0
body shape	5	2.5	medication	5	2.5	treatment	4	2.0
Miscellaneous	16	8.0	Miscellaneous	18	9.0	Miscellaneous	31	15.5
Total	207	103.5	Total	206	103	Total	228	114

Type of Responses Received

- Sharing experiential knowledge
- Passing on other healthcare providers' opinions
- Suggesting going for professional help

Design Implications

Stage-based, Timely, Continuing Care

Design of pregnancy-related technologies should consider ways to accommodate different physical and socio-emotional needs that accompany different stages of pregnancy to provide situated user experience instead of treating pregnancy as a unitary condition

From Fetus-Centered to Women-Centered Care

The design of maternity services and technologies needs to focus on woman-centered care, addressing both the mother's and fetus's needs. Designing for woman-centered maternity care requires a holistic approach integrating a range of functions.

Integrating Experiential and Medical Knowledge

Online health communities should improve the archiving, indexing, and recommending of experiential knowledge to enhance its accessibility and impact, supporting women as experts in their own care and fostering strong peer support networks.

Discuss: What is an imaginable next step from stage-based design for health technologies?

(Hint: Consider the uniqueness of experiences from person to person mentioned repeatedly by the authors)

Discuss: While the authors proposed improvements in the archiving, indexing, and recommending of experiential knowledge, how can technologies help in understanding medical knowledge?

(Hint: Consider what Deborah Lupton describes: “medical technologies of visualization, laboratory test results and written reports about the fetus, to which the woman has no access except through expert intervention and interpretation are the dominant source of knowledge”)

Recent studies...

Utilizing Large Language Models to Simplify Radiology Reports: a comparative analysis of ChatGPT3.5, ChatGPT4.0, Google Bard, and Microsoft Bing

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Abstract

This paper investigates the application of Large Language Models (LLMs), specifically OpenAI ChatGPT3.5, ChatGPT4.0, Google Bard, and Microsoft Bing, in simplifying radiology reports, t potentially enhancing patient understanding. We examined 254 anonymized radiology reports diverse examination types and used three different prompts to guide the LLMs' simplification p The resulting simplified reports were evaluated using four established readability indices. All L significantly simplified the reports, but performance varied based on the prompt used and the s model. The ChatGPT models performed best when additional context was provided (i.e., speci as a patient or requesting simplification at the 7th grade level). Our findings suggest that LLMs effectively simplify radiology reports, although improvements are needed to ensure accurate cl representation and optimal readability. These models have the potential to improve patient hea patient-provider communication, and ultimately, health outcomes.

Original Research

Retrieval augmentation of large language models for lay language generation

Yue Guo [a 1], Wei Qiu [b 1], Gondy Leroy [c], Sheng Wang [b], Trevor Cohen [a]

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Highlights

- **Problem:** Automated lay summary generation can improve the accessibility of health information, but is challenging because of the need to provide background information absent in source documents.
- **What is already known:** Current models face constraints due to corpus size, topic diversity, and untested utility of external information retrieval.
- **What this paper adds:** We approach lay language generation by simplifying content and also generating background explanations, achieved through innovative Retrieval-Augmented Lay Language (RALL) methods. This paper also introduces CELLS, the largest (63k pairs) and most diverse (12 journals) parallel corpus for lay language generation, with a specialized subset to advance background explanation capabilities.

Wrapping up

Discuss: Despite all the benefits of seeking information and support in online health communities, what are the risks?

Thank You!