



# Balancing Health Information-Seeking through Retrieval-Augmented Generation-Based LLM Chatbot

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## Abstract

Family caregivers play a vital role in supporting children with chronic health conditions, such as neonates diagnosed with hypoxic-ischemic encephalopathy (HIE). However, navigating complex medical information can be overwhelming due to the quantity and quality of available literature. This study leverages Retrieval-Augmented Generation (RAG)-based Large Language Models (LLMs) to develop a chatbot that integrates peer-reviewed scientific literature and provides personalized, simplified summaries for caregivers. A user study involving six caregivers and five healthcare providers demonstrated the chatbot's ability to enhance clarity, improve comprehension, and deliver essential medical information concisely. Our findings highlight the potential of RAG-based LLMs to enhance caregivers' health literacy and support their information-seeking behavior, while also underscoring the importance of thoughtfully navigating the differing expectations of caregivers and healthcare providers regarding the type, depth, and presentation of medical information.

## CCS Concepts

• Human-centered computing → Empirical studies in HCI.

## Keywords

large language models, chatbot, healthcare, HIE

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## 1 Introduction

Hypoxic-ischemic encephalopathy (HIE) is a severe health condition that occurs due to oxygen deprivation and reduced blood supply to an infant's brain during birth. This results in significant neurological damage to the newborn, leading to long-term developmental delays, motor impairments, hearing impairment, neurological impairment such as cerebral palsy, epilepsy, cognitive impairment, and other disabilities [16, 23]. Existing literature suggests considerable variation in HIE cases ranging from one to eight cases per 1000 live births and 15-20% die during the early neonatal period [23]. There are chances that children affected by HIE require long term care by their parents with significant financial and physiological stress [7, 17].

Family caregivers play a vital role in supporting children with HIE in supporting their health, well-being, and quality of life [2]. Quality care requires knowledge of specific health information that caregivers commonly use the internet to search for related information, including health symptoms, to gain a deeper understanding of the diagnosis or possible treatment options. This enables them to better comprehend what is happening to their child and make informed health-related decisions [8, 19]. One of the profound challenges individuals face during the information-seeking process is comprehending scientific literature. These literatures contain numerous medical jargons that pose significant challenges for individuals without a medical background to understand and absorb the information [13].

Research has investigated how well the general public comprehends common medical phrases. Many individuals misinterpret medical jargon, sometimes interpreting terms in ways that are opposite to their intended medical meanings. The complexity of medical literature presents challenges for those with limited or no medical knowledge [10]. It is also underexplored how healthcare providers would anticipate the use of Artificial Intelligence(AI) in helping caregivers and patients in health information-seeking practices.

This paper introduces the *AskHIE* chatbot, an application of Retrieval-Augmented Generation (RAG)-based large language models (LLMs) that embeds peer-reviewed scientific literature in fetal

and neonatal medicine [28]. The designed chatbot aims to provide personalized, simplified summaries for caregivers. Our research question is: *How can RAG-based LLM chatbots balance the informational needs of caregivers and the clinical priorities of healthcare providers in supporting infants with HIE?*

To answer this question, we conducted a user study with six HIE caregivers using semi-structured interviews. The study revealed the initial challenges faced by caregivers and the potential role of RAG-based chatbots in facilitating health information seeking behavior and comprehension. We then conducted a second round of interviews with three healthcare providers and one social worker to gauge their perceptions on using AI tools to provide health information to caregivers. Based on our findings, we propose design implications and challenges for leveraging LLMs to facilitate and improve health information seeking and personalized support for HIE caregivers.

## 2 Related Work

The use of technology artifacts, such as mobile apps or devices, has been shown to support caregivers by reducing physical pain and improving mental well-being [20, 24]. The recent rapid development of Large Language Models (LLMs) presents opportunities to leverage AI technology to enhance our exploration in this domain. LLMs have revolutionized summarization through methods like fine-tuning, prompt engineering, and chain-of-thought reasoning [14]. Advanced techniques like Retrieval-Augmented Generation (RAG) have demonstrated great potential in reducing hallucination, improving performance, and enhancing the information-seeking process by providing more tailored and context-based responses [18, 26]. Research has shown that RAG technology can improve LLM performance significantly, likely due to increased accuracy of answers without diminishing empathy [29].

The potential of LLMs in medical applications is significant, and RAG can address the weaknesses of these models in terms of data transparency and scientific accuracy by incorporating current scientific knowledge into responses. Studies have demonstrated the effectiveness of RAG in improving response quality and reliability of LLMs [27] and making scientific content more accessible to broader audiences [12]. Additionally, RAG has been explored in various other contexts within the healthcare domain, including personalized disease prediction models [15]. While generative AI has demonstrated excellent capabilities in summarization and reducing hallucinations, its application for caregivers of patients with chronic diseases is still underexplored. The literature suggests that such systems can empower caregivers, particularly those with limited or no medical knowledge, to more easily find and comprehend medical literature [4]. This enhancement in health literacy equips caregivers to better plan for long-term childcare needs and personalized support.

Despite these advances, a growing body of research highlights the importance of designing AI systems that balance the needs of multiple stakeholders—particularly in sensitive domains like healthcare. Gräßer et al. [11] developed a pharmaceutical recommender system to facilitate shared decision-making between patients and physicians. By integrating clinical guidelines and patient-specific factors, the tool supports physicians in identifying appropriate

**Table 1: Participant Demographics**

| Code | Region/Country             | Gen. | Experience*      |
|------|----------------------------|------|------------------|
| C1   | Indiana, United States     | F    | 2.5 Years/M      |
| C2   | Alberta, Canada            | F    | 2 Years/M        |
| C3   | Mississippi, US            | F    | 3 Years/M        |
| C4   | Florida, US                | F    | 16 Years/F       |
| C5   | Texas, US                  | F    | 8 Years/M        |
| C6   | Missouri, US               | F    | 3.5 Years/M      |
| P1   | Scarborough, United States | F    | Pediatr. Neurol. |
| P2   | Montreal, Canada           | F    | Neonat.          |
| P3   | Chicago, United States     | F    | Neonat.          |
| S1   | Atlanta, United States     | F    | Social Worker    |

\*Experience indicates the age/gender of the HIE child or expert occupation.

therapies while empowering patients in the decision process, thus balancing clinical evidence with patient preferences and improving the joint decision quality. Study conducted by Scholl et al. [25] examined a self-management support program for chronic disease that integrated personalized feedback with health coaching and digital tools. Their qualitative evaluation showed that while patients appreciated the program’s relevance to their needs, health professionals faced challenges in resource management and system integration. Similar study was conducted by [1] where they developed a personalized health tool that serves two primary stakeholders: patients (by empowering them with individualized diet guidance to manage their condition) and clinicians (by reinforcing dietary recommendations that improve clinical outcomes) By incorporating feedback from both groups during development, the system was tuned to be user-friendly for patients while delivering advice trusted by providers.

## 3 Methodology

### 3.1 System Design

To explore the implications of using RAG-integrated LLM to help caregivers in the health information seeker process and simplifying medical terminology, we developed and tested a chatbot prototype, called the *AskHIE* chatbot. This chatbot was build using LLAMA 3 8B model (fp16) and the interface was designed using Dify framework<sup>1</sup> which enabled a seamless and user-friendly design suitable for non-expert users. The chatbot’s primary functionality was to interact with caregivers, providing concise and understandable summaries of peer-reviewed scientific articles related to HIE. By integrating these summaries, the chatbot empowered caregivers to make informed decisions and improve their understanding of medical practices and guidelines. Figure 1. displays the snap shot of the interface and the sample prompts.

The embedded knowledge within the chatbot was derived from a specific peer-reviewed scientific article discussing a care practice guideline for Neonatal Encephalopathy (NE) during Therapeutic Hypothermia (TH) [28]. To ensure the knowledge base was comprehensive, accurate, and reliable, we collaborated closely with a faculty member of the Department of Neonatology, who is also one of the coauthors of this article. This partnership was pivotal in

<sup>1</sup><https://github.com/langgenius/dify>

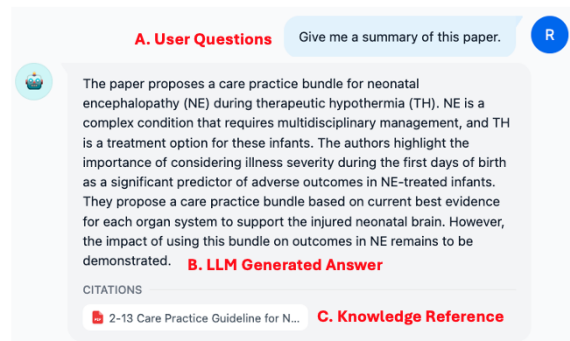


Figure 1: AskHIE Chatbot Interface

ensuring the inclusion of accurate and reliable information in the database. We utilized a vector database which stored the selected peer-reviewed article, with chunks length 500 characters and a total of 70 paragraphs. This approach allowed for efficient indexing and retrieval of scientific information. To further optimize the chatbot's performance, we implemented a hybrid search mechanism that combined full-text searches with vector-based searches. A subsequent re-ranking process was employed to prioritize and present the most relevant results for user queries, ensuring caregivers received precise and meaningful responses to their questions<sup>2</sup>.

### 3.2 Study Design

We conducted a semi-structured interviews to gather feedback from healthcare providers and HIE caregivers on the generated summaries and their overall experience interacting with RAG-based LLMs. For the study, we created a persona named 'Sarah,' whose child has been diagnosed with HIE. Sarah discovers an article, uploads it to the chatbot, and receives a summary of the article along with suggested questions. A total of six caregivers and four healthcare providers, including one social worker, participated in the study. Table 1. shows the demographic of the participants who participated in the interview where code C1-C6 denote the caregivers, P1-P3 denote the providers and S1 denote the social worker. All participants were recruited from an online HIE support groups with the help of one of our coauthors. All participants were contacted by email.

We scheduled interviews with the participants via Zoom. Each session lasted approximately 15–20 minutes. We began with a working demonstration of the chatbot using a simulation, after which participants were encouraged to explore the chatbot freely. This was followed by a discussion to understand their current information-seeking processes and gather feedback on their overall experience with the chatbot. All the interviews were recorded with the consent from the participants. After the interview, transcripts were collected and analyzed by the authors using thematic analysis [5]. The study received IRB approval from the university, and only the caregiver participants were compensated with a \$20 gift card each.

<sup>2</sup>we used Cohere Rerank API, <https://cohere.com/>

## 4 Findings

### 4.1 Comprehending and Navigating

HIE caregivers are eager to learn about their child's diagnosis and explore possible treatment options. They strive to be as knowledgeable and informed as possible about the condition, as HIE comes with many uncertainties. This is especially true for infants and toddlers, where predicting the exact impact on their development is challenging. However, accessing medical and scientific literature can be difficult, and this challenge manifests in several ways. Caregivers often struggle with complex medical jargon, identifying relevant and reliable articles, and determining the relevance of the information to their specific cases. Even when they do find useful resources, understanding the material can be overwhelming. As C1 describes, the process of searching for and interpreting medical terms is often tedious and time-consuming.

*"...but I did find an article one time that was talking about diagnosing newborns as HIE, or Stroke, and it was talking about all of the particular tests that can be done... [omitted] It was a lot of medical jargon, a lot of terms I didn't understand. So I would then go to Google and like search that particular term and it was very tedious and very time consuming to try to make sense of it."* - C1

Given their already demanding responsibilities—caring for their child and managing other aspects of daily life—this additional effort often discourages caregivers from reading these articles altogether. When they encounter something they do not understand, they may set the article aside and turn to their healthcare providers or trusted contacts in the medical field for clarification. Some caregivers rely on personal networks, such as friends in the medical profession, to help interpret and validate the information they come across. As C3 explains, she depends on her friends from medical school to help her make sense of complex medical literature.

*"I send white papers to 3 of my friends from college who went to medical school, and I say, when you get the time, if you could, please read this and tell me what you think. I kind of skim it, and then, if all 3 of them say a similar thing, I believe it."*-C3

In some cases, caregivers attempt to search for literature but find themselves unable to access it due to paywalls or subscription requirements. This frustration often forces them to abandon their search altogether, hindering their ability to expand their understanding. As C5 shares, the inability to access relevant articles can be a significant barrier:

*"...so many are really inaccessible, and the title makes it look like, or sometimes you can read the abstract with the title, and you're like. Yes, this is exactly what I want to read, but I can't access it because it's wily and I don't have a subscription, So I just give up."* - C5

### 4.2 Role of LLM Chatbot in Simplifying Jargons

Caregivers provided highly positive feedback on the LLM chatbot, seeing it as a valuable tool for overcoming the challenges of reading and understanding complex scientific articles. They appreciated its ability to summarize articles and allow them to ask specific questions or clarify unfamiliar terms. One of the most significant advantages they highlighted was the time-saving aspect. Instead of spending hours searching for and deciphering information, the chatbot provided quick, efficient, and comprehensive responses,

making it easier for caregivers to stay informed. In the quote below C5 explains the chatbot could help them save time.

*"The pain of looking for this information is that you need hours to sit there and read and search. Then you go down rabbit holes and find even more. So, it's great because it summarizes everything for you. If I already know I'm looking for a specific answer, I don't have to go through each article and search for it."* - C5

Another feature caregivers found particularly innovative was the chatbot's ability to engage in a conversational format, essentially allowing them to "chat" with an article. This not only saved time but also enabled them to extract relevant information without having to read the entire text. By simply asking specific questions, the chatbot could scan the article and generate clear, easy-to-understand responses, making scientific literature more accessible.

*"I could see myself even finding that same article putting it in here and being able to almost like you're chatting with the article. It is amazing how it can summarize it into terms that you can understand, it is so helpful"* - C1

Caregivers expressed a strong preference for using peer-reviewed scientific articles as their primary source of information. However, the challenges of accessibility and complex medical jargon often made this difficult. The ability to receive simplified yet credible summaries empowered them to navigate the uncertainties of HIE more effectively. With increased knowledge, they felt better equipped to ask informed questions and advocate for their child's needs.

*"I think it's great, because, obviously I'm not a doctor. So, being able to take that information that has been vetted, peer-reviewed by other doctors, and pull it into some way that I can understand it, and maybe even use that information to better understand what kinds of questions I might need to ask, or better understand, my child and what they're going through. I think that's helpful."* - C6

### 4.3 The Outlook of the Experts

In addition to caregivers, HIE providers and social workers also provided valuable feedback on the LLM chatbot, particularly regarding its ability to make scientific articles more accessible to caregivers. They recognized the ongoing need for information among parents of children with HIE, regardless of their child's age. As children grow—into adolescence or adulthood—parents often encounter new medical challenges, additional diagnoses, complications, or changes in treatment plans. Each of these situations requires them to seek out and understand complex medical information. Providers emphasized that the LLM chatbot could be a valuable tool in these scenarios, enabling parents to quickly access and comprehend detailed information about new medications, treatments, or conditions related to HIE. Essentially, the chatbot serves as a continuous support system for parents navigating evolving healthcare needs. As one provider explained:

*"Parents with children of any age, even adults navigating HIE, will be able to use this to get more details, because you may be receiving additional diagnoses, or you may be having different complications, or your provider may bring up a different medication or a different treatment plan that you're going to need to look up more information about."* - S1

Providers also noted that the chatbot could be particularly beneficial in inpatient settings, where caregivers frequently encounter

unfamiliar medical terms and concepts. In such use cases, providers could direct caregivers to the chatbot as a resource for better understanding these topics.

*"So I think this would be the most useful in the inpatient setting when they're trying to understand, like, where did therapeutic hypothermia come from? How did it become a standard of care so rapidly?"* - P1

### 4.4 The Concerns from Experts

While providers acknowledged the chatbot's potential benefits, they also expressed concerns about its possible drawbacks. One major concern was the risk of information overload. While the chatbot could help caregivers navigate the uncertainties of HIE, it might also lead to increased stress if caregivers became overwhelmed with too much information. A provider explained this concern:

*"My worry is that it would add stress to families if they're consuming scientific manuscripts that are talking about how much we don't know about this treatment."* - P1

Another challenge providers highlighted was the complexity of interpreting certain scientific papers. Some research studies, particularly clinical trials, present results in a way that may be difficult for caregivers to understand without a medical background. Misinterpretation of these findings could lead to confusion or misinformation.

*"A lot of these big clinical trials combine outcomes like death or moderate disability, and they describe moderate disability as a level of cerebral palsy. Being a person who takes care of a lot of kids with cerebral palsy, I know that's nowhere near the equivalent of death. It makes it confusing for physicians to read, and I think it would be way too confusing for families to read."* - P1

Additionally, providers raised concerns about the time required to address caregivers' questions after they read an article. Given their limited time, answering questions about potentially irrelevant or misleading information could be a challenge.

*"My first thought, too, was, 'Oh, my God! How am I gonna find the time to answer these questions?' Because if they read something that doesn't even apply to them or they get missing information, then I have to explain, 'Well, this doesn't apply to you for this reason.' I don't want to be the gatekeeper of all information."* - P1

## 5 Discussion

Our research findings reveal that this LLM chatbot has the potential in improving scientific literacy among the HIE caregivers thus helping them in the health information seeking process and receive much personalized information based on their individual needs and preferences. The findings highlight the perspectives of both caregivers and healthcare providers on the use of AI tools in healthcare information-seeking and understanding medical literature. Caregivers valued the RAG-based chatbot for simplifying complex medical jargon, clarifying terms, and personalizing explanations, which saved time and empowered them with clearer insights into medical conditions. Prior research indicates that caregivers with higher health literacy are better equipped to manage complex health tasks, leading to improved patient care. For instance, a study found that caregivers with marginal or low health literacy demonstrated poorer performance on everyday health tasks, such

as interpreting health information and recalling spoken communication. This suggests that improving caregivers' health literacy can directly enhance the quality of care provided to the patients[22]

On the other hand, while healthcare providers recognized the chatbot's potential to improve communication and understanding, they also raised concerns about information overload, misinterpretation, and the burden of answering questions about irrelevant or complex topics. They also emphasized the need for safeguards to ensure accurate, contextualized information and a balance between providing caregivers with details and preventing additional stress from medical uncertainty.

Our findings demonstrate how the LLM-based chatbot can simplify complex scientific information, making it easier for caregivers of children with HIE to understand. It helps them navigate medical jargon, while its conversational style allows them to quickly obtain answers and summaries of articles. This increases the likelihood that caregivers will consider scientific articles as a primary source of information. The implications extend beyond HIE caregivers and can make complex scientific information more accessible and comprehensible to non-expert caregivers. By reducing the fear of engaging with complex scientific content, this tool could also help combat the spread of health misinformation. When individuals understand how easy it can be to interpret peer-reviewed or vetted scientific information, they are more likely to turn to trusted sources instead of relying on unverified and easily digestible articles. Making medical science more accessible to the public is crucial in fighting misinformation [3, 9]. This chatbot design has far-reaching potential, promoting scientific literacy and personalized health behaviors across user modeling fields [21].

While the chatbot demonstrates potential in enhancing scientific literacy and supporting caregivers' understanding, its integration into real-world healthcare settings also raises important concerns around information management and communication flow. Both caregivers and healthcare providers may face information overload, especially when large volumes of AI-generated content are presented without appropriate filtering or context. For caregivers, the availability of complex medical information, though well-intentioned, can lead to confusion, stress, or misinterpretation if not carefully guided. On the provider side, increased caregiver engagement with AI tools may result in more frequent or nuanced questions that shift the nature of clinical conversations, potentially introducing communication burdens or redirecting time away from core clinical tasks. As noted by Daniel et al. [6] AI chatbots can provide caregivers with immediate access to information. However, it also notes that without proper filtering and context, the vast amount of information can overwhelm caregivers and potentially burden healthcare providers with increased and nuanced inquiries.

Our experiment results underscore the importance of developing AI systems that balance the informational needs of caregivers with the practical constraints and communication responsibilities of healthcare providers, ensuring the tool serves both groups effectively and sustainably. To effectively leverage Gen-AI in this context, it is essential to curate the information presented to caregivers, focusing on the most pertinent details rather than overwhelming them with exhaustive literature. While Large Language Models (LLMs) possess vast knowledge that can provide comprehensive coverage of diseases, a more personalized approach would involve

considering individual user profiles, including patient history, age, and educational background, to deliver tailored information that mitigates unnecessary anxiety. Furthermore, healthcare providers would benefit from a tool that offers insights into the interactions between caregivers, patients, and AI tools, enabling them to anticipate potential conversation topics and prepare accordingly. By recommending supplementary reading materials, providers can enhance their understanding of patient needs, optimize resource allocation, and minimize potential conflicts arising from AI-mediated interactions, ultimately ensuring more focused and effective support during visits.

## 6 Conclusion

This study explores the challenges faced by caregivers of neonatal Hypoxic-Ischemic Encephalopathy (HIE) patients in navigating complex medical literature and evaluates the potential of Retrieval-Augmented Generation (RAG) large language models (LLMs) in addressing those challenges. This study showcases the potential of RAG-based LLMs in enhancing information seeking among caregivers by simplifying and clarifying scientifically grounded literature. Our results provide insight into how generative artificial intelligence can be leveraged to facilitate patients' and caregivers' access to reliable information, thereby empowering their information-seeking practices and behaviors.

The implications of these findings could inform the design of health systems tailored to meet the needs of chronic patient caregivers. However, the healthcare providers had a slightly different perception to that of the caregivers. While they appreciated the chatbot's potential to enhance understanding and support families, they emphasized the importance of balancing simplicity with accuracy, ensuring that the tool does not inadvertently create stress or misunderstandings. Providers were also concerned that families might bring up numerous questions from reading articles that are not directly relevant to their case, leading to additional workload for healthcare professionals and at the same time overwhelm the families with too much of detailed information. This highlights the need for thoughtful attention to the informational needs and constraints of both caregivers and healthcare providers. To maximize impact and minimize unintended burdens, future implementations must prioritize clarity, accuracy, and alignment with clinical workflows.

Ultimately, AI systems like this chatbot hold significant potential to support collaborative, informed caregiving—provided they are designed with a balanced, stakeholder-aware approach at their core. Based on the findings, we discussed the design implications in the fields of AI, HCI, and UMAP communities.

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