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Exploring Potential Roles for Artificial Intelligence in Patient Education

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Background

In November of 2022, OpenAI previewed one of the most advanced large language models (LLMs) available to the public, Chat Generative Pre-trained Transformer (better known as ChatGPT).[1] LLMs like OpenAI's ChatGPT and Google's Bard are a breakthrough in artificial intelligence (AI) allowing automatic learning and communication through natural language interactions with human users, information from the world wide web, and even other LLMs.[2] The capabilities of LLMs have been expanding exponentially over a very short time.

What began as an interactive chat that could help identify, sort through, and uniquely communicate vast amounts of textual information by comprehending and generating natural language, is now being incorporated into audio, photographic, videographic, and even virtual reality mediums. While there are still concerns regarding accuracy, privacy, and barriers to adoption, AI generated-content (AIGC) is entering an exciting new era of abilities and potential applications.[3]

While the ability of AI to instantly synthesize huge swaths of natural written, verbal, and visual information will undoubtedly benefit many fields of life, perhaps the most valuable platform for its use is in public health. AI technology has already been used to develop apps that can scan and diagnose photographs of potential skin cancers[4] and has been found capable of instantly identifying early signs of disease from professional imaging.[5-7] It has been adapted to assist with interpersonal communications within virtual reality experiences[8,9] and even talk therapy for helping treat issues like social anxiety.[10]

The potential for AI as a tool for health equity is outstanding as it can deliver quality clinical expertise, screenings, outreach, and in some cases even treatment to individuals in any location, in any language, in real time, and free of charge. There is also hope that the utilization of AI may help mitigate implicit bias that compromises care for many minority patients.[11,12] With these capabilities, AI may be an excellent technology to assist with patient advocacy - helping empower patients to address certain barriers to receiving care.

Patient advocacy occurs when someone is brought into a healthcare team to help educate and empower patients to navigate healthcare systems and make informed decisions about their health.[13]

At KDH Research & Communication, we have designed and tested a series of interventions that use patient advocacy to increase minority representation in lupus clinical trials (CTs). While we have found that patient advocacy is effective in enhancing patient cognitive outcomes (increasing knowledge about and intentions) related to CT participation,[14] there are limitations of using individuals as patient advocates that may be circumvented with added support from a clinically trained AI LLM platform.

In this brief, we brainstorm potential supportive roles for AI LLMs in providing patient advocacy that addresses CT representation among historically underrepresented groups.

Patient advocacy and clinical trial representation

Systemic lupus erythematosus is an inflammatory autoimmune disease that varies largely by race and ethnicity in its prevalence and severity. Disproportionately affecting racial/ethnic minorities[15] who are underrepresented in CTs.[15,16] Such underrepresentation in lupus CTs can make it difficult for the FDA to approve efficacious treatments among these patient groups at higher risk of detrimental outcomes.[17] Because racial and ethnic minorities have the greatest risk of developing lupus and often experience more severe manifestations of the disease, it is imperative that diverse populations are well represented in CTs.

Disparities in CT representation occur when certain groups of the population hold shared reasons for not participating in CTs. These reasons, commonly referred to as barriers to care; include accessibility issues like access to transportation,[18] understandable information materials,[19] or child-care.[20] Patients may be unaware of CT opportunities[21] or that CTs may provide services at reduced-cost or even for free.[22] There may be trust issues among minority patients who have been historically discriminated against by medical systems,[18,21,23] or worries about potential deportation among patients who are undocumented migrants.[19] There are also health literacy issues where patients may not understand their disease[24] or how they may benefit from participating in CTs.[19,25]

Patient advocacy can help patients address barriers to care in hopes of enhancing the likelihood that these patient groups seek information about and ultimately participate in CTs. Health equity interventions have used various types of patient advocates to conduct outreach with minority lupus patients and have proven beneficial in increasing patient knowledge about and intentions towards participating in various CTs.[14,26,27] In regard to lupus CT participation, patient advocacy aims to educate patients about lupus and available treatment options, increase awareness around clinical research, and explain how ensuring diverse representation in CTs is important for identifying efficacious treatments. AI LLMs may be particularly efficacious with providing personally tailored logistic/educational forms of support.

Limitations of using individuals as patient advocates

Nurses have long served as patient advocates, helping educate patients about a wide variety of conditions and treatment options; however, due to the potential for time limitations, cultural mismatching, and concerns of power dynamics among medical professionals,[28,29] community health workers, and even patient peers have often been selected to provide patient advocacy.[30,31] While there are undoubtedly many aspects of patient advocacy which necessitate human connection, there are logistical and educational forms of support that humans may be limited in providing. For example, there are limitations on personal availability, concerns about accuracy of information, and limitations in the amount of dense medical information patient advocates can remember and accurately translate to other languages or literacy levels. AI LLMs can be used to address each of these limitations.

Current strengths of AI LLMs in patient advocacy, according to ChatGPT

While we explored the scientific literature on ways that AI LLMs are being used to support patients with engaging their healthcare, we have not seen any studies exploring the ability of AI LLMs to directly provide advocacy directly to patients, and thus the potential uses are still speculative at this stage. We decided to ask the publicly available ChatGPT 3.5 itself what barriers to care its capabilities would be most efficient at helping patients address. Specifically, we asked, “How do you think ChatGPT could be used to help patients who are underrepresented in clinical trials overcome barriers to care?” Here is the response received from ChatGPT, version 3.5:

“ChatGPT could help by creating accessible, easy-to-understand resources about clinical trials, breaking down complex medical information, and offering guidance on how to navigate the healthcare system. It could also provide information in various languages, increasing accessibility for a broader range of individuals. Additionally, it could address specific concerns or barriers that underrepresented patients may face, such as a lack of information, mistrust, or logical issues, thereby supporting their participation in clinical trials.”

Sounds willing and ready!

Roles for AI in patient advocacy

As LLMs improve and expand in their reliability and capability, AI patient advocacy (AIPA) will likely assist with a wide array of patient needs. For instance, AIPA could facilitate clinical-related triage and documentation,

and even assist patients in obtaining pre-authorizations from insurance companies. With the ability to conduct lightning fast, exhaustive literature reviews, and synthesize relevant findings from research papers, AIPA could effectively educate patients about their illness and the best practices for managing their disease. By learning and communicating via natural language, AIPA may interact with patients and care providers as an expert chatbot, answering questions for nurses, doctors, social workers, patients, and their family members.[32] AIPA may be used to provide up to date lists of local providers, services, and clinical trials. AIPA may be used to remind patients about appointments, procedures, and concerns related to clinical protocols. Moreover, LLMs are capable of communicating with patients through both text and speech, allowing blind and visually impaired patients around the world to access vital information at their fingertips that otherwise would have required personal assistance and access to extensive resources. AIPA can do all of this, while tailoring the language it uses with each individual patient user to match both language and literacy levels.

Ethical concerns of AI for patient advocacy

While both the reliability and trust in LLMs has been increasing in short time, there are serious concerns related to breaches to privacy, LLMs ability to protect private health information, the ability of LLMs to generate false or wrong information, and to learn bias from the content it processes.[33] Patients' ability to trust the information given by LLMs is an important concern regarding moving towards AIPA. Research on patient trust in LLM support is promising, with ChatGPT health-related responses being considered by patients as trustworthy, valuable, and not dangerous.[34] Any LLM being used for AIPA purposes would at a minimum necessitate guaranteed reliability, privacy, and a lack of bias based on patient characteristics. AIPA would require compliance with data protection laws like the health insurance portability and accountability act (HIPPA).

Discussion

The ChatGPT software was released to the public in 2022 as a research preview to gather feedback from users on its abilities and exactitude, as of November 2023, the software has been updated several times to enhance its accuracy, security, and overall capabilities.[35] While there are still concerns about LLMs ability to generate false information and/or bias, and whether LLMs have the security in place to protect sensitive personal information; the speed at which these technologies are learning, adapting, and advancing suggests that such concerns could be resolved in short time with careful consideration of the specific needs related to AIPA. Once these concerns are acceptably addressed, AIPA may be the most impactful tool for achieving health equity that the world has seen.

With the ability to instantly search and sort relevant and creditable local resources, synthesize and convey complex medical information in any language, through written or spoken platforms, at any time anywhere -- AIPA could be easily accessible to all types of patients, across all areas with Internet access. AIPA specifically targeting CT inclusion will likely be most beneficial in logistical and educational roles: helping patients easily comprehend relevant resources, translating complicated medical information, and assisting patients in navigating the health systems in their area. AIPA could also educate patient groups about the importance of CTs, the protective policies and levels of care provided in CTs and help identify services to help overcome physical barriers to care such as transportation.

While the capabilities of newly developed LLMs and the wide range of potential applications for their use are still being considered, it is undoubtable that AI will find new exciting roles in healthcare which can help improve patient health, engagement, and inclusion. The concept of AIPA is promising for being able to reach and inform a larger audience of patients than has ever been plausible. As such, AIPA may have tremendous impacts on diverse patient representation in CTs, and in turn in identifying effective treatments for underrepresented patient groups.

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