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A Qualitative Study with Informal Caregivers and Healthcare Professionals for Individuals with Head and Neck Cancer on the Usage of AI Chatbots

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Abstract. Informal caregivers (ICs), including the patient's spouse, close relatives, or friends, play an important role in caregiving individuals with head and neck cancer (HNC). AI-based chatbots might offer information and assistance related to caregiving. This study presents the viewpoints of ICs and healthcare professionals (HCPs) on using AI-based chatbots in caring for individuals with HNC. A total of six focus groups were conducted with 15 ICs and 13 HCPs from three Swedish university hospitals. The study uncovers a widespread hesitancy toward the intention to use AI-based chatbots among ICs and HCPs. Factors contributing to this reluctance include their distrust in chatbot-provided information, negative past experiences of using chatbots, and lack of human connection in chatbot interactions. Embracing a holistic approach is crucial when designing chatbots, ensuring active user engagement and incorporating their perspectives into the design process.

Keywords. AI, Chatbots, eHealth, Caregiving, Cancer, User participation, HCI

1. Introduction

The integration of artificial intelligence (AI) in healthcare is on the rise, featuring systems designed to replicate human intelligence and cognitive functions [1]. AI-based chatbots are one example of these innovations [2]. Chatbots are conversational agents that emulate human interaction through text, speech, and visuals. They might be helpful for delivering health-related information and services autonomously [3,4]. Despite these capabilities, the acceptance and willingness to use AI-based chatbots in healthcare face challenges, with users encountering several issues such as technical problems and moral

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concerns [5]. Therefore, it is important to investigate the potential usefulness of chatbots within specific contexts of use to better understand these challenges. This study seeks to explore and comprehend users' perceptions of utilizing AI-based chatbots in the context of eHealth interventions.

This study is a part of the Care eSupport project, a research initiative to prepare informal caregivers (ICs) of individuals with Head and Neck Cancer (HNC) for caregiving, decrease their caregiver burden and support their well-being. ICs, including spouses, partners, relatives, friends, or neighbours, provide care to patients voluntarily. The users' needs and preferences for the intervention have been identified by the ICs and healthcare professionals (HCPs), as detailed in our previous studies [6,7]. One of the project's objectives was to explore the potential integration of AI-based assistance to support ICs in caregiving.

This study presents the viewpoints of ICs and HCPs on using AI-based chatbots in caring for individuals with HNC. By exploring end users' attitudes, concerns, and preferences, we seek to contribute valuable insights to inform the development and implementation of AI-based chatbots in healthcare settings, ensuring that these technologies align with users' needs and expectations.

2. Methods

This study employed a qualitative research methodology, utilizing focus groups. A total of 15 ICs and 13 HCPs were recruited from three university hospitals in Sweden. HCPs from various caregiving fields, such as nurses, physicians, dietitians, a dental hygienist, and speech therapists, were selected for focus groups. Six focus groups, three with ICs and three with HCPs, were conducted online using a web-based video conferencing tool. Each focus group had 4 to 6 participants and lasted approximately 60 to 70 minutes.

Discussion topics included questions like "*How do you feel about receiving caregiving assistance from a robot or an AI-based chatbot?*" The data was analyzed using Braun and Clarke's thematic analysis process [8]. The authors ÅC, UL, and YTE conducted focus groups with ICs, while UL, YTE, and AA conducted focus groups with HCPs.The focus group recordings were transcribed and reviewed to familiarize with the data and initial ideas were coded. Next, these codes were organized into broader themes, supported by relevant quotations and observations, which were translated from Swedish to English. The themes were reviewed and refined to ensure they addressed the research question, and thoroughly discussed with all project members to reach a consensus on the final themes. Finally, the key themes, linked quotations, and commentaries are presented in the Results section.

This study is approved by the Swedish Ethical Review Council (Dnr: 2020-04650). Informed consent was obtained from all study participants, outlining the implications of the study, its purpose, and the procedures involved. An end-to-end encrypted videoconferencing tool was used for focus groups to ensure security. All data are securely stored at Uppsala University.

3. Results

The study highlighted a prevalent hesitation among ICs and HCPs in using AI-based chatbots in caregiving. The idea of receiving assistance and crucial information from a

robot or chatbot did not resonate well with them. Both ICs and HCPs cited various factors that influenced their hesitancy, with a significant factor being a preference for human interaction, especially in the context of seeking vital health information. They expressed inclination towards personal conversations when dealing with such sensitive matters.

"*The first thought that comes to the mind when something happens, is you want to talk with someone you know well. Is there anyone who can help me, who can talk, I think, usually you get calmer if you talk to a person rather than a robot.*" *[Wife of the patient]*

"I have worked with healthcare information and I believe in human contact, talking and reasoning…so I would say no. I am definitely not comfortable with robots." [Ex-wife of the patient]

The lack of trust in robotic technologies also emerged as a big factor that affected their intention to use them negatively. Most of the participants were concerned about the credibility of information obtained from chatbots. They were hesitant to retrieve critical information related to the patient's health.

"*I do not think I would feel comfortable asking medical or treatment questions to a robot." [Daughter of the patient]*

"*When you want to talk about things like Cancer, you still want a professional experienced person to answer." [Wife of the patient]*

The perception of receiving overly standard and generic responses from chatbots impacted participants' intention to use them. Some ICs who had experience with chatbots in different contexts felt that the chatbots lacked intelligence and needed to be more adept at providing accurate and context-specific answers according to their situations.

"I have tested it in other contexts and I got quite annoyed at the generic answers." [Ex-wife of the patient]

"It can be difficult with a robot because you only get standard answers, and it would be easily done by questions and answer lists." [Daughter of the patient]

Notably, only one IC expressed a willingness to use chatbots. However, this participant had high IT literacy and a comprehensive understanding of chatbots.

"*For easy information retrieval, if it is a good robot, then it works. There is a lot of intelligence in it today….and sometimes it can be very difficult to know if is it an actual person who writes or is it a robot. Absolutely for information seeking, it would work well*." *[Daughter of the patient]*

In general, study participants (both ICs and HCPs) strongly advocated against the use of chatbots in the context of caregiving. However, a few participants suggested that leveraging chatbots for disseminating basic caregiving information, specifically offering tips and suggestions for patient nutrition, could be beneficial. One HCP emphasized the value of such guidance, particularly for new and inexperienced caregivers, addressing challenges such as patient's food preparation.

"Maybe a little suggestion about which soft food is best suited for the patients because they usually have difficulty in swallowing, so a few tips about it because when the patients are in the hospital, we only order soft food and it works well, but when they go home, then they have to make it, and it should taste good too, and be good texture and everything so that they should get a little more tips and so on." [HCP, Nurse]

4. Discussion

This study presented the ICs' and HCPs' perspectives on utilising AI-based chatbots in the context of caregiving to individuals with HNC. The majority of participants showed great reservations about chatbots. Participants expressed reluctance to engage with chatbots during delicate moments, underlining the emotional complexity of healthcare discussions. Consistent with prior research, ICs highlighted the need for human contact, reasoning, and personal connection when seeking health-related information [5,9].

The scepticism towards chatbots is evident in our findings, with concerns about the credibility of information obtained from chatbots, particularly regarding medical or treatment-related queries. The previously encountered issues with chatbots, such as generic responses and a perceived lack of intelligence in chatbots further contributed to participants' reluctance. Existing Research shows that the tendency of such chatbots to provide hallucinated answers to questions also intensifies user distrust [3,10].

Many ICs may have concerns about relying on chatbots instead of consulting with healthcare professionals due to accuracy, personalization, and accountability issues. Chatbots operate on pre-existing knowledge and algorithms that might not be updated with the latest medical research or guidelines [11]. They cannot provide personalized medical advice that considers the care recipient's unique medical history, current medications, and other specific health conditions. In critical health matters, the nuance and depth of understanding provided by medical professionals may be irreplaceable, fostering scepticism toward substituting these interactions with chatbots [12].

AI-based applications are undeniably on the rise and high-tech IT companies often extol their virtues in every facet of life [13]. However, in reality, individuals are reluctant to use such applications [5]. This study revealed significant concerns among ICs and HCPs regarding integrating AI-based chatbots into their daily caregiving routines, particularly in providing care to patients with cancer. Citing limited resources and the preliminary work outlined by study participants, the decision was made to exclude AI-based chatbots from the Care eSupport project.

While the future of AI and human collaboration appears promising, it is crucial to acknowledge the importance of better understanding the relationship between humans and AI. This comprehension will play a pivotal role in shaping the future trajectory of AI development and its integration into various facets of human life. This study advocates for the research community in Human-Computer Interaction (HCI), design, and medical informatics to investigate the factors influencing the intention to use in their specific context before the practical implementation of such chatbots.

5. Conclusions

The relationship between humans and AI is complex and warrants a deeper understanding, particularly in the practical implementation of AI technologies. This study reveals a pervasive reluctance among ICs and HCPs to embrace AI-based chatbots. Factors contributing to this reluctance include their distrust in chatbot-provided information, negative past experiences of using chatbots, and lack of human connection in chatbot interactions. A holistic approach that involves users in designing AI-based chatbots is crucial to enhance user perception and acceptance of such technologies.

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