Co-Design to Meta-Design in Oncology Caregiving: Enabling End-User Development of an AI Mental Health Support System*

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Abstract

Oncology caregivers often experience significant psychological strain while supporting patients through demanding treatment journeys, yet many receive limited emotional support themselves. Although AI-driven mental health applications are available, most are designed as closed systems that provide predefined support with little opportunity for users to influence how the tools function. This limits their relevance for oncology caregivers whose needs evolve throughout the caregiving process. This study reports findings from a preliminary investigation in Nigeria, comprising a co design study (n = 18 formal and informal caregivers). It investigates how participatory co-design with oncology caregivers can inform the development of more adaptable AI-driven mental health support systems. A series of co-design workshops was conducted to explore caregiver experiences, identify emotional support needs, and generate design concepts for an AI-based support tool. The study examines how insights from co-design can inform a transition toward meta-design, where systems are intentionally designed to support end-user development. The findings highlight the desire of caregivers for emotional monitoring, personalized support, and enhanced control over the system. The study offers design insights for AI-driven mental health support systems that enable caregivers to shape and adapt user-facing digital support tools to their evolving needs.

Keywords

Participatory co-design, meta-design, end-user development, oncology caregivers, AI-driven mental health, Human-centered AI

1. Introduction

Caregiving for oncology patients involves sustained emotional and day-to-day caregiving tasks. Family carers and other informal supporters are often required to manage uncertainty, treatment side effects, and psychological distress over extended periods while also coping with their own mental and emotional burden [1] [2]. Although digital mental health tools have expanded rapidly, many remain predominantly designer-led, offering limited opportunities for caregivers to shape the support they receive as their situations evolve. In this paper, digital support tools refers to the user-facing features and resources that caregivers interact with directly, such as emotional monitoring. AI mental health applications denote app-based tools that use artificial intelligence to provide personalised emotional support and guided conversations [2]. Furthermore, AI-driven mental health support systems is used as the broader term for the full socio-technical system, including the AI application, caregiver-facing digital tools, and opportunities for user adaptation. As a result, these systems often struggle to remain meaningful across changing caregiving contexts. To address these issues, participatory design can be used to ensure that

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caregivers contribute directly to how these tools are shaped and adapted [3] [4]. Participatory approaches such as co-design emphasize involving end users and stakeholders throughout the design process. This approach recognizes that people hold expertise in their own lived experiences and can offer insights that support the creation of meaningful solutions. For example, co-design workshops allow developers, researchers, and stakeholders to collaboratively explore problems and build a shared understanding [4] [5] [6]. They further provide a space for generating design ideas rooted in real-world experiences. These collaborative processes help ensure that technological interventions align with users' needs, contexts, and expectations. However, participatory design alone may not be sufficient when systems must evolve over time to accommodate changing needs. Therefore, meta-design extends participatory approaches by developing socio-technical environments that encourage users to participate in the continual evolution of systems. Rather than acting as passive consumers of fixed solutions, users can take an active role in shaping system outcomes. In meta-design frameworks, users are empowered to adapt, extend, and reshape digital artefacts during use. This framework supports end user development (EUD) and enables continuous system improvement. This shift from designing for users to designing with and ultimately by users is particularly relevant for complex socio-technical challenges such as caregiver mental-health support [7] [8]. This paper contributes by showing how participatory co-design with oncology caregivers can do more than identify user needs in AI-driven mental health support systems. It demonstrates that insights generated through co design workshops can provide a foundation for meta design. This ensures that systems are intentionally designed to remain adaptable after deployment. In doing so, the study advances an end-user development perspective in which oncology caregivers are positioned not only as recipients of digital support but as active contributors who can shape, personalise, and influence system functionality over time to meet their changing mental health needs.

2. Background

Digital support tools and AI mental health applications are increasingly used to support mental health and well-being. However, many systems are designed as static tools that offer limited opportunities for users to influence how they function. In response to this limitation, participatory and user-empowering design approaches have gained attention in human-computer interaction (HCI) and digital health research [9] [10]. Three interrelated concepts are particularly relevant in this context: co-design, meta-design, and end-user development. These concepts offer a framework for designing digital systems that are responsive to user needs while also enabling ongoing adaptation and evolution. Co-design recognises that individuals possess valuable experiential knowledge about the contexts in which technologies will be used. Through participatory activities such as workshops and collaborative ideation sessions, stakeholders can jointly explore challenges and develop shared understanding [4]. These activities also enable them to generate solutions grounded in lived experiences. Studies by [12] [5] have shown that co-design processes help ensure that digital interventions are meaningful and aligned with the needs of the communities they intend to serve. In healthcare contexts, this approach is particularly important because patients, caregivers often face complex emotional and practical challenges. These challenges cannot be fully understood through traditional top down design approaches. Although co-design supports meaningful user participation during the early stages of system development, it does not necessarily address how systems can adapt after deployment. Meta-design extends participatory design by creating socio-technical environments that allow systems to evolve through continued user participation [11] [13]. This approach recognises that many real-world problems are dynamic and cannot be completely anticipated during initial design stages. By enabling ongoing collaboration between designers and users, meta-design supports continuous system evolution and sustained user engagement. Closely related to meta-design is the concept of end-user development (EUD), which refers to approaches that empower users to create, customise, or adapt digital systems without requiring advanced programming skills [11]. EUD techniques include configurable interfaces, rule-based systems, visual programming environments, or modular features that allow users to tailor systems to their specific needs. Rather than relying entirely on professional developers to implement changes, users

themselves can shape how technologies behave in their everyday contexts [3] [14]. These approaches are particularly relevant for caregiver mental health support systems. Oncology caregivers frequently experience emotional strain, uncertainty, and changing responsibilities throughout the caregiving journey. Their support needs may evolve as patients progress through different stages of treatment and recovery. As a result, static digital applications may struggle to accommodate the diversity of caregiver experiences [15] [16] [9]. Hence, participatory design approaches such as co-design can help uncover caregivers' needs and priorities. Meta-design and EUD then provide mechanisms through which caregivers can adapt digital tools to suit their evolving circumstances. By allowing caregivers to configure emotional tracking features, personalise interactions with AI systems, these approaches promote greater autonomy and sustained engagement. They also ensure that support remains relevant as caregivers' needs evolve. This study examines how insights from co-design workshops with oncology caregivers can inform the transition from co-design practices to meta-design principles within AI-driven mental-health support systems.

3. Methodology

The study was conducted through two participatory co-design workshops involving formal and informal oncology caregivers. Participants included individuals with direct experience supporting oncology patients. Their participation enabled the study to capture perspectives on caregiving challenges, emotional support needs, and the potential role of AI-based digital interventions. Participatory co-design was selected because it enables end users to actively contribute to the design process, ensuring that digital health technologies are grounded in lived experiences and real-world caregiving challenges [4] [5].

3.1. Participants and Sampling

Co-designers were identified and recruited through the oncology doctor at Nnamdi Azikiwe Teaching Hospital (NAUTH). Recruitment materials, including an advertisement poster and the Participant Information Sheet (PIS), were sent via e-mail to prospective co-designers. Inclusion criteria were as follows: aged 18 years and above, caring for a cancer patient, and able to communicate in English. Demographic information was collected using a short pre-workshop form completed alongside the PIS, and the aggregated results are presented in Table 1.

Table 1
Aggregated Demographics of Co-designers

Category	Value
Age	20–54 years (Mean = 37, SD = 10.39)
Sex	Male 10 (55.6%); Female 8 (44.4%)
Caregiver Role	Informal carers 12 (66.7%); Formal carers 6 (33.3%)
Duration of caregiving (years)	Mean 4.5 years (range 2.5–7.0)
Experience of mental health app	No experience 7 (38.9%); With experience 11 (61.1%)

3.2. Methods and Materials

Two co-design workshops were conducted in two phases, with all 18 participants attending both workshops. The workshops were conducted in two phases to allow iterative exploration and refinement of ideas. The first phase focused on understanding caregivers' experiences and identifying challenges related to emotional well-being and existing support systems. The second phase focused on generating design concepts and exploring how AI technologies could support caregivers' mental health while enabling users to adapt and personalise system functions. Design thinking methods were used throughout the workshops to support collaborative exploration and idea development [17]. These methods helped

participants develop a shared understanding of caregiving challenges, define key opportunities for intervention, and ideate potential solutions. Participants were asked to critique personas, reflect on caregiving journeys, verbalise their experiences while using the Wysa app, discuss the usefulness and limitations of existing AI support, identify unmet emotional support needs, and propose specific digital support tools for an oncology caregiver AI mental health app. Activities such as caregiver journey mapping and persona critique were used to explore caregiving experiences and identify emotional stress points and support gaps. Participants also engaged in brainstorming, clustering, and prioritisation exercises to identify opportunities for AI-driven mental health support systems. Following these exploratory activities, participants engaged in feature ideation sessions. In these sessions, oncology caregivers collaboratively proposed potential functionalities for an AI driven mental health application. In the second phase, participants developed design concepts that integrated these features into potential system structures using the how-now-wow matrix. Each workshop lasted approximately 45 minutes and was conducted in person.

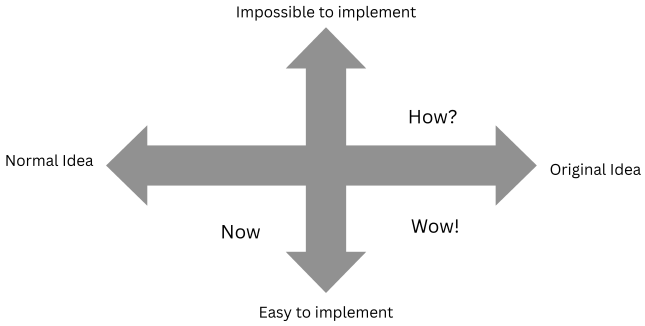

Figure 1: How-Now-Wow matrix

Participants further reflected on how caregivers could interact with and personalise the system. Qualitative data were collected during the workshops from the discussion transcript. The qualitative data from workshop discussions and design artefacts were analysed using Reflexive Thematic Analysis (RTA). Pseudonymised workshop transcripts, together with facilitator field notes and design artefacts, were used in the analysis. Two researchers independently coded the transcripts in NVivo, after which the primary researcher led the review and refinement of themes. This analysis identified recurring patterns related to caregiver needs, perceptions of AI mental health support, and opportunities for user-driven system adaptation. These insights informed design principles for AI-driven mental health systems that support user agency and ongoing system evolution.

4. Findings

The analysis of the co-design workshop discussions generated four key themes that reflect oncology caregivers' needs and expectations for future AI-driven mental health support systems. These themes highlight the importance of emotional monitoring, educational content personalisation, trust in AI-generated information, and opportunities for caregiver participation in shaping system behaviour. Together, the findings illustrate how participatory co-design insights can inform the development of adaptable AI-driven mental health systems that support caregiver well-being.

4.1. Theme 1: Monitoring Oncology Caregiver's Well-Being to Prevent Burnout

Participants emphasized that the emotional burden of oncology caregiving often develops gradually and may go unnoticed until it becomes severe. Caregivers also described how the continuous demands of supporting a loved one with cancer make it difficult to recognize early signs of emotional strain. As

a result, participants suggested that AI-driven mental health applications should include features that monitor emotional and physical indicators of well-being to help prevent burnout. Several caregivers highlighted the importance of monitoring sleep patterns and emotional states as early warning signals of distress. One participant noted that a "*sleeping monitor chart can be of great importance to caregivers. Not getting enough rest can trigger emotional stress"* [P13]. Others suggested that structured psychological assessments could help caregivers recognise changes in their emotional condition. As one participant explained, *"Have you heard of the Beck's Depression Inventory? It can monitor your level of depression"* [P2]. Participants also proposed integrating physiological indicators to support emotional monitoring, with one caregiver stating that *"when somebody is depressed or anxious, they need to know their blood pressure and blood sugar"* [P17]. These responses suggest that caregivers value AI systems that support continuous monitoring of well-being, enabling early detection of emotional strain and encouraging timely self-care.

4.2. Theme 2: Personalized Educational Content

Participants highlighted the importance of educational content that is tailored to the realities of oncology caregiving. They viewed knowledge not only as informational support but also as a resource for reducing anxiety, strengthening confidence, and improving their ability to care for patients. Caregivers emphasised that educational content should address both practical caregiving responsibilities and emotional well-being. As one participant stated, "*I want educational content for oncology caregivers to provide information more about how to manage their emotional well-being"* [P10]. Another added, *"It's very necessary to have psycho-educational content on the app because, you know, knowledge is power. With proper knowledge they will be able to take care of cancer patients better"* [P15]. Participants also stressed the need for up-to-date information, with one caregiver noting that *"educational content will be very important because in this generation, every day there is new information"* [P9]. Following the responses, it shows that caregivers are keen about educational content that can adapt to their knowledge needs and caregiving context. Rather than generic advice, participants wanted flexible and relevant information that could empower them and support their caregiving practices.

4.3. Theme 3: Trust in AI-Generated Information

Participants showed interest in AI-driven mental health support, but their responses suggest that trust depends on the quality, relevance, and safety of the information provided. Caregivers valued AI tools that could offer timely guidance and emotional support, yet they also wanted the system to recognise its limits and direct users to professional help when necessary. One participant suggested that *"the first thing I would say is that it should have a screening diagnostic tool"* [P14], while another noted that *"if there were a feature where a chatbot could inform you that based on the information you provided right now I think you need to seek professional help"* [P8]. Participants also proposed *"AI-guided conversations or brief self-help exercises tailored to individual emotional states"* [P1], showing interest in AI support that is responsive but still responsible. This shows that oncology caregivers are willing to trust AI-generated information when it is transparent, supportive, and clearly connected to pathways for professional care. Trust, therefore, is not based on automation alone but on whether the system can provide safe guidance without replacing human expertise.

4.4. Theme 4: Emerging Opportunities for End-User Development

Participants expressed interest in features that allow caregivers to actively shape how AI mental health applications could provide digital support tools that support their caregiving responsibilities. During the ideation activities, caregivers proposed several systems features that could help them manage both emotional well-being and practical caregiving tasks. For example, participants highlighted the value of reminders and organisational tools, with one caregiver noting that *"with proper calendar notification, oncology caregivers will be able to meet up with hospital appointment"* [P16]. Others suggested incorporating social support through shared experiences, explaining that *"when you are bored you*

can just switch to that group and chat with some of your colleagues and even share experiences" [P5]. Participants also emphasised the importance of self-care prompts, suggesting *"gentle reminders for hydration, meals, and sleep help caregivers take care of themselves when supporting oncology patients"* [P18]. This indicates that caregivers want systems that not only deliver support but also allow them to shape features that respond to their daily caregiving realities. Such contributions highlight the potential for AI mental health systems to incorporate elements of end-user development, where caregivers influence how support tools evolve and function in practice. This demonstrates that caregivers are already engaging in design activities, suggesting that AI mental health systems should be intentionally structured to support end-user development, where users can configure, extend, and personalise system behaviour without requiring technical expertise.

5. Discussion

The findings from the co-design workshops highlight how oncology caregivers perceive AI-driven mental health support systems and what they expect from the digital support tools embedded within them. Through activities such as caregiver journey mapping, persona critique, and concept ideation, participants articulated the emotional challenges associated with caregiving and the types of digital support they consider meaningful. These insights demonstrate the value of participatory co-design in surfacing caregivers' lived experiences and identifying opportunities for designing more responsive mental health technologies. However, the findings also suggest that caregivers' needs are dynamic and evolve throughout the caregiving journey. Participants expressed interest in systems that could adapt to these changing needs and allow them to personalise certain aspects of the technology. This highlights the limitations of traditional user-centered design approaches, where systems are typically developed as fixed solutions. Instead, the results point toward the relevance of meta-design frameworks that enable systems to remain flexible and evolve with their users. Meta-design approaches support this evolution by creating socio-technical environments in which users can actively shape and extend system functionality during use. In the context of caregiver mental health support, this could involve enabling caregivers to configure emotional monitoring features, adjust support resources, or contribute coping strategies based on their experiences. However, the concept of end-user development empowers users to customise digital systems without requiring advanced technical expertise [19] [20]. Allowing caregivers to influence system behaviour in this way can support greater autonomy and engagement with digital support tools. Each theme identified in this study reflects a specific requirement for meta-design and end-user development. Emotional monitoring highlights the need for adaptive systems that continuously respond to caregiver well-being. Personalised educational content reflects the importance of configurable knowledge systems that evolve with user needs. Trust in AI-generated information emphasises the role of human-in-the-loop design and safe system boundaries. Finally, the emergence of user-generated features such as reminders and community support demonstrate early forms of end-user development where caregivers actively contribute to system functionality. These findings demonstrate that caregivers can transition from participants in the design process to end-user developers who actively shape and adapt AI-driven mental health systems. This shift extends user involvement from design-time activities to use-time adaptation, enabling systems to evolve alongside caregivers' changing emotional and practical needs. The findings also align with human-centred AI principles, which emphasise transparency, user agency, and collaboration between humans and intelligent systems [21]. Participants' concerns about trust and human oversight highlight the importance of designing AI systems that support caregivers while maintaining connections to professional care networks [22]. Overall, these insights suggest that AI-driven caregiver support systems should move beyond predefined applications toward adaptive platforms that integrate co-design insights with meta-design and end-user development principles.

6. Conclusion

This study explored how participatory co-design with oncology caregivers can inform the development of AI-driven mental health support systems, including the digital support tools caregivers may interact with during use. During the workshops, oncology caregivers shared their lived experiences and highlighted emotional and practical caregiving challenges. They also collaborated to generate ideas for an AI-driven mental health support system. The findings demonstrate that participatory approaches are valuable for uncovering the complex and evolving needs of caregivers, particularly in relation to emotional monitoring, personalised support, trust in AI systems, and the desire for greater control over how digital tools function. The study also highlights important implications for the design of AI mental health applications. Rather than developing static systems with predefined functions, future AI systems should be designed as adaptable platforms that allow caregivers to personalise and shape the support they receive [23] [24]. Such flexibility is particularly important in caregiving contexts, where emotional needs and responsibilities change throughout the illness trajectory. By linking co-design insights with meta-design and end-user development, this study provides a conceptual pathway for designing AI-driven mental health systems that evolve with their users. Rather than treating caregivers as passive recipients of support, the findings position them as active contributors who shape and adapt digital tools to meet their changing needs. This approach advances the design of human-centred AI systems that prioritise user agency, adaptability, and sustained engagement.

Declaration on Generative AI

During the preparation of this work, the author used Copilot for grammar and spelling check. After using this tool, the author reviewed and edited the content as needed and take(s) full responsibility for the publication's content.

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