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Co-Design Approaches Involving Older Adults in the Development of Electronic Healthcare Tools: A Systematic Review

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Abstract

We present evidence on the current state of utilizing co-design approaches involving older adults in developing electronic healthcare tools (EHTs). Research gaps were identified in defining the stages, involvement processes, and levels of participation using existing theoretical frameworks. Future studies should explore both involvement processes and levels of participation to optimally empower and collaborate with older adults in developing EHTs.

Keywords:

Universal Design, Aged, Digital Technology

Introduction

Co-design approaches elicit ideas and foster a non-hierarchical environment in which concepts, tacit knowledge, and lived experiences of stakeholders, including the target population are applied to develop tools that meet the needs of the population [1-2]. For co-design to work effectively, stakeholders must be provided opportunities to equally engage, and their values and culture incorporated into the development process.

There is heterogeneity in the terminology of co-design approaches leading to confusion as to the stages and levels in which stakeholders should participate in the development process. Failing to optimize co-design approaches across the development process limits the representation and empowerment of stakeholders [1]. Determining the value of the stages and levels of participation is difficult because less has been done to evaluate the outcomes associated with involving older adults at the various stages and levels during the development of EHTs. Our aim is to evaluate the extent to which co-design approaches engage older adults throughout the development lifecycle.

Methods

We conducted a systematic review of articles published from January 2010 to March 2021 using keywords such as (Co-design, participatory design, user-centered design) AND (aged, older adults) AND (eHealth, mHealth) in PubMed, Scopus, and Embase. Studies were included if they employed co-design approaches in the development of EHTs, and the study population included adults aged 60 years and older. We used the National Institute of Health (NIH) assessment tool to evaluate for bias in the selected studies [3]. Summary characteristics were extracted to provide an overview of studies, including participant population, study settings, location, and year of publication. Data from each study were extracted and divided into 3 additional categories (co-design approaches, stakeholder involvement, and EHTs). The variables extracted for co-design approaches consisted of terminology and definitions, theoretical frameworks or design principles, and iterative development. We also extracted variables for stakeholder involvement including participant types, types of involvement processes, and levels of participation. The variables for EHTs included types of healthcare tools, older adults' needs addressed by EHTs, and user testing. We used widely reported classification methods to categorize the included studies on the EHT classification [4], and older adults' needs addressed by EHTs [5] involvement processes used [6], and levels of participation [7]. We mapped the included studies on involvement processes used and levels of participation and cross-classified the type of EHTs with the needs of older patient's addressed by EHTs.

Results

A total of 835 studies were identified for the title and abstract screening. After removing 210 duplicate studies, an additional 469 were excluded for not meeting the study criteria. 156 studies underwent full-text screening, with 25 having met the criteria for study inclusion. Overall, studies included participants in the age range of 60-91 (with a mean of 71.4) and a mean sample size of 40.8 including all participants. The study settings included laboratories, clinics, homes, community and senior centers, as well as remote sessions via Zoom. Studies were completed in Canada (1), Denmark (1), Hong Kong (1), Ireland (1), Italy (1), Netherlands (5), Sweden (3), and the United States of America (12).

Overall, 9 different co-design approaches were represented in the 25 studies: co-creation, co-design, human-centered computing, human-centered design, human factors, interaction design process, participatory design, usability evaluation approach, and user-centered design. Eighteen different theoretical frameworks were reported in the included studies. Nineteen of the studies were conducted in multiple phases, with an overall mean of 3.4 phases per study.

151 involvement processes representing 4 distinct stages (contextual inquiry, participatory design, product design, and functional prototypes) were extracted from the included studies. Each study utilized between 2 to 11 involvement processes, with a mean of 6 processes per study. The levels of participation were also extracted and classified based on Vaughn's framework, representing 5 levels of participation [7]. All 25 studies were classified as Level 1 (Inform-sharing information among community members) and Level 2 (Consult-solicit feedback at a decision point). 24 of the 25 studies were classified as Level 3 (Involve-participants provide feedback throughout the full process). 16 of the 25 studies were classified as Level 4 (Collaborate-participants are involved as co-leaders, and have an

Type of Technology	Surveillance	Prevention	Adherence	Treatment	Lifestyle	Patient Engagement
Transmit targeted health information to client(s)					1	1
Transmit targeted alerts and reminders			1		1	1
Transmit diagnostics result, or availability	1					
Peer group for clients					2	2
Access by client to own medical records			1	1	1	2
Self-monitoring of health/diagnostic data by client	3		1	1	3	4
Active data capture/documentation by client	2	1	2		3	6
Reporting of health system feedback by clients		1			1	
Client look-up of health information		2	3	6	5	14

Table 1-Cross-classification of older adults' healthcare technology needs & WHO digital health interventions

equal role in decision-making). 15 of the 25 studies were classified as Level 5 (Empower-participants take a lead in engaging others on the usefulness of the tool). Comparing all 25 studies to those classified as Level 5-Empower (Yes), (Figure 1) we noted an increase in contextual inquiry (from 4% to 5%) and functional prototypes (from 10% to 14%), and a decrease in the utilization of participatory design (from 60% to 55%) and product design (from 24% to 23%). This is more distinct when comparing the utilization of processes in studies classified as Level 5-Empower (No) versus Empower (Yes), specifically regarding the decrease in participatory design (from 69% to 55%), and increase in functional prototypes (from 2% to 14%), respectively.

Of the 25 studies, 12 developed EHTs that spanned multiple categories in the World Health Organization (WHO) classification of digital health interventions [4]. 16 of the 25 studies focused on EHTs that supported searching for health information on a particular topic. 18 of the studies focused on health tracking, 3 were specific to accessing a personal health record, 7 focused on wearables or sensor technology for tracking purposes, and 8 focused on journaling or documenting current health status and activities. Additionally, 4 studies focused on reporting on interactions with healthcare workers.

We categorized the older adults' needs by using Hermann et al.'s [5] definition and adapted these definitions to identify older adults' health needs addressed by EHTs. Through further cross-classification, we indicate that most EHTs in the included studies were focused on patient engagement (Table 1).

Conclusions

Evidence suggests that co-design approaches aim to involve end-users in the development of EHTs. However, there are gaps in the evidence to support the levels at which older adults should be involved and the extent to which this involvement can increase the user's knowledge of the technology, either limiting or encouraging their collaboration and empowerment. Additionally, gaps exist around which measures should be employed when conducting user testing with older adults. To optimize the involvement of older adults in the development of EHTs, there is a need to develop co-design frameworks that meet the needs of older adults.

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References

- P. Vandekerckhove, M. de Mul, W.M. Bramer, and A.A. de Bont, Generative participatory design methodology to develop electronic health interventions: systematic literature review, *Journal of Medical Internet Research* 22 (2020), e13780.
- [2] J. Sumner, L.S. Chong, A. Bundele, and Y.W. Lim, Codesigning technology for ageing in place: A systematic review, *The Gerontologist* (2020).
- [3] Study Quality Assessment Tools, in: *Health Topics*, U.S. Department of Health & Human Services, 2021.
- [4] Classification of Digital Health Interventions, in, World Health Organization, Geneva, 2018.
- [5] M. Herrmann, P. Boehme, T. Mondritzki, J.P. Ehlers, S. Kavadias, and H. Truebel, Digital Transformation and Disruption of the Health Care Sector: Internet-Based Observational Study, *Journal of Medical Internet Research* 20 (2018), e104.
- T. Leinonen, Designing Learning Tools Methodological Insights, Bookwell Ltd., Finland, Jyväskylä, 2010.
- [7] L.M. Vaughn and F. Jacquez, Participatory research methods – choice points in the research process, *Journal of participatory research methods* (2020).

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