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Empowering Mental Health Care Technology in Low- and Middle-Income Countries: Establishing Ethical Development Guidelines

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Abstract

The rising use of technologies and internet in Low- and Middle-income Countries (LMICs) hints at the opportunities of utilising digital tools to bridge the significant gap in mental health care delivery. As more mental health care technologies are used in research projects and even emerged to the market of LMICs, it is critical to establish guidelines to address issues on the existing products and ensure the ethical development of future technologies. Previous guideline research was mainly established based on mental health care technologies in High-Income Countries (HICs), and scarce work has been conducted under limited-resource settings or LMICs. This paper proposes a research plan to (1) identify the factors challenging the ethical development and implementation of mental health care technologies in a representative middle-income country with high inequality, China, and (2) translate the findings into development guidelines to empower future mental health care technologies in China and other LMICs.

Keywords Digital Health, Mental Health Care, Ethics, Development Guideline, Under-Resource Environment
1 Introduction

Low- and Middle-Income Countries (LMICs) have developed rapidly in the last two decades and now share over 80% of the global population (The World Bank 2021). Nevertheless, absolute poverty, social disparity, stigma and social disenfranchisement still heavily impact the mental health and wellbeing of those living in LMICs. As predicted by Mathers and Loncar (2006), depression will be the second-highest cause of disease burden in MICs and the third-highest cause in LICs by 2030. Compared with the rich resource provided in High-Income Countries (HICs), the healthcare systems in LMICs are underdeveloped, with a minimal mental health focus and care delivery (Thornicroft and Semrau 2019). The scarcity of well-trained mental health providers even resulted in a more significant and continued burden of mental disorders in LMICs. A previous study identified that the ratio of mental health workers in LMICs is 200 times lower than the ratio in HICs (Saxena et al. 2007), and up to 90% of those suffering from mental disorders in LMICs are failed to be associated with any mental health care services (Patel et al. 2010).

Given the paucity of resources available in such settings, it is feasible to use technologies to bridge the mental health care delivery gap in LMICs. Naslundet et al. (2017) evaluated the feasibility of implementing digital mental health intervention in LMICs and affirmed the improvement of reaching well-trained mental health care providers for patients with fewer resources available. According to a systematic literature review regarding healthcare technologies implementation, LMICs mostly used technologies such as Short Message Service (SMS) for mental health promotion and raising awareness in the past decade (Abaza and Marschollek 2017). The usage of mobile applications or wearable technologies in LMICs, which proved to be more effective for monitoring and intervening in mental disorders, is significantly less than the usage in HICs. Thereby, identifying the enablers promoting digital mental health care awareness and investigating the issues preventing digital mental health usage in LMICs becomes research trends. Nevertheless, the adoption of digital technologies in the health sector in LMICs also faces many barriers, including the high operational and maintenance cost of technologies, the poor internet connectivity in remote areas, the unreliable electric power supply, the lack of expertise in the use of health technologies (Alunyu et al. 2020).

Development guideline research has been undertaken in HICs, raising attention to the ethical design, development and implementation of mental health care technologies. Most development guidelines can adapt to LMICs, covering topics of patient engagement, patient-physician dynamics, technology familiarity and risks and data security and privacy (Doherty et al. 2010; Jones and Moffitt 2016; Yew 2020). However, Kumar et al. (2018) argued that the development of mental health care technologies for LMICs can encounter even more ethical challenges at higher significance levels. Still, limited research has considered the emerging concerns that can critically challenge the ethical development and implementation of mental health care technologies in LMICs, such as constant urbanisation (Chen et al. 2015), historical stigmatisation (Li et al. 2018) and underdeveloped regulations regarding the mental health care market and mental health data (Sahay 2016; Tan et al. 2020). Thereby, there is still a need to identify further guidelines that attend to the additional issues brought by the different technological, economic and cultural backgrounds of LMICs during the technology development process.

This research-in-progress paper is organised as follows. Section 2 presents relevant literature comparing existing development guidelines established for high- and low-resource settings. Section 3 outlines the research gaps and the research questions of this study. Section 4 illustrates our proposed research plan, and section 5 demonstrates the expected contributions to academic research and technology development.

2 Literature Review

Since the early 2000s, research has been undertaken to guide the ethical development of technologies in the health and mental health sector. One of the foundational development guideline research was conducted by Doherty et al. (2010). They studied three mental health care technologies developed and adopted in HICs (e.g. the UK, Ireland) and established guidelines to ensure an ethical development lifecycle covering the design, development, and evaluation stage for mental health care technologies. Doherty et al. (2010) emphasised the importance of design for outcomes and proposed guidelines to adapt the user-centred design process to mental health care settings. Standard strategies such as design workshops or interviews with patients and therapists are also suggested in the other guideline literature (Jones and Moffitt 2016; Lederman et al. 2014). Furthermore, Doherty et al. (2010) proposed guidelines for ensuring ethical development from three perspectives: patients, mental health professionals and public health systems. Recommendations include (1) utilising patients’ interests, strengths and ideas to increase intervention engagement; (2) using technologies that are more familiar to the users to improve
accessibility and reduce clinical burden, (3) building the system based on researched theoretical models to ensure clinical validity as well as (4) avoiding the incorporation of identity-sensitive data to the system to reduce privacy threats.

In addition, another guideline research has considered resource availability as a factor impacting the development cycle of mental health care technologies. Jones and Moffitt (2016) suggested that special considerations are required for designing and developing health and mental health care mobile applications for rural and low socioeconomic communities in the US. Due to a significantly lower rate of accessibility of mobile technology among rural populations, the study outlined four ethical considerations: (1) privacy and confidentiality, (2) data transfer, (3) education, and (4) financial difficulties and insurance, to be included in the development guideline. Most concerns identified in rural regions of an HCI are aligned with the challenges of the current mental health care provision in LMICs. For instance, similar to people in rural communities, people from LMICs may ask unnecessary questions and increase information insecurity when a tablet or digital tool that is not commonly used is provided to patients for digital intervention. Hence, it is also vital to develop digital mental health care with a widely accepted technology in the targeted LMIC. Likewise, patients in rural communities of HICs and LMICs are less likely to use any application for treatment on their devices if it is not free or covered by health insurance. Despite the fact that these identified guidelines (Doherty et al. 2010; Jones and Moffitt 2016; Lederman et al. 2014) were developed by studying mental health care technologies in HICs, they are applicable to lead the ethical development of LMICs.

Nevertheless, the mentioned guidelines lack some elements that are uniquely crucial in LMICs, and more efforts are required to consider the practicality of LMICs. First, many patients are still challenged in accessing any clinical support due to the lack of mental health workers in LMICs. Guidelines regarding patient-caregiver-system relationships from Doherty et al. (2010) and Lederman et al. (2014) both neglected the discussion on improving accessibility or building more sustainable relationships with mental health professionals, which are the priorities in the LMIC settings (Patel et al. 2010). Second, as discussed, the significant mental health care gap alerts the burnout of mental health service providers and professionals in LMICs (Saxena et al. 2007). The current development guidelines only proposed strategies to reduce the burnout of mental health professionals caused by the addition of technology, without any assumption on pre-existing burnouts. Therefore, there is a need to evaluate the degree of burnout in mental health professionals and service providers of the targeted mental health disorder in LMICs and establish guidelines accordingly. Otherwise, the ethics of the developed technologies need to be further questioned in the later implementation stage. Third, unlike the rural communities in the HCI, mental health care in most LMICs still fail to be included in the local health care system or primary care (Thornicroft and Semrau 2019). The existing guidelines (Doherty et al. 2010; Jones and Moffitt 2016; Lederman et al. 2014) only suggested involving patients, mental health professionals or researchers in mental health care technology development. They omitted the discussion regarding involving policymakers or insurers, which are crucial in effectively scaling up and ensuring the mental health care provision in LMICs (Petersen et al. 2019). It is foreseeable that the lack of resources and opinions from authorities during the development process may challenge the legalisation, validation and acceptance of the developed technologies.

Last but not least, Doherty et al. (2010) indeed suggested strategies regarding the social and cultural background of patients to ensure ethical development. However, the discussion only focused on patients’ life events and social backgrounds without considering the impact of their cultures and religions. Rathod et al. (2017) suggested that culture and religion can influence patients in LMICs seeking mental health care support. Patients tend to find therapies incorporated into religion or ancient scriptural philosophies easier to accept and more effective (Rathod et al. 2017). Notably, particular cultures may not even recognise mental disorders as health conditions, conversely seeking super-nature explanations and recognising the disorders as divine retribution for misconduct (Chen et al. 2009). To date, literature proposing a framework or strategy integrating culture or religion to guide the ethical design and development of mental health care technologies is still scarce.

3 Research Gap

This study proposes a plan for researching how to ensure the ethical development of mental health care technologies in LMICs, aiming to establish a set of guidelines for future mental health care technology development. The research will analyse the experience of mental health care technologies developed and implemented in LMICs. It will focus on mental health care technologies dependent on human (both clinical and non-clinical) guidance.
To develop a comprehensive set of guidelines, there are two second-level questions to tackle in sequence: 1) what ethical issues are appearing in the current development and implementation of mental health care technologies in LMICs; 2) what guidelines are missing or needed to improve in the current work. The first question will be answered during the research investigative stage. After identifying the ethical issues, the second question will be addressed during the guideline establishment stage. The research will consider all sorts of ethical issues but concentrate more on the issues resulting from low resource availability and the unique characteristics of LMICs and develop guidelines accordingly.

4 Research Design

4.1 Research Context and Participants

This research will be conducted in a Middle-Income Country with the largest population and high living inequality, China (The World Bank 2022). A systematic literature review of digital mental health outlined that understanding the trends and concerns in China can inform the development of mental health care technologies in other LMICs, due to the complexity of the Chinese mental health care crisis (Zhang et al. 2021). To understand the current development environment from full perspectives, we will recruit participants from three provinces with distinct income levels: (a) Shandong, (b) Henan and (c) Heilongjiang. The GDP per capita of three provinces ranks 11th, 18th, and 30th among 31 provinces and compares to the GDP per capita in Malaysia, Mexico and Peru, respectively (Wikipedia 2022). This research will invite representatives from four key stakeholder groups: patients, mental health professionals (social workers, counsellors, therapists, psychologists), technology developers and management personnel (digital health regulators, mental health policy researchers) to participant in the interviews. Each stakeholder group is anticipating between 2 to 5 participants from each province, and higher numbers will be expected in the two end-user groups, patients and mental health professionals.

Participants representing the two end-user groups will be recruited through advertising on WeChat, a popular digital communication platform in China with 797 million monthly active users and over 3.5 million public accounts delivering topic-based content to users sharing the same interests (Wang et al. 2020). Advertisements will be placed on selected mental health-related public accounts to invite patients and mental health professionals. Criteria for selecting patient-participants includes: 1) has been diagnosed with mental health conditions at any severity; 2) has used at least one mental health care technology in the past year. Mental health professionals need to be certified and have at least six months of working experience with mental health care technology. Based on the assumption that mental health care technology developers and management personnel are interconnected, the peer-nominated snowball technique (Farquharson 2005) will be used to invite participants from these two groups. Initial emails will be sent to developers or researchers identified from the literature. The email will introduce research aims, invite participation and explain the assistance required, such as nominating peers that share expertise and insights on a related topic to launch the snowball. All participants will receive informed consent about the research aim, investigative approach, interview topics, data usage and ethical considerations once confirming participation. Participants need to return the signed consent prior to the interview. All participants will be anonymised, and recordings will be transcribed verbatim in Chinese to NVivo, a qualitative research software for later analysis.

4.2 Interview Design

Semi-structured interviews are considered the most appropriate approach to query participants’ perspectives on a particular topic (Crouch and McKenzie 2006). The approach allows the flexibility of following deeper discussions arising from the predetermined dialogue (Whiting 2008). In the digital mental health domain, rich research has used similar approaches to understand topics such as the experience of patients and specialists as well as implementation factors of the technologies (Carolan and Visser 2018; Hamilton et al. 2014; Lindgren et al. 2014). Interviews will be conducted via video conferencing tools, such as Zoom. Each interview will take between 30 and 45 minutes and will be recorded after receiving permission from the participant. The interview will include four questions surrounding the perceptions of digital mental health care, the experience of their involved care technologies, challenges encountered in their roles and expectation of future digital mental health care.

4.3 Data Analysis Approach

Qualitative research methods are commonly used to answer how and why specific outcomes occur (Anderson and Aydin 2005). The research will adopt the thematic analysis method suggested by Boyatzis (1998) to identify, analyse and report the patterns (themes) from the collected data. The analysis will undertake an inductive approach, driven by data, without trying to fit into any pre-existing
frame (Braun and Clarke 2006). It also aims to analyse beyond the content of the collected data and search for latent themes (Braun and Clarke 2006) that are underlying ethical issues and factors challenging the development of mental health care technology in LMICs.

This research will follow the six phase of thematic analysis proposed by Braun & Clarke (2006). Phase one will include familiarising the transcribed data and noting perceptions, issues, barriers, and expectations described by participants. Phase two will begin with generating initial codes, which are the elements related to the research aim (Boyatzis 1998). Data associated with ethical concerns as well as development and implementation barriers, will be coded inclusively with the context. Phase three will start searching for patterns and developing initial themes from the list of identified codes. Codes will be sorted by broader topics, such as ethical concerns raised from mental health data ownership, to create code clusters. The clusters will be visualised on a thematic map to organise relations between codes and assess the prevalence of initial themes. Phase four will continue to review the collated themes. Themes will be not only evaluated by the prevalence shown on the thematic map but also by the significance of the ethical development topic (Clarke and Kitzinger 2004). Thus, actions in this phase will include deleting themes that have insufficient evidence or minimal connections to the research aims and merging themes that share similar evidence and well connect. Phase five will name themes by defining the critical factor underlying each finalised theme. Each theme name aims to describe one ethical concern to address in the future mental health care technology development. Finally, phase six will produce the report to tell the complete journey of identifying the themes and present evidence and context to support the validity of each identified ethical concern. The report will anonymise any sensitive or identifiable information from the transcribed interview data.

5 Intended Outcome and Contributions

After the data collection and analysis process, specific recommendations and guidelines will be developed to target each ethical concern in mental health care technology development in China and wider LMICs. The process will follow the framework of developing guidelines suggested by Shekelle et al. (1999), translating the findings into a set of guidelines for future mental health care technology development. The established guidelines will be compared with existing guidelines in the digital mental health domain to ensure completeness and pertinency. The guidelines will also receive external reviews by researchers in the digital mental health domain, interview participants and experts in mental health care technology development to validate the applicability and clarity.

This research will contribute directly to the development guideline research and mental health care technology development in China. For instance, it will propose development recommendations to reduce the stigmatisation brought by Chinese cultural perception. This research can also be referenced to digital mental health care development of technology of any kind and its guideline research field in other LMICs. For example, Patel et al. (2016) suggested many similarities in mental health care delivery between China and India, so future digital mental health care technology development in India can also refer to this research outcome. Given the scarcity of digital mental health development guidelines researched in the under-resourced environment, this research can also provide guidance for future mental health care technology research in rural or low socioeconomic areas in HICs. Moreover, individual guidelines established from this research will attend to a different ethical challenge. Hence, this research can also contribute to the environment that shares a particular ethical concern regardless of resource availability.

6 Conclusion

In conclusion, the research aims to guide future mental health care technology development and assist the ethical conduct not only specifically in China and similar LMICs but also provide a broader reference to where shares similar backgrounds or ethical challenges. The outcomes will improve the research gap in mental health technology development guidelines for resource-limited settings.

7 References


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