RESEARCH ARTICLE

Ethical issues in m-Health applications in community health work in India — a scoping review

VIJAYAPRASAD GOPICHANDRAN, SUDHARSHINI SUBRAMANIAM, RAJESWARAN THIAGESAN

Abstract

Background: *Mobile phone-based interventions are being increasingly used in community health work in India. The extensive use of mobile phones in community health work is associated with several ethical issues. This review was conducted to identify the ethical issues related to mHealth applications in community health work in India.*

Methods: *We performed a scoping review of literature in PubMed and Google Scholar using a search strategy that we developed. We included studies that mentioned ethical issues in mHealth applications that involved community health work and community health workers in India, published in peer reviewed English language journals between 2011 and 2021. All three authors screened the articles, shortlisted them, read them, and extracted the data. We then synthesised the data into a conceptual framework.*

Results: *Our search yielded 1125 papers, from which we screened and shortlisted 121, after reading which we included 58 in the final scoping review. The main ethical issues identified from review of these papers included benefits of mHealth applications such as improved quality of care, increased awareness about health and illness, increased accountability of the health system, accurate data capture and timely data driven decision making. The risks of mHealth applications identified were impersonal communication of community health worker, increased workload, potential breach in privacy, confidentiality, and stigmatisation. The inherent inequities in access to mobile phones in the community due to gender and class led to exclusion of women and the poor from the benefits of mHealth interventions. Though mHealth interventions increased access to healthcare by taking healthcare to remote areas through tele-health, unless we contextualise mHealth to local rural settings through community engagement, it is likely to remain inequitable.*

Conclusion: *This scoping review revealed that there is a lack of well conducted empirical studies which explore the ethical issues related to mHealth applications in community health work.*

Keywords: *mHealth, community health work, scoping review, ethics, justice, equity, quality of care, access to health care*

Introduction

Access to mobile phones has increased hugely in India. This has created the scope for use of mobile phones for health applications [1]. mHealth is the abbreviation for mobile health, which is the practice of medicine or public health supported by mobile phones, as also, tablets, personal digital assistants, wearable devices, and other such gadgets for delivery of health services, collection and sharing of health-related information [2]. mHealth includes creating awareness in communities, training of healthcare providers, setting up helplines for community members, support in diagnosis and treatment decisions, support in medication use and adherence through reminders, tracking of communicable disease outbreaks, monitoring vital parameters remotely through wearable devices, job scheduling and reminders for healthcare providers and collection of timely and accurate data [3]. A recent systematic review of mHealth applications for health system strengthening in India revealed a great surge in the use of mobile applications in health since 2012, with a primary focus on service delivery and awareness raising in community health [4].

The frontline community health workers (CHW) such as Auxiliary Nurse Midwives (ANM), Accredited Social Health Activists (ASHA) and Anganwadi Workers (AWW) are using mobile phones to deliver their everyday community health work including maternal and child health work and nutrition and growth monitoring of children [5]. With such

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extensive use of mHealth applications, there are likely to be several important ethical issues associated with it. Digital data is subject to hacking and compromise of privacy. This can lead to compromise of confidentiality of health information of communities. Moreover, mobile phones can be expensive to maintain, and in remote areas, adequate facilities may not be available for maintenance and repairs. Patchy electricity supply for charging of the mobiles and patchy network coverage can also render them useless in certain areas [6]. The Covid-19 pandemic has led to more ubiquitous and legitimised forms of close surveillance of human health and behaviour in the name of protecting people's health. Digitalisation of health has greatly contributed to this phenomenon in India during the Covid-19 pandemic in the form of the Arogya Setu digital application [7]. The digital devices of the CHWs have also been used for tracking their location and work through the Global Positioning System thus invading the privacy of the CHWs [8]. However, when used appropriately the mHealth applications have the potential to overcome gross health inequities by taking good quality healthcare to all people. Though there are reports of ethical concerns and issues related to mHealth applications, there is no comprehensive documentation of the range of ethical concerns in mHealth application in community health work in India. It is not clear what unique problems arise in the Indian context given its social, cultural and economic conditions. To better understand the various ethical concerns related to mHealth applications in community health work, we carried out a scoping review of literature. We also anticipated that this scoping review will point out areas for empirical and theoretical research on the ethics of mHealth in community health work. The research question that we addressed in this scoping review was: What is known from literature about the various ethical issues that arise in mobile health utilisation for community health work in India?

Methods

We developed a protocol for this scoping review using the guidelines for Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols (PRISMA). This protocol was not published earlier. We can make the protocol accessible on request made to the corresponding author of this paper.

We included papers which met the following criteria:

i. They were published from India

ii. describe an mHealth application

iii. mHealth applications used in community health work

iv. mHealth applications used by community health workers including ANM, ASHA, AWW

v. describe any ethical issue including benefits, risks, harms, autonomy, justice, equity, access to healthcare, privacy, confidentiality, sustainability, and accountability

We included papers published in peer reviewed journals between 2011 and 2021 in English language. We included empirical research papers as well as theoretical papers, narrative reviews, editorials, commentaries, and perspective articles. Papers which did not meet the inclusion criteria, did not involve a community health worker, involved hospital or clinic based mHealth applications, and were from outside India were excluded. We performed the search in two easily accessible open-source databases namely PubMed and Google Scholar. All three authors brainstormed and developed the search strategies for both the databases. After performing the search, the results were exported to MS Excel spreadsheet. All three of us worked on the exported results to screen and include papers in the scoping review. The search strategy that we use for PubMed is provided below.

((Community AND Health AND Worker) OR (Frontline AND Worker) OR (Field AND Health AND Worker) OR (Social AND Health AND Worker) OR (Village AND Health AND Worker) OR (Rural AND Health AND Worker) OR (Community AND Health AND Nurse) OR (Health AND Care AND Provider) OR (Health AND Worker) OR (Health AND Volunteer) OR (Community AND Health AND Aides) OR (Family AND Planning AND Personnel) OR (Barefoot AND Doctor) OR (Health AND Human AND Resource)) AND

((mHealth) OR (Mobile AND Health) OR (Telehealth) OR (Tele AND Medicine) OR (Mobile AND Phone AND Health) OR (eHealth)) AND

(Ethics OR Ethical OR Moral OR Values OR Justice OR Equity OR Equality OR Fairness OR Autonomy OR Privacy OR Confidentiality OR Respect OR Integrity OR Sustainability OR Accountability OR (Informed AND Consent) OR Transparency OR Professionalism OR Beneficence OR Nonmaleficence OR (Conflicts AND of AND Interest) OR Harm OR Benefit)

We divided the total number of search results among the three of us and initially screened the titles and abstracts of the papers for inclusion. After this, we exchanged our lists of included papers and validated each other's shortlisting process. Inconsistencies and discrepancies were resolved through discussion and consensus. After this, we identified the full texts of the included papers, downloaded and read them, and confirmed whether they were eligible to be included in the final review. We developed a data charting form in MS Excel spreadsheet including all the variables to be extracted from the included papers. We divided the included papers amongst ourselves and extracted the data in this form. The extracted data was then validated.

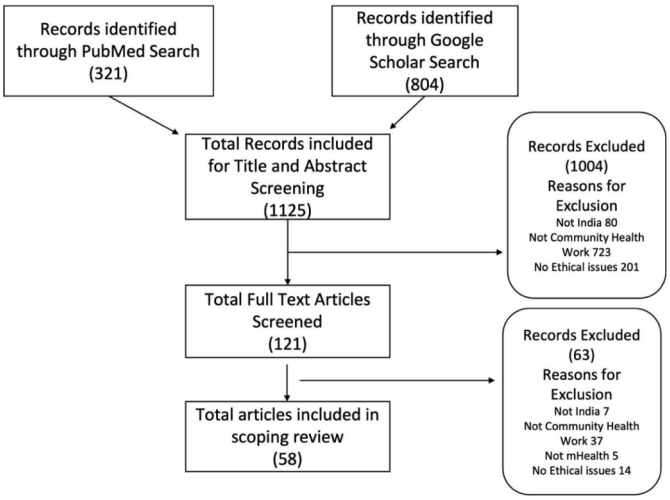
We extracted the following data from the included papers: whether it was an empirical research paper or theoretical paper; the study design if empirical, whether the main

research question included an ethical issue; the state of origin of the paper; the underlying condition or health state which the mHealth application addressed; the function of the mHealth application; access to mobile phones; access to network; difficulties in maintaining the mobile phone; and community acceptance, benefits, risks, privacy, confidentiality, and access to healthcare. We also extracted any other ethical issues that were included in the papers. We did not do a critical appraisal of the included research papers. This was because often the ethical issues identified were not part of the main research question and were included as a discussion point or an explanatory note in the paper. This was beyond the scope of critical appraisal. We grouped together all the ethical issues that were explicitly identified by the authors of the papers as well as issues which we considered to be ethical issues, although not explicitly identified as such by the authors in the papers and organised them into a conceptual model.

Results

The PubMed and Google Scholar searches gave us a total of 1125 papers to screen. After initial screening of titles and abstracts, we excluded 1004 papers and accessed the full text articles of 121 papers. We screened the full text of these 121 papers and excluded 63 of them and finally included 58 papers in the scoping review. This is shown in Figure 1.

Figure 1: PRISMA flowchart of studies identified for scoping review



Of the 58 included papers, 13 were theoretical papers and 45 were empirical research studies. Of the empirical studies, 7 were of mixed method design, 12 were purely qualitative, and 26 were quantitative studies. Only 8 of the included studies had an ethics issue as the focus of the main research question. The conditions for which the mHealth application was used were reproductive, maternal, newborn and child health, nutrition, delivery of primary healthcare, and screening and treatment for non-communicable diseases. The applications were commonly used to create awareness, as data capture tools, decision support tools, and for the training of community health workers [9–67]. These specific details are shown in Supplementary Table 1 (available online only).

Various ethical issues were extracted from these 58 articles. These are shown in Supplementary Table 2 (available online only). Several of the studies included the ethical issue of difficulty in accessing a mobile phone among community members. Therefore, these people would be excluded from the benefits of the mHealth intervention. Many of the studies reported poor access to mobile network in the rural areas. Four of the studies mentioned that the community health workers found it difficult to maintain the mobile phones. Most of the studies reported the benefits of the mHealth application in the respective health-related conditions. These included reproductive, maternal, newborn and child health, nutrition, non-communicable disease screening and control. Some of the studies reported harms caused due to the mHealth interventions, including hurried interaction of the community health workers with community members, excessive workload, stigma, compromise in privacy and confidentiality. Most of the studies reported that the mHealth intervention improved access to healthcare in communities. One of the studies reported that the mHealth intervention empowered the community health workers and increased their self-esteem, self-confidence and motivated them to perform better [35]. Another study indicated the importance of community engagement in design of the mobile interventions so that contextual factors are considered [32]. Another important ethical issue that was identified was that while the mobile phones created a demand for healthcare at the primary health centres, the primary health centre and the doctor working there did not command the trust and respect of the community. Demand generation without provision of good quality service could end up doing more harm than good [31].

The main ethical considerations identified in this scoping review can be divided into four broad themes, namely benefits due to the intervention, risks, issues of justice, and improved access to healthcare.

Benefits

The mHealth interventions included in this review mainly focused on service delivery. Therefore, the important benefit that emerged from this review was improvement in healthcare service delivery [1,10–13,16,20,27,28,30,32–36,39,40,42,43,46,47,49,52,55–57,64,66–75]. One of the mHealth interventions used mobile phones to register complaints and problems by community members regarding their health status and health services. This increased public accountability in health [52]. Several mHealth applications were used for creating awareness among community members on a diverse set of issues such as maternal and child health, nutrition, tuberculosis and other health conditions. These demonstrated effectiveness in generating awareness of health and illness. The use of

mHealth empowered community health workers, and increased their confidence and self-esteem, leading to improvement in their performance. A study of mHealth application in Andhra Pradesh in cardiovascular disease prevention in communities revealed that use of the mHealth decision support system increased the community's trust in the CHW [10]. The mHealth interventions were cost effective and reduced healthcare costs [57]. A study on nutritional interventions using mobile phones showed that the data collection was accurate and timely, and this led to improved data-driven decision making [15].

Risks

In a study of mHealth implementation in the mental health sector, the risks associated with it were fear and apprehensions among the community members about the gadgets [27]. In a study of mHealth for delivery of reproductive, maternal and child health services it was seen that the community health workers got too engrossed with the mobile, so that it made their interactions with the community members impersonal [12]. The community health workers consequently spent less time in the community [21]. The mHealth interventions also increased the health workers' workload [32–34]. The health workers were expected to update all data online in almost real-time mode and this consumed a lot of their time. The mobile health interventions carried a potential risk of breach of privacy and confidentiality of health information [11,13,16,19–21,23,27,47,60,63]. This was particularly important in the case of stigmatising illnesses. While the mHealth application increased the demand for healthcare in the local primary health centres, the quality of care in the primary health centres did not improve. The primary health centres did not command the community's respect and trust due to the poor quality of services. Thus, it was found that creation of demand without appropriate improvement in services could lead to more harm than good [3,11,12,16,20,27,31,32,45,47,60,63,64,66,71,72,76,77].

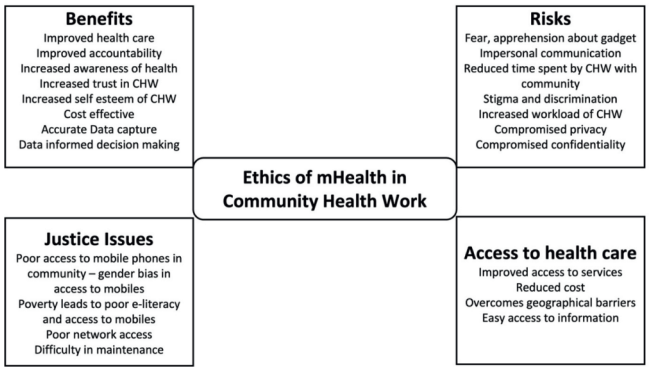
Justice issues

There are inequities in access to mobile phones in the community. Women have little access to mobile phones. People of the lower socio-economic class have poorer access to smart phones and poor digital literacy. Because of this, these vulnerable sections of society are excluded from the benefits of mHealth interventions. Rural and remote areas have poor network coverage, depriving those most vulnerable of access to the mHealth intervention [11,13,48,63,73,78].

Access to healthcare

mHealth leads to improved access to healthcare. This improved access to healthcare is due to increased awareness in the community, and increased access to telemedicine facilities in geographically remote areas [9,11,13,21–23,26,27,39,63,64,66,67,72,73]. These ethical issues are shown in Figure 2.

Figure 2: Ethical issues in mHealth application in community health work in India



Discussion

This scoping review identified some of the important ethical issues related to mHealth applications in community health work. The benefits included improved access to and quality of service delivery in terms of antenatal, postnatal and child care, as well as screening and treatment of non-communicable diseases. The risks included loss of a personal connectedness of the community health worker with her clients in the course of her work in the community. There were inherent inequities in access to mobile phones in the community and this widened the inequities in access to health, when increasingly mobile phone-based health interventions are used in communities. Overall, mHealth applications increased access to healthcare in geographically remote areas, reduced the cost of healthcare and improved the quality of services. Some important ethical considerations to be borne in mind while expanding mHealth applications in community health work are active community engagement to contextualise the applications and simultaneous improvement in health system functioning to meet the increased demand created by the mHealth applications.

Reducing the compromised interpersonal communication associated with mHealth interventions

This scoping review identified that mHealth applications reduced the time spent by the community health workers in communities due to greater demands on their time for doing online work on their mobiles, and made their interactions with communities impersonal. This is a common problem associated with mobile phone use. Even in households and among friends and relatives, talking and interpersonal communication has reduced and has been replaced by virtual communication. This needs to be carefully considered while expanding the scope of mHealth interventions in community health. While text messaging and reminders can be easy alternatives to physical visits by the community health worker, they may never be able to replace the home visit by the community health worker where she can talk to, examine and understand the family

context of her client. A judicious mix of interpersonal and mobile-based communication must be encouraged. When using tele-health consultations, one of the greatest limitations is the lack of opportunity to examine the patient. This must also be borne in mind while promoting telehealth and telemedicine.

Addressing the breach of privacy associated with mHealth interventions

Often rural households in India have only one mobile phone. Usually it is owned by the male member of the household. So when a community health worker uses the mobile to reach out to her lady clients, she may risk breaching the client's privacy. The community health worker may have to negotiate around this to ensure that her client has adequate privacy while utilising the mHealth application. Sensitive health information may have to be shared in person rather than over text messages or over the phone. Digital privacy must be taken seriously and community health workers must be provided adequate training and sensitisation to ensure digital privacy.

Addressing breach of confidentiality and data leaks

Many mHealth applications store the private health information of community members in data servers. These are identifiable information. They are also now increasingly linked to the unique ID of the Aadhar. The servers which store these data are not leak proof. There are many instances where the private health information of community members has been leaked. Such breach of confidentiality and data security can be a serious ethical concern in mHealth applications. The Electronic Health Records Standards 2016 provides specific guidelines for data protection, data security and data ownership of digital health records [79].

Contextualising mHealth applications to the local rural context

It is important to bear in mind that the mHealth applications are implemented in India in a diverse socio-cultural and economic milieu. In remote tribal areas with poor penetration of technology and gadgets, the mobile applications may incite fear and apprehension. Moreover, there may be no network access and therefore, offline work with the mobile, with the facility to synchronise data when the health worker has network access, should be enabled in the mobile applications. Access to mobile phones in the community may be variable. Women may have poorer access to mobiles. These contextual factors may be understood only through ongoing community engagement in the design stage of the mHealth interventions [80].

Limitations

This scoping review has a few limitations. Firstly, we could search only two open source databases, PubMed and Google Scholar. This is likely to have restricted the number of articles obtained. In many of the studies included, ethical considerations were not the primary objective of the study. Ethical concerns were discussed only when they were observed. In some instances, we have interpreted some of the reported issues as ethical considerations. For example there were observations of community health workers spending less time with clients and more time on the mobile. This was interpreted as a harm done to the clients. In most of the included studies, the design and methods of the study were not aimed at identifying ethical considerations. Therefore, a critical appraisal of the methods is unlikely to provide insights into the validity of the ethical considerations that were reported. So we omitted the process of critical appraisal of the evidence. Most of the included studies, if analysed from the point of view of the ethical consideration that is extracted, are likely to have a high risk of bias. Though mHealth applications increased rapidly in India only after 2010, the restriction of our search to the past ten years, from 2011 to 2021, could have led to our missing some early studies.

Conclusions

Through this scoping review, we have identified some of the key ethical issues in mHealth applications in community health work. However, the most important finding of this scoping review is that there is a dearth of empirical studies focusing on ethical considerations of mHealth in community health work. There is a need to explore the important ethical concerns through well designed and conducted empirical studies in communities. There is also a need for normative theoretical work on the principles that must guide and underpin the mHealth applications in community health work.

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RESEARCH ARTICLE

Medical negligence in cases decided by the National Consumer Disputes Redressal Commission: A five-year retrospective review.

SANJAY SUKUMAR

Abstract

Background: *There has been a gradual increase in disputes between doctors and patients in the healthcare system over the years. The aim of this review was to determine the speciality-wise prevalence of medical negligence in cases decided by the National Consumer Disputes Redressal Commission (NCDRC) and the factors responsible for it.*

Methods: *A total of 253 cases of medical negligence decided by the NCDRC from 2015 to 2019 were reviewed and categorised with respect to the number of cases compensated, the speciality involved, the compensation payout for the specialities involved, and the nature of the error leading to negligence.*

Results: *Among the cases analysed, negligence was identified in 135(53%) cases. Of these, the incidence of negligence was highest in surgery [37(27%)], followed by obstetrics and gynaecology (OBG) [29(21%)]. The highest compensation payouts were Rs 1.38 crore and Rs 1.1 crore in the paediatrics and OBG specialties, respectively. The common errors were lack of skill/care in the treatment of the patient [62(36%)] and failure to maintain accurate medical records [38 (22%)].*

Conclusion: *The study of adverse events in healthcare practice can improve the quality of patient care, and steps can be taken to reduce such events. Many adverse events are preventable by improving the skill/care in treatment and meticulous record keeping.*

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The Consumer Protection Act, 1986 (COPRA) was passed to protect consumers' interests, and state bodies were established to deal with consumer problems, conflicts and grievances, and to ensure that these disputes were resolved at the earliest. All doctors and hospitals that charge for their service (including hospitals that give partial free service), are covered under COPRA.

The onus of proving negligence lies on the complainant. The essential components of negligence are: duty owed to the patient, breach of the said duty and consequential damage [1,2,3]. Deficiency of service means "any fault, imperfection, shortcoming, or inadequacy in the quality, nature, and manner of performance which is required to be maintained by or under any law for the time being in force or has been undertaken to be performed by a person in pursuance of a contract or otherwise in relation to any service" [3].

Public awareness of medical negligence is growing in India. Hospital managements are increasingly facing complaints regarding their facilities, standards of professional competence, and the appropriateness of their therapeutic and diagnostic methods [4]. These complaints give rise to many medical malpractice claims accompanied by financial liability [5].

Retrospective studies of hospital case records in the United States and Australia have shown a substantial number of adverse events, defined as unintended injuries caused by medical management rather than the disease process [6]. However, error prevention and error management for better healthcare are largely feasible goals [7].

Previous review studies of retrospective records in several countries have shown that 2.9% to 16.6% of patients in acute care hospitals experience one or more adverse events (AEs), of which 4.5–20.8% of the AEs have resulted in the patient's death [8]. Approximately 30 to 50% of such AEs are judged to be preventable [8-12].