Community perceptions of ethics and professionalism of community health workers – a qualitative exploration

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Research Article

Keywords: Community Health Workers, Ethics, Professionalism, do good, do no harm, autonomy, justice, fairness, discrimination, disrespect

Posted Date: August 5th, 2024

DOI: https://doi.org/10.21203/rs.3.rs-4690603/v1

Additional Declarations: No competing interests reported.

Abstract

Background

Community health workers (CHW) work closely with communities and therefore encounter several important ethical issues in their work. Community perceptions about their practice of ethics and professionalism is important.

Methods

We conducted 4 focus group discussions (FGD) among pregnant women and lactating mothers, 4 FGDs among women in the community, 3 in depth interviews (IDI) among women and 2 IDIs among men in two districts of Tamil Nadu, India. We explored the various practices of ethics and professionalism in these discussions and interviews. We transcribed the data, coded the transcripts, and built themes by combining the codes meaningfully.

Results

The CHWs ensure good quality of services by effective use of mobile phone and by going beyond the call of duty. They face several challenges in doing good to the community. On the other hand, there were many instances where they failed to deliver their duties which led to harms. Living far away from the community, spending less time there, delegating their work to lay persons all compromised the performance of their duties. CHW's lack of good communication skills, lack of updated knowledge, and inefficient work were pointed out by the community. Treating the people as mere statistics and not caring for them as people was a reason for dissatisfaction. The quality of a CHW's work was assessed relatively in comparison with other CHWs who were perceived as good and not in comparison with standards or expectations. Lack of honesty, demanding bribes, disrespectful treatment, discrimination of the marginalized communities, coercion, and lack of privacy and confidentiality were also reported in the CHW's work. Reports of such unethical practices were more from people belonging to scheduled castes and tribes compared to those from dominant castes. The attributes of professionalism of a CHW reported by the community were altruism, empathy, inspiring confidence and trust, honesty, humility, kindness, relatability, adaptability, care, and tolerance.

Conclusions

The community identified important good and bad practices among CHWs. There is a need to share this information with CHWs and train them to improve practices of ethics and professionalism in their work.

Introduction

Community Health Workers (CHW) are the frontline workers who deliver primary health care at the community level. In India there are various cadres of CHWs including Auxiliary Nurse Midwives (ANMs), Accredited Social Health Activists (ASHAs), Anganwadi Workers (AWW), Multipurpose Health Workers (MPHW).(1) Apart from these cadres who work in the public health system, there are numerous CHWs working in non-governmental organizations. Ethics of CHWs refers to the principles of right and wrong that govern the everyday decision making and behaviours of the CHWs during community health work. Considering Community Health Workers as health care professionals performing an essential skilled community based health care activity, the various attributes such as values, commitments, behaviours and goals that define their work is referred to as professionalism. Not much is known about the practice of ethics and professionalism in their everyday work in the communities. A case study of a senior CHW from Tamil Nadu, India by a member of this research team revealed that ethics and professionalism is inherent in their work. (2) Based on this case study we explored the experiences and the practices of ethics and professionalism of CHWs in a previous study. We conducted in-depth interviews and focus group discussions among CHWs and identified that though there were several ethical principles embedded in their work, the CHWs did not have the appropriate training and skills to handle ethical conflicts that they encountered in their work. (3)

In an elegant ethnographic study of the work of CHWs in Odisha, the researcher reported that trust and teamwork were the key principles underpinning the work of a CHW. The CHWs espoused the values of cooperation, continuous and open communication, empathy and trust as crucial elements of their work in communities. Sometimes they resorted to ‘gaming behaviour’ or behaviour that manipulated the loop holes in the guidelines such as fabricating data to ensure that the community member got the benefits that were due. But this created a false picture of the health related state and events in the community.(4) In yet another interesting exploration of ethics of community health work the researchers reported the ethical challenges faced by frontline workers doing ‘body work’. Apart from physical and social challenges, they also faced ethical challenges such as conflicts between their personal values and values prescribed by the institution, moral distress when there is a conflict between community needs and institutional demands, unrealistic community expectations and their work not being aligned with the needs of the community.(5)

Several factors such as connectedness, familiarity, perceptions of receiving support from the CHW, respect, competence, honesty, integrity, fairness and recognition influenced the relationships between the community and the CHW. These directly reflected on the effectiveness of the work of the CHW. (6)

In this background we wanted to know the community perceptions of the practices of ethics and professionalism of their CHWs in the local context in Tamil Nadu, and also wanted to triangulate the information with the perceptions of the CHWs about their own practices of ethics and professionalsim. This would help us understand the ground realities of ethical practices more comprehensively. We embarked on this qualitative study with the objective of exploring the community perceptions of practice of ethics and professionalism by the CHWs.

Methods

Qualitative Approach and Research Paradigm:

We conducted a qualitative inquiry by which we encouraged the participants in the study to narrate their experiences with the CHW and reflect on the CHW's practice of ethics and professionalism. Our ontological position was one of multiple truths and we adopted a subjective epistemological stand in this inquiry. Our exploration was informed by our previous qualitative work in the same community among CHWs. We explored the community perceptions on ethical practices of the CHWs on the following domains – doing good, doing no harm, challenges in doing good, honesty and integrity, autonomy of the community members, fairness and non-discrimination, privacy, and confidentiality of the health-related information, resolving ethical conflicts and handling power imbalances in community. (3)

Theoretical underpinning:

Ricouer in his important book "Oneself as another" writes that it is not sufficient to discuss what is an ethical act and why it is an ethical act, but also important to explore who is the one who is undertaking the action.(7) According to Ricouer, ethics is a tripartite relationship between 'the self', 'the other' and 'the institution'. In the case of the community health worker this refers to 'the community health worker', 'the community' and the 'health system'. Applying Ricouer's theory to community health work, it is not sufficient to study 'what' is an ethical act, and 'why' it an ethical act, but also to study the interactions between the CHW, the community and the health system. If the needs and demands of the community are in conflict with the demands of the health system, an ethical CHW will be less concerned about breaking the rules of the health system. Ricouer's theory has largely informed this qualitative exploration. We have explored the community perceptions of ethics and professionalism of the CHWs keeping in mind that the CHW will balance the demands of the community, with that of the health system. Wherever this has not happened, we have identified it as an ethical conflict.

Researcher characteristics and reflexivity:

Two of the authors, VG and SS conducted some of the interviews. Both are doctors by training and work in the local area providing primary care medical services. One of them VG, is a male and the other SS, a female. The female researcher facilitated four of the FGDs, where the male researcher sat in a corner without participating and made extensive notes of the discussions. The fact that the facilitator and note taker were doctors is likely to have introduced a power differential in the discussion, leading to a possibility of inhibitions. Rest of the FGDs and in-depth interviews were conducted by a team of five field investigators, four women and one man, who were provided a brief training on conducting qualitative interviews and discussions. These field investigators were from the local area and had prior rapport with the participants. As these field investigators are CHWs themselves, it is likely that their own experiences and perceptions have colored the interviews and discussions with the participants. It has its advantages

as it provides an ‘emic’ perspective of the interviews. There could be a minor disadvantage that the interviewers captured and probed only issues that mattered most to them.

Context:

The study was conducted in two districts of Tamil Nadu with some of the best health indicators in India. The state has a long history of community health worker led primary care service delivery model. This is one of the states where the Village Health Nurse (VHN) is a regular state government employee with all the perks of regular government employment. (8)

Sampling:

In our previous study, we found that the experiences and practices of ethics of the CHWs were similar across the various districts of Tamil Nadu. Therefore, we decided to sample two districts which were easily accessible to the researchers. In these two districts, we sampled rural as well as urban areas, so that we can capture any urban-rural differences in perceptions of ethics and professionalism of CHWs. A major part of primary care delivery at the community level comprises of care of women during pregnancy, childbirth, post-delivery period, and care of children. Therefore, we decided to sample pregnant women and women who were in the post-partum phase. To obtain perspectives of other community members we also sampled women who were not pregnant or breastfeeding as well as men from these communities. While pregnant and lactating mothers provided the much-required perspective from direct active interactions with the CHWs, the other women and men provided the perspective of a distant observer. The interviewers had prior work experience in the community and were familiar with the members. So they were instructed to sample persons with unique experiences and who were articulate in expressing their views. We iteratively analyzed the FGDs and IDIs as we completed each of them and actively looked for data saturation, which we obtained at the end of 8 FGDs and 3 IDIs. Two additional in-depth interviews were conducted to confirm the saturation.

Data collection methods:

We developed a separate FGD and IDI checklist for supporting the data collection in the field. The bilingual checklist in English and Tamil is provided as Supplemental Material 1. We provided training to all field investigators so that there is a standardization of the process of conducting the interviews and discussions. We scheduled the FGDs in a convenient location in the local areas at a time convenient to all the participants. We obtained informed consent, got permission to record the discussion, and then started the discussions. While one of us facilitated the discussion, the other person took extensive notes. All discussions and interviews were conducted during the months of September and October 2023 in the local language Tamil. We transcribed the discussions on the same day in Tamil by elaborating the notes and listening to the recordings. The in-depth interviews were conducted in private by the field investigators in a similar manner. We adopted two methods, FGDs and IDIs. the two methods complement each other’s strengths and weaknesses and provide wholesome data. While the FGDs provided general opinions and consensus, the IDIs provided information which is sensitive and can only be discussed in private. We collected data from a variety of participants to get diverse perspectives.

After completing three FGDs, we did a preliminary analysis of the data and found that there was a caste and class difference emerging in the perceptions of the community. To take this idea forward, we re-framed the checklist to specifically capture these dimensions and purposively sampled two FGDs comprising of scheduled tribes and scheduled castes. In each FGD we had about 6–8 participants. The FGDs were only among women who belonged to homogeneous caste groups and approximately the same age range.

Data Analysis:

VG read all the transcripts and extracted meaningful data units from the text and compiled them in an MS Excel spreadsheet. A meaningful data unit is a phrase, sentence or paragraph of the transcript which captured a single idea or concept. This spreadsheet was shared with SS, BP and PC. VG coded each data unit in the spreadsheet in an adjacent column. While the data unit was in Tamil, the code assigned to it was in English for convenience of theme building and conceptualization. SS, BP and PC simultaneously coded some of the transcripts. VG reconciled all the codes and differences were resolved by discussion and consensus. VG then grouped the codes into meaningful themes, elaborated the themes and identified appropriate verbatim quotes from the data units. These verbatim quotes were than translated to English for representation. At each stage of the analysis fidelity of the codes, themes and concepts to the underlying data was checked and confirmed.

Techniques to enhance trustworthiness:

All the researchers and field investigators have been involved in delivering primary care services in the local area for several years. The prolonged engagement with the research context helps us identify that the discussions and interviews are credible. All of us have training in qualitative data collection methods and we also had our methods and checklists standardized before starting the data collection process. We had a social media network exclusively among the researchers in which we periodically discussed our interviews and discussions. This helped all of us align our methods. After each data collection, we had a team de-briefing, and ensured that we all perceived and understood the discussion / interview in a similar manner. We have kept extensive field notes, which provide us a significant audit trail to ensure dependability. As described above we attempted method, participant, and analysis triangulation to ensure confirmability. Transferability was ensured by purposively sampling as mentioned above and by ensuring data saturation.

Ethical considerations:

This research was conducted in compliance with the National Ethical Guidelines for Biomedical and Health Research involving Human Participants as recommended by the Indian Council of Medical Research in 2017. The study proposal was reviewed by the Institutional Ethics Committee of ********** and approved. We obtained a written informed consent from all participants in the FGDs and IDIs before starting data collection. We also obtained their permission for audio recording of the discussions and interviews. All data were collected with adequate privacy and the data were

transcribed in an anonymous manner. The audio recordings and transcripts of the interviews and discussions were stored in password protected hard drive at the study facility with access only to the researchers. In the following section, we present the main findings of the study.

Results

We present the findings of the study under the broad subheadings of perceptions about services offered by the CHWs, perceptions of quality of services, ethical practices including honesty, respect to people, protecting autonomy, ensuring equity and justice, protecting privacy, confidentiality, and various attributes of professionalism of CHWs.

Perceptions about types of services:

The community identified maternal and child health services as the primary work performed by the CHWs. They described antenatal care, contraceptive counseling and supply, and immunization as their major activities. The other main work ascribed to them was support in availing government benefits and incentives. Other primary care services like treatment of minor ailments, prevention and treatment of diabetes, hypertension, health education and outbreak management were mentioned sparingly. This indicates the high emphasis placed by the public health system on maternal and child health care at the primary care level.

"…she gives very good care for pregnant women and children…" – a woman in an FGD in a rural area

"…mainly she cares only for pregnant women. That too disbursing the maternity cash incentive is her main job…" – a pregnant woman in an FGD in an urban area

Perceptions of good work by the CHW:

The CHWs were seen as adopting various strategies to provide good quality services to the community. Even in situations when it was not possible for her to be physically present in the community, she constantly stayed in touch through the mobile phone. The mobile phone connectivity has greatly improved her accessibility and availability to provide primary health care services.

"…she visits the village once a month to check on pregnant women. But even if she cannot come, she checks on everyone over phone…" – a man in an in-depth interview in a rural area

The women appreciated and respected the fact that the CHWs phone number was given without any hesitation to the people of the village, always making her accessible in case of an urgent need. This was perceived as being a great reassurance for the community.

"…giving one's phone number freely to everyone is a huge thing. And attending every phone call and patiently responding to every call is a great thing. I have kept sister's (CHW's) phone number safety and I find it extremely useful…" – a pregnant women in an FGD in a rural area

A recurrent theme in many discussions was that the CHW often goes out of her way to help the people in the community. Sometimes they went beyond the call of duty with a sense of responsibility to the health and wellbeing of the people.

"…after my delivery, I had lost a lot of blood. They advised that I must receive a blood transfusion. But blood was not available in the hospital. The sister (CHW) roamed across the entire district in search of my group blood and finally arranged for it…" – a woman in an FGD in a rural area.

The community held deep reverence for the CHWs who put themselves in harm's way to serve them. They referred to such CHWs as selfless and altruistic.

"…that settlement near the stone quarry is very remote. No buses ply in that area. Despite this, the sister (CHW) goes there every month. She goes by walk. She has to walk through dense forest to reach that area. She goes alone. Anything can happen on the way. Wild animals can also attack her. But she doesn't mind. She goes there regularly and delivers her services to those people. She is great…" – an older woman in an FGD in an urban area.

Perceptions of challenges in delivering her duties

Ensuring that she performs her duties well in the area was challenging for the CHWs as perceived by the community. Though the CHWs of yesteryears used to live in the same local community and serve them, nowadays many CHWs choose to stay in towns and cities near the villages and commute to the community daily for work. Therefore, they travel long distances to reach the community. This consumes a large part of the CHW's duty time. In areas with limited public transport facilities, it makes it challenging for her to reach her community on time and deliver her services to her best ability.

"…she comes from a 15 km distance. The bus to our village is rare. There is one which arrives at 10 AM and leaves and comes back only at 3 PM. She can spend only this much time in our village. We cannot blame her for that…" – a woman in an IDI in a rural area.

Another challenge that she faces is that she doesn't have a dedicated space within the village to carry out her activities. She shares space with the Balwadi, which is the local centre for Integrated Child Development Services (ICDS), which serves as a day care center and non-formal pre-school for children below 6 years of age. This limits her ability to deliver her services properly.

"…in the Balwadi, everyone is watching when the sister (CHW) does check up for pregnant women. The children are running around and making noise. We cannot talk to the sister properly…" – a woman in an FGD in an urban area.

Perceptions that the CHW doesn't do her duties well:

While they pointed out these strengths, they also highlighted several situations where the CHWs failed to deliver their duties.

While some women mentioned that the mobile phones have greatly improved the accessibility of the CHWs, others felt that she was compromising on face-to-face interactions with the community and predominantly communicating with them over phone, which they thought was not as effective.

"…she must be physically available when we need her the most. Just checking on us over the phone is not enough…" – an older woman in an FGD in a rural area.

Some CHWs who lived far away from the community where they work, delegate their duties to other lay persons in the community. This was perceived as inappropriate as it has the potential to lead to errors and complications.

"…as she must travel to many villages, she sometimes asks me to share all the information with other women in the village. I like doing this…" – a woman in an FGD in an urban area.

"…once she gave a bag full of different diabetes and high BP tablets to another woman in the village. She gave a list of people's names and asked her to distribute the tablets among them. This other woman is not a trained health worker. What if she gives the wrong drug to the wrong person? This other woman cannot even explain when and how to take each tablet. This is so wrong. It can lead to errors…" – an older woman in an FGD in a rural area.

Some CHWs instead of making home visits and visits to the local village to deliver primary health care services, go to a central location and ask all her clients to come and visit her there. The community found this to be inconvenient.

"…she does not ever come inside the village. She comes up to the Balwadi (ICDS Centre) in the nearby village and asks us all to come there. Rain or shine, we only have to go to her. She doesn't ever come to us…" – a pregnant woman in an FGD in a rural area.

As the CHW did not visit the community frequently, the community members feel a sense of disconnect with her. Some had never interacted with their CHW even once.

"…If we are regularly seeing her and interacting with her in the area, we will know her well. For those of us who are not pregnant or not having a baby, there is no interaction with her. So, we don't know her that well…" – an older woman in an FGD in an urban area.

Another important factors that led to community's perception of default of services was the CHWs focus on numbers and targets. A woman in one of the FGDs was very upset when she narrated an incident that happened to her daughter,

"…my daughter has O negative blood group. So, they said it is a high risk case. We went directly to the tertiary care facility for delivery without informing the sister. Later the sister called us and scolded us. Her point is, she wants to document my daughter as a number in her tally of deliveries. For her this is just a number game, and we are all just numbers…" – an older woman in an FGD in a rural area.

Some CHWs were perceived as sometimes being careless about their work.

"…my daughter delivered in the hospital and they discharged us after 2 days. The doctors told us that the sister will come and visit us at home and check on the newborn baby. The sister never came home. When we called and asked her, she replied rudely that she had other important work to do. So, I spoke back to her rudely and cut the call. It was a very careless attitude…" – an older woman in an FGD in a rural area.

The women in the community had to remind the CHW about her pending work in the village. They must remind her and ask her specifically for the services. Otherwise, they felt that she would never do those works. While it is the CHW's primary job, and it is she who must remind them to come for checkup etc. the whole thing was happening the other way round.

"…we must keep calling her over the phone and asking about where she is and when she will come to our village. If we want to properly vaccinate our children, we have to refer to the immunization card given to us in advance and track the date of vaccination. We must call her and remind her to bring the vaccines. If we don't remind her, she won't bring and only we will suffer…" – an older woman in an IDI in a rural area.

Some CHWs were perceived to be unfriendly and noncommunicative. The community felt that when a CHW is unfriendly, then they don't feel like approaching her for their health problems.

"… she doesn't move with us in a friendly manner. She doesn't talk well. Even if we ask her some questions, she answers in monosyllables. So, we are not comfortable approaching her…" – an older woman during an IDI in a rural area.

In some cases, the community members felt that the CHW was less knowledgeable and so they directly approached the hospital bypassing her.

"…our nurse does not know much about contraception. So, there is no point in discussion these options with her. Even if I ask her, she will only ask me to go to the hospital and ask the doctor. So, I prefer to go directly to the hospital…" – an older woman in an IDI in a rural area.

The community's assessment of the work of the CHW was based on comparison between two CHWs that they had interacted with and not based on whether they delivered their duties. Especially women who were pregnant for the second or third time, had different CHWs serving them during different pregnancies, or women who were in two different areas for different pregnancies and therefore interacted with different CHWs, shared such comparative insights. They compared the CHWs on their communication skills, approachability, and appropriate delivery of their duties.

"…the sister (CHW) who was working here earlier, used to constantly be in touch with me. She herself arranged an ambulance when I went into labour. She reached the hospital before me and stayed with me throughout the delivery. After the baby was born, she bought lunch for me and then only left. What can I

say about the sister who works here now? She doesn't care at all. She doesn't even visit me…" – a pregnant woman in an FGD in a rural area.

Following the discussions on perceptions of the CHW's delivery of her duties, the main theme of discussion were the practice of ethics in the work of the CHWs.

Ethical Practices: Honesty and Integrity

The community discussed in detail about the practice of bribery in the work of CHWs. Some CHWs demanded an informal bribe payment for performing her maternal and child health duties in the community. They demanded a bribe at the time of registering the pregnant woman to obtain the government cash incentive. If they did not bribe the CHW in advance, she would make it difficult for the people to avail the cash incentive.

"…at the time of registering my first pregnancy, the sister (CHW) asked me for money. I gave her the money, and everything went on smoothly. Later, I realized that the money was a bribe. Now for this pregnancy, I refused to pay. So, she is now not giving me proper care like the other women in my village who bribed her…" – a pregnant woman in an IDI in an urban area.

In another discussion on honesty, an older woman was very upset about the attitude of their CHW, and she described an incident where the CHW committed an error, but conveniently lied about the treatment procedures to protect herself.

"…my daughter delivered her baby and we were sent home without giving the injection that is to be given to women who have negative blood group. They told us that it must be given within 72 hours of delivery. When we asked the village sister, she lied to us that it can be given up to 1 week after delivery. She lied to protect herself for her error. If the delay in getting the injection had been on our side, they would have blamed us badly…" – an older woman in an FGD in a rural area.

Ethical Practices: Respect to people

The community discussed the level of respect that they received from the CHWs. In some instances, they reported that the CHWs were respectful. But in a few discussions, especially among women belonging to marginalized communities of scheduled castes and scheduled tribes, there were strong narratives of disrespect that they faced from the CHWs. Some CHWs formed strong stereotypes based on caste and socio-economic status and spoke to the women with disrespect. The women were also judged by the CHWs as 'bad mothers' if they sought an abortion of an unwanted pregnancy or if they fail to keep up appointments for checkup, blood tests or scans due to unavoidable social circumstances.

"…I am 16 years old. I got married very early. I got pregnant immediately. When I went for checkup, the sister (CHW) spoke in an insulting manner about my young age…" – a pregnant woman belonging to a tribal community in an FGD in a rural area.

"…one time the sister had asked me to come to the Balwadi (ICDS Centre) for a pregnancy checkup. But I could not go because of family reasons. The next day she called me on my phone and shouted at me calling me "saniyan" (derogatory abusive Tamil word). I was very upset when she abused me and started crying…" – a pregnant woman belonging to a tribal community in an FGD in a rural area.

"…sometimes if we go to get tablets from her for cough and cold, she makes fun of us and says that we people are always working in water and never stay dry, and we are always dirty. We are not like that for fun. It is the nature of our job…what can we do? Why does she make fun of that?..." – a woman belonging to a tribal community in an FGD in a rural area.

Ethical Practices: Autonomy

The other main ethical discussion was about autonomy and how CHWs attempted to respect the right of the community to determine their own health care choices. While there were some instances where women mentioned that the CHWs respected their choices regarding care during pregnancy, ultrasound scan, place of delivery, contraceptives, and immunization of their children, largely the community felt that the CHWs did not respect the women's autonomy. The women felt coerced to go to government health facilities for pregnancy care and delivery, with a threat that they would not get the cash incentive if they went to the private sector. They also felt forced to undergo ultrasound scan at an imaging center suggested by the CHW. Sometimes intrauterine contraceptive devices were also inserted without the awareness and permission of the women immediately after delivery. While many community members found this trend disturbing, some rationalized it saying it is for the benefit of the community.

"…the sister sometimes forces and compels us to do what she asks us to do. We feel forced…" – a pregnant woman in a FGD in a rural area.

"…sometimes without asking the women, they insert a copper T device. The women later on comes to know only when she develops pain, severe bleeding or other complications…" – an older woman in an FGD in an urban area.

"…she insists strongly on certain matters and forces us. One example is doing scans during pregnancy. She asks us to save money and get it done in a private center. It is difficult for us. But we understand because she is doing it for our benefit…" – a pregnant woman in an FGD in an urban area.

Ethical Practices: Equity and Fairness

One of the most important ethical considerations in the work of a CHW is equity and fairness. This is because a CHW works closely with the community and the vulnerable sections of the population. It was noted that discussions among marginalized communities of scheduled castes and scheduled tribes had a strong description of experiences of discrimination by the CHWs. They narrated anecdotes that explained how the CHWs discriminated against them based on caste and socio-economic status.

"…when they (rich people from the dominant castes) visit her, she treats them with respect. But when we go, she won't even see us. She treats us badly. When they take their babies for vaccination, she holds

them plays with them and checks them up (gestures how the CHW holds the baby and plays with it). But when we show our babies, she touches them with some disgust and holds the babies at a distance (gestures holding a baby at a distance) …" – a woman belonging to tribal community in an FGD in a rural area.

"…they (the rich people from dominant caste) are up there in the social ladder, but we are down here. (shows hand up and down indicating the position in the social ladder) So when we go to visit her and if one of them is there before us, she will not even allow us to enter the centre. She will finish talking to them and then only permit us inside…" – a woman belonging to tribal community in an FGD in a rural area.

Some community members belonging to dominant castes and relatively higher up in the socio-economic status rationalized this discrimination.

"…tribal people are highly ignorant. They won't cooperate with the sister (CHW). They will make her angry. They will run away and hide even if the sister comes to their colony. But despite this the sister patiently visits them and gives her services even to them…" – a woman belonging to dominant caste and relatively higher socioeconomic status in an FGD in a rural area.

People belonging to scheduled castes and belonging to lower socio-economic status in their discussions brought out the point that performing an ultrasound scan during pregnancy is the greatest source of discrimination by the CHW.

"…the sister asks us to do the scan. Those who have money, get it done soon and show it to the sister and earn a good name. Those of us who are poor must slowly work and earn and save the money. It takes time for us to save enough and then go for the scan. Because of this delay she insults and humiliates us…" – a woman in an FGD in a scheduled caste community.

Ethical Practices: Privacy and Confidentiality

CHWs who work closely with communities and have access to their sensitive health information have an ethical obligation to protect the privacy and confidentiality of the people. Like the differences in discussion noted between dominant castes and scheduled castes and tribes in the domains of respect, equity and fairness, there were differences in narratives of privacy and confidentiality. Women from marginalized communities described how the CHW compromised their privacy and confidentiality.

"…a girl in our village got pregnant before marriage. The sister (CHW) called for a meeting of all pregnant women in the village and declared in front of everyone about her unmarried pregnancy. She used that as an example to tell everyone how it is not right to get pregnant before marriage. She humiliated the girl in public…" – a woman belonging to tribal community in an FGD in a rural area.

"…I kept written document of the dates of periods from the time of my marriage. When I got pregnant, I took the written record in private and showed it to the sister (CHW). She laughed at it and mocked me for

keeping a written document of my periods. Not only that, she showed it to others and they all laughed at me…" – a pregnant woman belonging to tribal community in an FGD in a rural area.

The failure of CHWs to protect the privacy and confidentiality of the community members, eroded trust and prevented the women from approaching her for their health needs.

"…when I want to ask some doubt about a sensitive health problem, I ask the sister (CHW) as though the problem is for a friend. This way I am be sure that the information will not spread around. We cannot trust the sister…" – a woman in a FGD in a rural area.

Women from the marginalized scheduled tribe community had a sense of resignation and acceptance that privacy and confidentiality are luxuries they cannot ask for.

"…my sister is pregnant at a very young age. So, she was too scared to go to the nurse. I only took her with me to meet the nurse. The nurse scolded both of us in front of everyone for getting pregnant at such a young age. This is something I am used to. We cannot expect to talk to the sister in private. She has no respect for us and will not give us that space. I must go to her in front of everyone and get the scolding. We don't have a choice…" – a woman belonging to tribal community in an FGD in a rural area.

In stark contrast to this, a person belonging to dominant caste and higher socio-economic status felt that confidentiality and secrecy are detrimental to good health.

"…secrets are usually negative. If we discuss our problems openly with the nurse, she will use our story as an example and help others in the community…" – a woman of dominant caste and higher socioeconomic status in an FGD in a rural area.

Following the detailed discussions on ethical practices by the CHWs, the community reflected on various attributes of professionalism of a CHW.

Professionalism:

The community outlined various attributes of a good CHW that they would want to work in their community. A professional CHW acts as a bridge between the community and the health system and advocates for the community in matters of health and wellbeing. She cares for the community like her own family. She is altruistic, performing her duties without expecting anything in return. She is a pillar of strength and support for the community and inspires confidence in the people. Other attributes of professionalism of a CHW listed by the community are, honesty, humility, kindness, relatability, adaptability, caring, tolerance, and trustworthiness.

"During my second pregnancy, I went into labour before the given time. There was heavy bleeding. I went to the PHC. There suddenly the pain stopped. I got scared. They referred me to the higher centre. I started crying. I was afraid that they would do a cesarean operation for me. At that time, it was the sister who gave me confidence. Based on her confidence only I went to the higher centre. There I had a normal delivery." – a women in an FGD in a rural area.

Discussion

Several important ideas related to practice of ethics and professionalism by CHWs in their work emerged in this study. The community perceived that the CHWs are doing good work by effective use of mobile phones and often go out of their way to help the people. But they also had negative perceptions about their work in terms of less time spent with the community, delegation of their work to other lay persons, poor communication skills, outdated knowledge and skills and treating people as mere statistics. The community also pointed out some unethical practices such as dishonesty, demanding bribes, disrespect to people and their culture, discrimination against people belonging to certain castes, coercion in certain situations, not respecting people's privacy and confidentiality. These narratives of unethical practices came more from the scheduled castes and tribes, the most marginalized in the community. The community members also identified various attributes of professionalism of CHWs. In the following paragraphs we discuss these findings and interpret them. From this we discuss ways in which this understanding can inform making community health work more ethical and professional.

Mobile phone and ethics of CHW's work

Two important perspectives emerged from the community regarding the use of mobile phones by the CHWs in their work. On one hand they felt this made the CHW readily accessible, but on the other, some felt that it compromised her personal visit time to the community. A detailed scoping review revealed that use of mobile in community health work improved quality of care, increased accountability, and accessibility. However, the risks identified were impersonal communication by the CHW, increased workload for the CHW and potential breach of privacy and confidentiality.(9) While the mobile increased the accessibility, it seemed to make the work of the CHW impersonal and distanced from the community. Many members of the community felt that they are not familiar with the CHW and feel disconnected with her as she has drastically reduced the amount of time she spends in the community. This has been facilitated by using mobile phones.

CHW's workload and its implications for ethical work

One of the greatest challenges faced by CHWs in India is the ever-increasing workload. Increasing population size, and diversification of the work portfolio has resulted in work dumping on the CHW.(10) The recent COVID 19 pandemic saw an inordinate work dumping on the ASHAs and AWWs in various parts of the country.(11) Not only is the workload high, it is also not remunerative. ASHAs are voluntary workers, and they work on a performance-based incentive. The high workload is a major reason for compromise in quality of her care work. This is probably a reason for reduced time spent in the community. With increasing proliferation of mobile phones into community health work, the health system expects the CHW to update data real-time. So, she is compelled to spend a large part of her time capturing data in her mobile device. These pressures also make her less communicative with the community. The pressure from the system also makes her look at her clients as mere numbers and statistics. These observations were made by the community members. Every CHW enters her job with a

lot of aspirations to serve the community. We speculate that the increasing workload is one of the factors thatmakes her non-communicative, less community oriented and more focused on the statistics than the people. Ethics and professionalism are the least priority for this over-worked underpaid and frustrated CHW.

Challenges in privacy

The community health worker faces many key challenges and one of them is negotiating privacy in the community for carrying out her work. When the CHW enters the community, she is surrounded by community members, and she often must perform her duties in public. In most situations she doesn't have her own private health center where she can examine and talk to her clients with adequate privacy. In this study the community members highlighted how the Anganwadi center (ICDS center), which is usually the site selected by the CHW to provide care for pregnant women and for immunization of children, is an open space without privacy and prevents them from having a reasonable clinical encounter with the CHW. In some contexts, the CHWs adopted innovative techniques for ensuring privacy such as talking over the mobile when nobody else is around, meeting and talking in crowded public spaces where nobody can guess what is being discussed.(12)

Concept of confidentiality in community work

The Code of Medical Ethics Regulations 2002 provides a clear clause to medical doctors to protect the confidentiality of sensitive health information obtained during the process of providing medical care.(13) However, such a confidentiality clause is not emphasized in community health work. Ensuring confidentiality of health information obtained by the CHW while serving in the community can be quite challenging. Firstly, she may be part of the same community and so the patient may want to keep the information confidential from her too. Secondly, the mere fact that a CHW is visiting a household frequently is reason enough to raise suspicions and provide fodder for rumors. Thirdly, a CHW may have competing interests within her own community that force her to breach the confidentiality. This study very clearly points out that the community has specific expectations of confidentiality of their health information from the CHW. Some of the interviews pointed out the breach of trust in the CHW consequent to her violating their confidentiality.

Deficit of respect

Respect to persons is a core principle underpinning community health work. It is not just respect to the individual, it is an understanding and sensitivity to their culture and shared values. It is in this context that a CHW must demonstrate respect not just to individual patients, but also sensitivity to their culture. In this study there were narratives where the community members perceived that the CHW stereotyped them and disrespected them based on their culture, values, and lifestyle. Sensitizing CHWs to the importance of understanding people's culture and values will probably remedy this deficit of respect. Providing training to CHWs on cultural competence will greatly contribute towards trust building in the community and in reducing health care inequities. (14)

Social dynamics of community perceptions about ethics of CHW

This study provided some important insights into the social dynamics of the perceptions about the CHW and her work. We observed that the people belonging to scheduled castes and tribes who are the most oppressed and marginalized in the caste system in India, had strong perceptions of disrespect, being treated as mere statistics and not as persons, breach of confidentiality, and denial of good quality care based on their caste. On the other hand, people belonging to dominant castes described that confidentiality and secrecy are negative and should not be encouraged. This is probably because the people of dominant castes have not been subject to the stigma and insults associated with breach of confidentiality as much as those from oppressed castes. We also observed that women who were currently in contact with the CHWs, namely the women who were pregnant and lactating, were more forgiving and lenient in their perceptions of ethics and professionalism of the CHWs, but other women who had worked with the CHW in the past and not currently actively involved with her, were more critical. Moreover, these women who had past experiences with the CHW also were providing comparative input between a good and a bad CHW from their own experiences of both. In the previous qualitative exploration among CHWs about their practice of ethics and professionalism, we observed that though CHWs mentioned that they did not discriminate based on caste, their inherent caste and class biases reflected in their work.(3) In this study, the community mentioned that they perceived the caste and class based biases and discriminations of the CHW and thus confirmed our inference in the previous study.

Strengths and Limitations of this study:

The strengths of this study include the purposive sampling of women who were currently in contact with the CHWs and those who were past users of their services, people belonging to different castes and social classes. This provided the wide variety of perspectives which lent itself to understanding the social dynamics of the perceptions of ethics and professionalism of CHWs. The iterative process of collecting data, analyzing it, and revising the checklist and retraining of all researchers based on the revisions helped in moving the study forward in a robust manner. We also believe that the long engagement of the researchers in the local community and the familiarity with the social dynamics helped us identify some key aspects that were emerging and explore them deeper. The limitation of the study is that we did not set out to obtain a theoretical understanding of the concepts of ethics and professionalism, therefore we did not achieve theoretical saturation.

Conclusions

Some of the major points identified in this study are systemic such as overburdened CHW, and CHW not residing in the community where she works. Some of the points such as lack of cultural competence, lack of communication skills and outdated knowledge and skills are remediable by ensuring capacity building in these domains. Other points pertaining to ethics and professionalism need training. The

findings of this study will help develop key agenda points for advocacy with policy makers to implement systemic changes to enable CHWs to carry out their duties effectively. Capacity building programs in cultural competence, communication skills and continuing professional education programs can improve the quality of the work of CHWs. There is also a need to train CHWs on ethics and professionalism. Sensitizing them to various aspects of ethics and professionalism will help make the health care services delivered by them equitable and of good quality.

Abbreviations

ANM
Auxilliary Nurse Midwife
ASHA
Accredited Social Health Activist
AWW
Anganwadi Worker
CHW
Community Health Worker
FGD
Focus Group Discussion
ICDS
Integrated Child Development Services
IDI
In Depth Interview
MPHW
Multipurpose Health Worker
VHN
Village Health Nurse

Declarations

Funding:

This research was conducted as a part of a project on developing a training curriculum for ethics and professionalism of community health workers funded by the Thakur Foundation, St. Petersburg, Florida, USA.

Competing Interests:

The authors declare that they have no competing interests.

Ethics Approval and Consent to participate:

This research was conducted in compliance with the National Ethical Guidelines for Biomedical and Health Research involving Human Participants as recommended by the Indian Council of Medical Research in 2017. The study proposal was reviewed by the Institutional Ethics Committee of Rural Women's Social Education Center, Chengalpet District and approved. We obtained a written informed consent from all participants in the FGDs and IDIs before starting data collection.

Consent for Publication:

Not Applicable

Authors' Contributions:

VG, SS, BP, and PC conceptualized and designed the study, developed and standardized the tools for data collection. VG and SS conducted some of the FGDs, took detailed notes, recorded and transcribed them. VG did the initial coding and analysis of the data. SS, BP and PC verified and triangulated the coding and analysis. VG drafted the manuscript. SS, BP and PC gave critical inputs and edited the manuscript. VG, SS, BP and PC, all agree with the final version of the submitted manuscript.

Acknowledgments:

The authors would like to acknowledge Mrs. Mary, Mrs. Sathya A, Mr. Ponnusamy, Mrs. Valli and Mrs. Jayaselvi for support in conducting the focus group discussions and in depth interviews in the community.

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