Maternal mortality and severe morbidity in rural Indonesia Part 2: Implementation of a community audit

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Abstract

Introduction: In the absence of unifying conceptual and operational frameworks, there have been calls to share practical experiences of community participation in health (CPH) to document the contexts and dynamics of participatory practice.

Objectives: This article describes the implementation of a participatory community-based audit of care in obstetric emergencies that was conducted in rural Indonesia.

Methods: Four village-based groups were convened to review a series of cases of maternal death and disability and to develop recommendations for

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health planning. Thematic narrative analysis of the discussion transcripts was employed to describe how participation occurred.

Results: Participation was complex and dynamic and evolved over the course of the study. Although blame and defensiveness characterized the early discussions, over time, participants became less condemning of individuals and more so of systems and services, situating individual behaviors within the wider health system context. Participants also increasingly shared personal experiences, generating rich and explicit assessments of care. Eliciting this information was contingent on skillful facilitation, assuring anonymity, and instilling "permission to criticize" among the participants. Sufficient time was also required to convey the necessary principles and reassurances. Despite evidence the process had resulted in women and community members being more prepared, informed, and responsive toward obstetric emergencies in villages, the short-term nature of the study meant that implementation and evaluation of the recommendations were not possible. Without a sustained and ongoing approach, the potential for impact, sustainability and empowerment were limited.

Conclusions: The study demonstrates that when carefully implemented, CPH can yield rich explanatory accounts of adverse health events, providing unique information for health planning. We recommend the method for routine district health planning, configured as a continuous process characterized by autonomy, authority, and self-reliance, and involving those excluded by health and social systems. Despite its potential and relevance, authentic CPH may be threatened by wider socio-economic and political conditions, as well as by prevailing evidence hierarchies that exist in public health research. We recommend policy and research to establish a firmer foundation for this progressive, yet obscured, public health concept.

Introduction

Community participation in health

Community participation in health (CPH) refers to the active involvement of people in the design, implementation, and evaluation of healthcare. In 1978, CPH was enshrined as a central principle of, and enabling mechanism for, universal access to essential healthcare, in the Alma Ata Declaration. Here, CPH was defined as

the process by which individuals and families assume responsibility for their own health and welfare and those of the community, and develop capacity to contribute to their and the community's development... This enables them to become agents of their own development instead of passive beneficiaries of development aid (WHO, 1978).

The Declaration was adopted by over 150 member states, and the following decades saw widespread implementation of CPH projects and programs (O'Rourke, 1998; Ahluwalia et al, 2003; Osrin et al, 2003; Manandhar et al, 2004; Rosato et al, 2006; Chigudu, 2007; Cornwall & Shankland, 2008; Skinner & Rathavy, 2009).

There is no universal definition of CPH. The extent to which decision-making processes can be legitimately devolved to communities depends upon prevailing political ideologies regarding the roles of states and citizens in the provision of public services. The Alma Ata statement itself makes simultaneous reference to two distinct (and arguably opposed) interpretations of CPH. These relate to individuals assuming "responsibility" for personal and public health, and "agency," the creation of social networks for political engagement. Perhaps unsurprisingly, following Alma Ata, participatory programs were implemented according to a variety of related terms and concepts. A non-exhaustive list includes: community participation (Cohen & Uphoff, 1980; Rifkin, 1990; Mayoux & Chambers, 2005); community development (Foster, 1982; Jackson et al, 1989); community involvement (Oakley, 1989; Kahssay & Oakley, 1999), community engagement (NICE, 2008); community empowerment (Craig & Ma, 1995; Rifkin, 2003); community mobilization, 2005); and community action (Donahue & Mewea, 2006). These concepts reflect divergent positions on what participation is, and how it should be achieved.

To organize disparate approaches, Rifkin developed a continuum of passive-to-active CPH (Rifkin, 1985). This typology delineated marginal participation, characterized by externally driven agendas and compliant participants, through substantial participation, involving more meaningful involvement in which participants contribute time and resources, to structural participation, which refers to the active involvement of participants, control over proceedings, and the empowerment of participants (Figure 1). Rifkin's typology corresponds to Arnstein's classic "ladder" of citizen participation in which the rungs of the ladder progress from participant nonparticipation (lowest rung) through tokenism to citizen control (highest rung) (Arnstein, 1969).

Although these typologies are useful, they do not completely account for how participation occurs. A recent review of participatory theory also identified the tendency for a normative, and somewhat artificial, dichotomization of CPH into approaches that are "good" or "bad." The review concluded in support of documenting the context, dynamics, and purposes of participation, considering "who is participating, in what, and for whose benefit" (Cornwall, 2008, p. 269). Cohen and Uphoff provide a detailed planning framework in this regard, considering situated participatory practices for rural development. Their framework considers: who participates, how participation takes place, what kind of participation occurs, and for whose purposes. They also consider how project characteristics are situated within task environments (Cohen & Uphoff, 1980). Evaluation is similarly complex. CPH is not simply an intervention, but an approach: instrumental and substantive, an interchangeable means and end (Cohen & Uphoff, 1980; Rifkin, 1985; Cornwall, 2008). As a result, it does not conform to the conventional input-process-outcome format of program evaluation. Reflecting the theoretical debates, calls have been made for practical experiences to be shared, examining how participation is achieved in particular environments (Rosato et al, 2008).

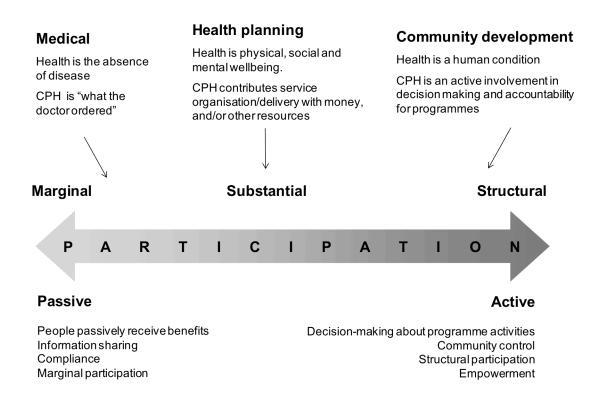
Objectives

This article responds to these calls. The objective is to describe the implementation of a participatory community-based audit of care in obstetric emergencies in rural Indonesia. The audit sought to demonstrate the utility of the "communityperspective" as a valid source of information for health planning. The results and implications for health planning are presented elsewhere in this issue (D'Ambruoso et al, 2013).

Context of the study

The audit was conducted as part of a larger project examining care in obstetric emergencies in Indonesia (D'Ambruoso, 2011) and was preceded by two discrete studies. First, an assessment of quality of care in cases of maternal mortality and severe morbidity was conducted from the perspectives of Indonesian service providers. This study demonstrated the insights possessed by local practitioners quality care and feasible intervention into (D'Ambruoso et al, 2009). The analysis suggested that conventional clinical audit might be limited by virtue of the lack of attention to the circumstances and events that occur outside facilities. In the second preceding study, access to care was considered in its own right. This study was conducted with relatives of women who had died during pregnancy or childbirth regarding pathways to care, preventability, and cause of death. Relatives' narratives provided detailed accounts of medical care and conditions and of the wider social and cultural landscapes, demonstrating that the explanatory frameworks of service users differ substantially from those of providers (D'Ambruoso et al, 2010). The preceding studies suggested that examining the pro-

Figure 1: A continuum of community participation in health (adapted from Rifkin, 1985)



cesses and negotiations that characterize care in obstetric emergencies, from a range of perspectives, has the potential to provide useful information on how and why adverse outcomes occur. As a result, the present study aimed to conduct a participatory audit of access to care and quality of care in obstetric emergencies from the perspectives of those who use, as well as provide, this care.

Methods

The methodology is described in detail in the accompanying paper in this issue (D'Ambruoso et al, 2013). In brief, four village-based audit groups were convened: two comprised of women of reproductive age and two of village midwives, traditional birth attendants (TBAs), volunteer community health workers (CHWs), village leaders, and family members. The groups engaged in a series of weekly meetings examining cases of delivery complications that had resulted in death or severe disability. Discussions on quality of and access to care in the emergencies were invited in semi-structured focus group discussions. Each meeting was also audiorecorded, and the recordings transcribed and translated from Bahasa Indonesian, and indigenous languages Javanese and Sundanese, into English for analysis.

Narrative analysis was employed to describe how participation occurred (Pope & Mays, 2006). The data were read and re-read and arranged according to the Cohen and Uphoff (1980) planning framework to consider who participated, how participation took place, the influence of context, whose interests were served in the process, and what kind of participation resulted. The latter element was considered in terms of Rifkin's continuum of participation (1985). The analysis was conducted during and after completion of the meetings in order to allow preliminary findings to inform subsequent data collection. NVivo software (QSR International, 2007) was used to support data management, analysis, and the construction of coding frameworks.

Results

Who participated?

Thirty-five participants were recruited into four audit groups (see Table 2 in D'Ambruoso *et al*,

2013). The majority were educated, employed, and married with children. Most had been resident in the community for many years and four were pregnant. Six participants dropped out (due to family or work commitments) and replacements were recruited by the second meeting. Participation did not differ substantially between the groups. Within groups, however, older, richer, and more educated individuals were more relaxed with the process, while others found it difficult and stressful.

Midwife: I felt tense at the outset. Husband: I was afraid of making mistakes. [Group C1, Feedback meeting]

How did participation occur?

Across all groups, blame and defensiveness characterized the early discussions and fault was frequently found with individuals in the cases. Participants also often distanced themselves from their counterparts in the cases, with whom fault had been found.

TBA: I am not like the TBA who said that there was no need to take the woman to hospital. I would always suggest that, it is the woman who refuses.

[Group C1, meeting on Case 1]

Woman: The TBA was belegug [stupid].^{*} She knew that she could not manage [the hemorrhage], but she called for a second and third TBA, even a male TBA. She should have called the midwife.

[Group W2, meeting on Case 3]

Creating an environment in which participants did not feel threatened required careful facilitation. We devoted timed at the outset of each meeting to establish principles of inclusion, non-blaming, and confidentiality, and made efforts to foster friendly, informal, and non-threatening discussions. This approach proved to be beneficial. As the meetings progressed, it was apparent that "permission to criticize" had become instilled, as fear, blame, and defensiveness gave way to more open and frank discussions. The assessments became less condemning of individuals and more so of systems and services,

^{*} A severe form of stupidity, a harsh word (Sundanese).

situating individual behaviors within wider health system contexts. These informed multi-level accounts of care (D'Ambruoso *et al*, 2012). Participants also increasingly shared personal experiences during the discussions, providing explicit accounts of healthcare in the district.

Village secretary: Sometimes the community, who are not eligible for health insurance for the poor, force me to give them insurance certificates... If we give it then we break the rules, but if we do not, those uneligible community members push and force us.

[Group C2, meeting on Case 1]

Despite these changes, some (usually poorer and younger) participants continued to express concerns about the consequences of criticizing the authorities.

Woman: The nurses were not nice.

Facilitator: Oh really? Do you mind sharing it with us?

Woman: <*There won't be anything that happens to me right*? $>^{\dagger}$ *He...he...* <*I'm afraid...*>

Facilitator: <You don't have to be afraid, nothing will happen to you. No one will know about this, other than us here.>

Woman: <Just people in this room would know it right?>

Facilitator: <Yes.>

[Group W2, meeting on Case 4]

Eliciting discussions in which all participants felt sufficiently secure to disclose their critical views was contingent on fostering open and frank discussions without fear of repercussions. Although the weekly meetings allowed us to reinforce principles of inclusion, non-blame, and positive accountability, it took time and effort and did not occur spontaneously. Sufficient time was necessary to convey these reassurances and to establish trust.

Over the course of the study, several modifications were made to the original approach based on dynamics observed and suggestions from participants. Discussion guides were revised to include prompts for reassurances and encouragement. Based on participants' suggestions, additional discussions on focus issues were held for each case. We also changed the process so that one participant recorded the assessment during the discussion, a job that was rotated at each meeting (Figure 2).

At the end of the series of meetings, a final session was held with each group to determine whether participants found the results of an initial analysis plausible, to develop recommendations, and to gather feedback on the process. There was evidence that, as a result of the audit, participants felt more prepared, informed, and responsive toward obstetric emergencies in villages. Participants also stated that they had enjoyed the process. The fact that the cases were real made for engaging discussions.

Village secretary: Before these discussions, maybe only the midwife who knows what to do. The volunteer community health worker only knows [what to do] when she encounters the midwife ... but after this, we know that we have to respond fast when an emergency happens.

[Group C2, Feedback meeting]

Woman: The cases were real. At least we can know, we can open our mind thus there are some things that we can improve, or some things we can do to prevent such cases.

[Group W1, Feedback meeting]

What kind of participation?

During the course of the study, a shift in the type of participation occurred. At the outset, we had aimed to achieve a moderate degree of participation with resources (information) contributed by the community. According to Rifkin's continuum (1985), this could be described as marginal/substantial participation. As the series of discussions progressed, however, participants made increasingly meaningful inputs into the process. Participants were involved in decision making, implementing the audit, administration and co-ordination of project activities, and made substantial contributions to articulating local needs and how they could be addressed. Participants also had control over the outcomes of the study and evaluated the process and outcomes in a final dedicated discussion. In this sense, participation became substantial/structural.

[†] Angled brackets denote a change in language from Bahasa Indonesian to Sundanese (indigenous language).

Despite this, the study was designed to demonstrate the utility of the community perspective for health planning. Although materials containing details of the methods and findings were prepared and distributed (KKM 2008; 2010), the implementation and evaluation of the recommendations generated was neither planned nor possible. As a result, the results of the study may have limited impact and sustainability on health behaviors and outcomes, potentially observed in the manner in which learning outcomes were articulated. Although participants could easily articulate "lessons learned," changes in their own behaviors may not necessarily have resulted. The following exchange was with a participant who was herself pregnant:

Woman (pregnant): Pregnant women should check their blood, if she knew her blood type then she could get someone to be a donor. If there is no blood in the hospital, then it would be possible to find a donor in the village who matches her blood type.

Facilitator: Have you checked your blood type?

Woman (pregnant): Not yet.[‡] [Group W2, meeting on Case 5]

Although sustainability was likely to have been limited, the process had encouraged women and community members to critically reflect on the healthcare systems and services in their locality. Several participants reported that they felt more confident to express their views on healthcare as a result.

Woman: I feel happy that my opinions will be heard by the government from the village level... I felt enjoyment!

[Group W1, Feedback meeting]

Context

Fears of the consequences of criticizing systems of authority may have arisen from strong traditions of social hierarchy and civil obedience that exist in Figure 2: Participants record the case assessment in an audit meeting



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rural Indonesia (Johnston, 1982; Hunter, 1996; Bebbington *et al*, 2006). Officials are said to be untrusting of villagers and unwilling to confer responsibilities to communities (Johnston, 1982). Consequences include that "people seriously doubt their ability to articulate useful opinions or to assume responsibility for group activities" (Johnston, 1982, p. 205). This was directly observed in several discussions.

Woman 1: There have been three meetings, but I'm still feeling tense.

Woman 2: Maybe it is because we are village people. [Group W2, meeting on Case 3]

TBA: Maybe that is how foolish people feel... when in front of smart people.

[‡] In Indonesia, "not yet" is often used to avoid saying "no," which is regarded as impolite. As such, the response "not yet" may not necessarily imply that the woman intended to establish her blood type prior to delivery.

Facilitator 1: We are actually the same.

Facilitator 2: It is us who learn from you, ladies and gentleman.

[Group C1, Feedback meeting]

In whose interests?

The final dimension of the Cohen and Uphoff framework considers "whether the purposes that the authorities have in mind for getting people to participate is the same, or compatible with, the purposes [of] the people themselves" (1980, p. 227). Participants wanted to help generate information that would improve the chances of women in villages reaching life-saving obstetric care when it was required.

Village secretary: We should communicate the uses of [social health insurance] to the community. All of us here know the uses of it, right? From this meeting, we know that social health insurance can be very useful. Before, the community health worker, the TBA, did not know about the use of it. So they did not inform the community. So hopefully with this, we could give that information to the community

[Group C2, Feedback meeting]

Woman: Now, if I think that pregnant women here are poor, I tell them to arrange the ID card and family card, and they complied.... Some of them are now starting to save their money for delivery, five thousand [Rupiah, ~ 0.5 USD] per month.

[Group W2, Feedback meeting]

Participants also informed us that they had shared information from the case assessments with the surrounding community, among whom the study had generated interest.

Woman: Yesterday, there was an event at which community health workers and pregnant women gathered at village health posts. I could tell them the results from our discussion. There were also students from the Midwifery Academy from [city name]. I could contribute by expressing some opinions from this discussion.

[Group W1, Feedback meeting]

We wanted to demonstrate the ability of communities to generate useful information for health planning. The interests and purposes of the investigators and participants, although different, were clearly compatible. A shared overarching purpose – improving the situations for women in obstetric emergencies in rural villages – was likely to have helped develop a common platform for the study.

Discussion

The study sought to involve people who are typically involved in obstetric emergencies in villages in critical reviews of healthcare and to develop recommendations for reform based on their needs, experiences, and perspectives. The participants made substantial and meaningful inputs into the process and developed sophisticated multi-level descriptions and explanations of care in obstetric emergencies. The depth and coherence of information provided demonstrates the potential of the community perspective to inform the delivery of essential healthcare services (D'Ambruoso *et al*, 2013).

Eliciting these data was dependent on a robust approach. Through a reflexive and responsive process, participants increasingly considered the contexts in which individual behaviors were constructed and shared personal views and experiences. Although this may be attributable to the creation of an environment in which people felt sufficiently secure to disclose such information, it is unlikely that the dynamics of power and hierarchy were ever entirely eliminated. This was evidenced in the concerns expressed by poorer and younger participants regarding the consequences of expressing their views and in people's opinions regarding the validity of their critical perspectives more generally. The presence of international researchers was also likely to have influenced dynamics within the group.

These findings suggest that time devoted to creating an environment in which the views, opinions and experiences of all participants can be shared without fear of repercussions is critical to foster participation, particularly in societies with strong hierarchical systems. Furthermore, people who are poorer, live in more rural locations, and/or who are more disadvantaged may be less likely to be recruited to research efforts, but may have insights on exclusion from access to good quality public services that are central to what this type of research seeks to achieve. Specific efforts to involve disadvantaged or marginalized individuals should be made in CPH activities, as well as mechanisms to promote democratic involvement. Researchers conversant in the relevant vernacular languages are also essential.

An appreciation of context should be a key consideration in CPH activities. In this study, the community health workforce, village health infrastructures, devolved district governance, and historical traditions of community involvement would appear to provide a favorable setting for CPH. Despite this, however, control over local participation by both state and international organizations (Hunter, 1996), a weakened civil society base (Shiffman, 2002), tensions, conflict, confusion, and a lack of trust at local levels have been observed (Johnston, 1982; Ahmad & Mansoor, 2002; Bebbington et al, 2004). These contextual features may threaten successful CPH. There may be considerable merit in CPH, but the political implications of the approach should not be overlooked (Chambers, 1998).

The process appeared to be acceptable and enjoyable, generated unique information on villagebased care, and engaged local people in contributing to a common good. Impacts were detected in terms of learning outcomes, but the short-term nature of the study meant that the sustainability of any observed impacts was likely to have been limited. To realize the potential of the approach, we recommended the method be applied in routine (i.e., nonresearch) district health planning schedules. This should be part of a sustained and self-reliant process, moving from community-based to communityled, with trained facilitators, and community groups granted the credentials, remuneration, and authority to conduct activities and liaise with authorities. Given that an association with health authorities may not be neutral and may limit an open and frank exchange of information, activities that are linked to, yet autonomous from, health authorities are likely to be of merit. In this sense, CHWs are well placed to mediate the link between communities and health authorities.

Documenting the process using theoretical frameworks of CPH allowed us to demonstrate that participation was complex, dynamic, and evolved over the course of the study. As stated above, the evaluation of CPH does not lend itself to conventional impact assessment. Evaluation should therefore reflect the nature of CPH, as a simultaneous means and end and a dynamic process conditioned by context. Explicit articulation of the relevant purposes and processes according to organizing frameworks such as those provided by Arnstein (1969), Rifkin (1985) and Cohen and Uphoff (1980) is likely to foster more consistent implementation and evaluation. The contribution of the rural poor to service organization is a process in which many interests are at stake. Whether they are conflicting or congruent, balanced, open or implicit, these interests should feature in planning, analysis, and debate.

Finally, CPH employs qualitative methods that allow for contextualized explanations and descriptions of enabling processes and mechanisms. These modes of inquiry command little favor within the public health academic establishment. A recent systematic review of community-based interventions for maternal health reflects this situation (Kidney et al, 2009). Despite concluding that community interventions can reduce mortality and warrant investment, a shortage of so-called "high quality" studies (i.e., with randomized experimental design) was noted, with only two South Asian studies being selected for inclusion (Kidney et al, 2009). Without shifts in prevailing evidence hierarchies, research on CPH may continue to be considered as of low quality and gain limited exposure. Methodological recommendations for community-based participatory research are provided in Table.

Conclusion

In our study, participation was complex and dynamic, conditioned by context, and subject to change. With careful facilitation, a reasonable level of participation occurred over a relatively short period of time, yielding explicit accounts of care in the locality. Examining the process using theoretical frameworks helped to document key processes and dynamics and suggested circumstances for more sustained, active, and widespread adoption of the approach. Participatory programs are implemented according to a variety of models ranging from those that emphasize individual responsibility to those which involve social organizing to foster political engagement (agency). Given the importance of this

| Element of participation | Recommendation |
|--------------------------|---|
| WHO | Sufficient time is required to foster trust and participation particularly among younger less educated participants Researchers may be considered as representatives of authorities, which may threaten trust and rapport. People who are poorer and live in more remote locations may be "less visible" to recruitment but may have insights worthy of inclusion Researchers from the region and conversant in relevant vernaculars is essential CHWs can provide entry-points into communities, although association with health authorities needs to be neutral |
| HOW | Instilling permission to criticize without fear of reprisals is necessary to elicit meaningful critical dialogues Ensure a self-reflective and responsive approach based on participant input Provide credentials, remuneration, lunch, social gathering Seek effective stimulus for discussions Establish a regular format to increase familiarity with an otherwise atypical event/process |
| WHAT KIND | Prepare for the nature and content of discussions to change during the process |
| CONTEXT | Develop an ongoing self-reliant process with a continuous cycle of implementation, evaluation, and review CPH groups should be linked with, but remain autonomous from, local health authorities A change in traditional relationships between communities and authorities may be required for more active CPH. A focus on transparency and accountability in community-based research will likely foster trust and more productive relationships. Capacity building for, and investment in, community organizations is also required. Alternative forms of "evidence" need to be adopted in academic and policy environments |
| PURPOSE | A process and outputs that reflect local situations and needs should be developed CPH should be applied in routine district health planning schedules, as part of a sustained and self-reliant process, moving from community-based to community-led, with trained facilitators, and community groups granted the credentials, remuneration, and authority to conduct activities and liaise with authorities The purposes of different stakeholders (communities, health authorities, and researchers) should be reconciled to harmonize efforts |

Table: Methodological recommendations for community-based participatory research

political context, political agency can be seen as a way to promote individual responsibility (rather than the reverse), so that responsibility and agency become the necessary and sufficient conditions for successful community participation. Successful participation means the voices of marginalized people are heard, experience is regarded as expert opinion (i.e., as evidence) and, ultimately, democracy and rights are sought as part of a socially-legitimized process. We conclude that CPH in Indonesia should be embedded within the ongoing devolution of health services and capacity building for community organization to facilitate democratic decision making and public participation in health. Despite its potential and relevance, however, the adoption of meaningful CPH may be threatened by wider socioeconomic and political conditions, as well as by prevailing evidence hierarchies. Substantial shifts may be necessary to legitimize and align alternative forms of knowledge with conventional wisdoms. We recommend policy and research to establish a firmer foundation for this progressive, yet obscured, public health concept.

Author contributions

LD devised the study design, contributed to data collection, led the analysis, and drafted the manuscript. EM and YI devised the study design, led the data collection, contributed to analysis, and contributed to versions of the manuscript. AK supervised analysis and contributed to the manuscript. AC conceived of the study and contributed to the manuscript. The manuscript has been prepared on behalf of the Serang District Community Health Partnership for Maternal Health. The participants made substantial direct intellectual contributions: participants devised the study design (during implementation), led data collection, and contributed to the analysis. Given conditions of informed consent and anonymity, the participants did not directly contribute to the preparation of the manuscript, although their contributions and assessments are the subject of it.

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Abbreviations and acronyms

| CHW | Community health worker |
|-----|-----------------------------------|
| СРН | Community participation in health |
| TBA | Traditional birth attendant |

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