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# Community participation in social innovations in health: a qualitative study of women's engagement in a local tuberculosis clinic in the Philippines

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## ABSTRACT

**Background** We explore the perspectives and experiences of the Kalinga Leaders (K! Leaders), who are community volunteers of the social innovation, Kalinga Health. It is a 360° facility providing quality, affordable and comprehensive TB care in two urban cities in the Philippines. It acts as an intermediary agency between the public and private sector partners, ensuring continuity of care for patients. We explored how gender and other gender intersecting inequities and inequalities impact health conditions. Specifically, we explored how community engagement helps improve access to and uptake of health services.

**Methods** A grounded theory approach was used to generate data from the perspectives of the community members and K! Leaders, which were explored through site visits, key informant interviews and a focus group discussion. Field notes and recording transcripts were used for thematic analysis to identify key patterns.

**Results** Despite intersecting social factors that hinder their participation, K! Leaders remain motivated to become an integral part of the tuberculosis referral system in two urban cities in the Philippines, helping improve access to and uptake of health services in the communities they serve.

**Conclusions** The K! leaders' desire to help their communities and at the same time, empower themselves, motivates them to do a balancing act, which is facilitated by the culture of Kalinga Health, enabling them to thrive in an environment that champions gender diversity and equality.

### WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Gender interacts with other social variables depending on social, political, economic and historical circumstances. These affect people's vulnerability to illnesses, their access to health services and their responses to treatment.
⇒ Community participation is a key driver of effective social innovations in health, which has the potential to improve uptake and access to health services among broader populations.

## INTRODUCTION

### Social innovation in health

Social innovation in health is defined as a "solution (process, product, practice and market mechanism) implemented through diverse organisational models. The solution has been developed by a range of actors in response to a systemic health challenge within a geographic context. It profoundly challenges the current system status quo which enables healthcare to be more inclusive, effective and affordable".[1] Participation is a distinguishing feature of social innovation, and unlike technological innovation, it is its participatory process that promotes social inclusion.

### Case profile: Kalinga Health and its efforts to curb tuberculosis

Innovations in community health (ICH) established Kalinga Health, a 360° facility that uses a hub-and-spoke social enterprise model to conduct consultation,

**WHAT THIS STUDY ADDS**

⇒ The study demonstrates that social innovations in health are crucial in creating opportunities for community participation, improving health outcomes and facilitating social impact.

⇒ Knowing the context in which the lives of women are embedded and analysing their participation in a social innovation that purposefully designs interventions that involve the systematically vulnerable, have been shown to help create an environment that champions gender diversity and equality.

**HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY**

⇒ The results of the study have highlighted how the social innovation, Kalinga Health, has created opportunities for community participation.

⇒ K! Leaders were instrumental in improving health outcomes at the community level while cultivating personal and professional growth in the process.

⇒ The intersection of gender and other social stratifiers, and how this shapes social innovations in health at the community level and contributes to the transformation of health systems, was demonstrated.

diagnostics, treatment, case-holding and follow-up for patients with tuberculosis. It is a social innovation that addresses several health system factors that contribute to the rising number of tuberculosis cases in the Philippines, such as unregulated private practice, fragmented health service delivery and high healthcare costs in the context of poverty. To date, the country has one of the highest per capita burden of tuberculosis in the world, with 500 people affected per 100 000.[2] The Kalinga Health case demonstrates an innovation process involving the thorough examination and understanding of the pain points of different stakeholders in the healthcare delivery system, building partnerships and adopting creative public–private mechanisms to ensure sustainability.

### Community participation in social innovations in health

It is important to recognise that apart from improving screening, detection and treatment, a grassroots approach which offers social protection for the vulnerable populations must also be adopted.[3] To facilitate this, Kalinga Health engaged K! Leaders, community volunteers who are active participants in the tuberculosis referral system. They conduct house-to-house visits to monitor patients with tuberculosis and spearhead patient education activities to increase the community's knowledge of tuberculosis care and health.

The engagement of a community, as reflected by the active participation of K! Leaders, is perceived as an operative and innovative approach for achieving health outcomes,[4 5] particularly as one of the main drivers of social innovations in health. It has been recognised as an important element in achieving universal health coverage when successfully integrated into existing health systems.[6] However, the specific role of women and the dynamics occurring in this context remain unexplored. There is, therefore, a need to understand community participation and gendered aspects and dimensions of social innovation in health at the community level.[7 8] This will allow the development of socially acceptable and culturally appropriate social innovation and research implementation activities, which are tailor-fit and locally designed to increase access to health information and services within communities. This study, therefore, sought to explore and document processes in Kalinga Health, as they feature gendered dimensions of social innovations in health at community level. We explored how gender and other gender intersecting inequities and inequalities impact health conditions based on the perspectives of these women, delving into their lived experiences, motivations and sentiments, particularly within the context of community engagement as a means to improve access to and uptake of health services, and the health outcomes they experience throughout the life course. Ultimately, we sought to look into and appropriately address sex and gender and their intersections with other drivers of inequalities and ill health, with equality, diversity and inclusivity.

## METHODS

### Study design

This is a qualitative study based on site visits, in-depth individual interviews and a focus group discussion (FGD) facilitated by members of the research team.

The study participants consisted of women K! leaders, men and women recipients of care, and men and women clinic staff, who were selected using the purposive and snowball sampling method. Purposive sampling, which involves the deliberate choice of respondents, was used to identify the social innovators and community members who were volunteers for, patients of and clinical staff of Kalinga Health. Snowball samples, networking out from the purposive sample, were used to reach out to more participants who also met the sample criteria. Participants were recruited using print and in-person recruitment strategies. Due to the nature of the study design, the sample size was not predetermined and was dependent on the point of saturation, which was reached after three face-to-face interviews among clinic staff, one face-to-face interview with a clinician and eight face-to-face interviews with patients. Each interview took approximately 20–40 min. The research team conducted one FGD among K! Leaders, which lasted for approximately an hour. These interviews and FGD were instrumental in reaching theoretical saturation.

The time and location of data collection activities were also planned accordingly to ensure full participation from respondents. Interviews were conducted

virtually and in person. Data were collected in the Kalinga Health clinics. There were clinic staff in the facility during the time of interview, but only the participants were interviewed by the researchers in a separate room.

Data collection tools were guided by the gender analysis domains and questions in the TDR Toolkit on Intersectional Gender Analysis.[9] These include a discussion of their roles and responsibilities as K! leaders, the social innovation's role in addressing the issues at hand, the profile and extent of participation of key stakeholders, gender and other intersecting inequalities in relation to the social innovation, its effect and impact on the personal and community levels and their role in its sustainability mechanisms. The interviews and FGD were audio recorded and field notes were constructed during and after the interviews.

### Data management and analysis

Data analysis began as soon as data were collected—field notes and recording transcripts have been used for thematic analysis to identify key themes and patterns in the data. Recorded interviews and the FGD were transcribed and translated from Filipino to English. Two senior research associates used inductive approaches to build the coding structure and coded the transcripts using MaxQDA software. The constant comparative method was used as an iterative procedure for the qualitative analysis of text, a process wherein themes emerge from the data via inductive reasoning as opposed to coding the data based on predetermined categories.[10] Data validation was used by soliciting feedback about the data and conclusion provided. After each main topic during data collection, the researcher summarised the information to ensure the accuracy of the interpretation of the information.

### Participant and public involvement

The public's insights during the FGD and research uptake meeting were taken into consideration in the accomplishment of the study deliverables. Although participants, including clinic staff, patients and K! Leaders, were not involved in setting the research question and the outcome measures and the recruitment and conduct of the study, they were active participants in the discussion and dissemination of the study's results and future direction. The results of the study were disseminated through a virtual meeting with members of Kalinga Health and representatives from the community.

### Researcher characteristics and reflexivity

Our research team established rapport and engaged with the community participants in a collaborative manner. Reflexivity was facilitated through the analysis and writing by recording, discussing and challenging established assumptions. The research team ensured that personal biases did not in any way interfere with the approach to the study and the participants.

## RESULTS

From the qualitative data gathered, six categories emerged, which were then synthesised into three subthemes and two overarching themes: (a) Social innovations in health (SIH) creating opportunities for community participation, improving health outcomes and social impact and (b) Gender norms, gendered labour and volunteerism influence participation in SIH, as seen on table 1.

### Theme 1: social innovation in health creating opportunities for community participation, improving health outcomes and social impact

K! Leaders have been serving their communities through Kalinga Health's initiatives. According to one of ICH's officers, community members listen to them because they are lay health workers whom community members trust and relate to, in the words of one of KH's staff, *"K! Leaders are empowered to be lay workers. I am a nurse, but sometimes, patients do not listen to healthcare professionals. They, however, listen to K! Leaders because they are their neighbor or friend whom they trust and relate to."*

#### SIH providing opportunities for community participation

Kalinga Health engages community members to be active partners in addressing the long-standing barriers to and pain points of tuberculosis care. Its role in creating opportunities for participation and increasing participants' access to information has been facilitated by K! Leaders in their respective communities. During the course of their engagement with KH, they have

**Table 1** Summary of coding and qualitative processing

| Units of analysis | Categories | Subthemes | Themes |
|---|---|---|---|
| 23 units of analysis derived from 132 coded responses | 6 categories | 3 subthemes | 2 overarching themes |
| | ► Role of community engagement in the SIH<br>► Roles and responsibilities of K! Leaders<br>► Motivations of K! Leaders<br>► Community perspectives on gender norms and roles<br>► Gender and volunteerism<br>► Gender norms, roles and expectations as K! Leaders | ► SIH providing opportunities for community participation<br>► Gender norms, roles, expectations and volunteering as K! Leaders<br>► Roles, responsibilities and motivations of K! Leaders | SIH creating opportunities for community participation, improving health outcomes and social impact<br>Gender norms, gendered labour and volunteerism influence participation in SIH |

SIH, social innovations in health.

been provided with training which improved their skills and broadened their knowledge of tuberculosis and of the importance of health. Through these engagements, they have also expanded their networks, building rapport with community members and connecting with other relevant stakeholders as they fulfil their duties. These K! leaders also expressed their gratitude to Kalinga Health, in their words, "*Kalinga takes good care of us. We return the favor by working hard, which is reflected by the satisfaction of the community members in the work that we do*." They are also grateful to serve as Kalinga Health's bridge to the community—making healthcare accessible to the communities. It is also important to note that even after they stopped being K! Leaders, they are still able to apply the knowledge and skills they developed in serving the community. As one of the K! Leaders shared, "*…many people were happy, telling us that we were doing a great job with taking BP readings everyday and being patient with attending to community members.*"

### Theme 2: gender norms, gendered labour and volunteerism influence participation in SIH

The women K! Leaders have multiple roles to fill, as one K! Leader shared, *"At home, I am a mother who is in-charge of cooking food, washing clothes, and most importantly, looking after my children everyday. I always have to be home to welcome and assist them when they get home from school. Between having a job and being a volunteer, I need to be able to balance my time to fulfill multiple roles."*

#### Gender norms and gendered labour

While men are expected to be outside of the home at work, women are expected to be at home, and therefore, take on volunteering roles by default, and that this is a 'natural tendency'. This was expressed by the founder when asked if Kalinga Health purposefully chose women, *"We're not systematically engaging or preferring women. It just so happened that they are the ones with the natural tendency [to volunteer]. Men are probably busy with work*." He also shared that, *"women usually have the mother's instinct to take care of others"*, which he believes explains their propensity to volunteer and participate in similar initiatives.

#### Women and volunteerism

Volunteering, even though incentivised, is largely considered unpaid labour, which in the case of K! Leaders, only get in the way of their responsibilities at home. A husband of a K! Leader expresses that he gets flustered at times when his wife goes out to volunteer, *"Sometimes, I get irritated when I see that she's going to go out and volunteer again. She's barely home. But I know that it's her legacy because she really likes to volunteer."* These expectations to maintain their domestic responsibilities while pursuing their volunteer work often leaves K! Leaders in a balancing act between the two. *"We have to strike a balance between being a mother and being a volunteer, so we do our best to allocate time for both*." And for the most part, K! Leaders end up having to adjust their waking hours to accommodate both, as one explains, *"In our home, I do everything. To be able to accomplish all these tasks, I have to wake up at 4 am. I still even have to prepare my husband's coffee."*

#### Roles, responsibilities and motivations of K! leaders

In spite of needing to balance their responsibilities at home, K! Leaders express that their main motivation to continue volunteering is their desire to help people: *"It's great because we are of service to the community*." Another K! Leader explains, "*We want the community to value and take care of their health*." Aside from being able to help others, K! Leaders are also motivated by the social relationships they are building, describing their work as "*A form of bonding*". They explain that they now consider each other as friends, and maintain these relationships through regular communication.

Their approach to community self-monitoring has not only improved the health outcomes of community members but also empowered the K! Leaders themselves. In their words, "*We were able to serve them. We were happy to serve as the link between Kalinga Health and the community*." They even perceive their work as a stress reliever, sharing that they feel happier outside the home. Their dedication is also evident in how they make ways to fill in multiple roles, as one K! Leader mentioned, "*When you love what you do, you can always find ways to make everything work."*

## DISCUSSION

### Gender and intersecting social determinants influence social innovations in health

The study has shown the nuanced ways in which women are engaged in social innovations, particularly within their roles as community volunteers or K! Leaders, in a society that gives less merit to domestic roles that women traditionally fill. There are social expectations and norms that exist and affect their daily lives, which affects their roles as volunteers. It has been established that the responsibility of work at home is greater for women than men, therefore, accommodating work and volunteer activities is perceived to be more difficult for women.[11] Women with more children and with a low educational attainment are also found to be less likely to volunteer, highlighting how intersections between gender, education and socioeconomic status influence decision-making and volunteerism. However, when perceived as a form of leisure, women still engage in such activities, as is the case with most of the K! Leaders, who perceived volunteering as a stress reliever.[12] This emphasises the important role of motivation in spite of unfavourable situations (eg, low socioeconomic status, multiple responsibilities, lack of social support and low educational attainment).

### Participation and empowerment: analysis using Arnstein's ladder of participation and Longwe's women empowerment framework

We turned to existing frameworks of community participation and women empowerment in examining how gender and intersecting social determinants affect social innovations in health.[13 14] K! Leaders were able to meet their basic needs and had access to resources such as training and benefits on an equal basis with men. They have also started to recognise that gender roles are not to be strictly observed, but they do maintain that women are mainly in charge of household work. This puts them at the level between consultation and placation in Arnstein's ladder, where they actively participate in the implementation but are not able to take part in the decision-making process.[13] They are granted a limited degree of influence in the process, but have yet to be part of joint policy boards nor be engaged in mechanisms for resolving impasses. To ensure that their involvement is meaningful, it must be analysed in the context of empowerment. Longwe's framework includes five levels of women's empowerment: welfare, access, conscientisation and awareness raising, participation and mobilisation, and control, where the K! Leaders are at the level of access.[14] This framework is helpful in that it perceives both the practical and strategic elements of development interventions. However, these frameworks have some limitations, as they cannot take into account the complexity of the varied power dynamics in our ever-changing society. Nevertheless, from these we observe how the K! Leaders! lived experiences, motivations and sentiments, particularly within the context of community engagement, translates into and influences their level of participation and empowerment in the community as lay health workers. By being able to participate in implementation, K! Leaders were able to help improve access to and uptake of health services by community members. Their role in the referral system has been instrumental in improving health outcomes, particularly among patients with tuberculosis.

It must also be noted that while we were not able to observe intersecting social determinants of ethnicity or disability, that does not mean that such factors do not exist. Particularly for persons with disabilities, we acknowledge that there might have been potential participants in the study who could not physically be present during the field visits, due to mobility limitations. Hence, we were not able to gather and analyse their insights and experiences.

Lastly, it is important to note that Kalinga Health's main goal was to provide tuberculosis care by serving as an intermediary agent between the private and public sector. Empowering women served as a secondary objective that was instrumental in fulfilling the primary goal. Nevertheless, the SIH demonstrates the dynamic relationship between the two models—establishing equality in an increased number of spheres leads to higher degrees of participation, ultimately resulting in higher levels of empowerment. Furthermore, the next steps should involve engaging more health practitioners, policy-makers and researchers to ensure that intersecting vulnerabilities are minimised and equal opportunities and rights across all contexts are upheld.

## CONCLUSIONS

Gender norms and societal expectations affect various aspects of women's lives.[15] Their roles as K! Leaders, while mostly perceived as beneficial to the community, are sometimes seen as a hindrance to their domestic responsibilities. Despite these challenges, their desire to help their communities and at the same time, empower themselves, motivates them to do a balancing act. Moreover, Kalinga Health believes that 'innovation is culture', which enables them to purposefully design interventions that involve the systematically vulnerable and create an environment that champions gender diversity and equality.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by Philippine Social Science Council—Social Science Ethics Review Board. Reference Code: CE-22-28 (Full Review). Participation in this research was voluntary. Each participant was provided with an informed consent sheet, in both English and Filipino. Participants were advised of their right to withdraw their participation from the research at any time and were provided with the contact details of both the principal investigators and the ethics board for any additional inquiries. Written consent was secured prior to the interviews and focus group discussion.

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