

Strengthening Community-Based Surveillance on Deaths and Diseases: Perspectives of Lady Health Workers and Supervisors

Jazbia Kanwal¹, Haya Ali¹, Dania Sofia Rahim¹, Mohammad Sharjeel Rehman¹, Faiza Bashir¹, Nighat Murad¹, Ali Rehman²

¹Health Research Institute, ²Integrated Disease Surveillance & Response System, National Institutes of Health, Islamabad.

Introduction

Community-based surveillance (CBS) is a proactive public health strategy that engages local health actors in the identification, reporting, and response to health-related events at the grassroots level. In Pakistan, the National Lady Health Worker Program are pivotal to CBS implementation, given their embedded role in the community and the health system.¹⁻³ Despite their outreach, community-level surveillance of both deaths and diseases remains fragmented and underutilized both at the hospital and community level. Understanding the lived experiences of LHWs and LHSs is critical for strengthening surveillance frameworks and improving early disease detection and mortality reporting. This study was aimed to identify and quantify the mental and socioeconomic enabling factors and challenges reported by LHWs and LHSs while performing their community-based surveillance (CBS) duties at Barakahu, Islamabad.

Methods and Results

The study was conducted in the Rural Health Centre, Barakahu. Two focus group

Corresponding Author:

Dania Sofia Rahim

Health Research Institute

National Institute of Health, Islamabad.

Email: daniarahim23@gmail.com

Received: 07 August 2025, Accepted: 11 March 2026

Published: 28 April 2026

Authors Contribution

JK, DSR, FB, NM & AR conceptualized the project. JK, HA, DSR & MSR did the data collection and literature search. JK & MSR also performed the statistical analysis. Drafting, revision & writing of manuscript were done by JK & DSR.

Copyright © 2026 The Author(s). This is an Open Access article under the CC BY-NC 4.0 license.

discussions (FGDs) were conducted comprising of six participants (2 LHSs and 4 LHWs). One facilitator, three note takers and one observer were present during these FGDs. The facilitator used a semi-structured questionnaire to assess the enablers and barriers for the participants to carry out their duties. A verbal informed consent was taken prior to the interview and for audio recording. The inclusion criteria included only LHWs and LHSs who have served at least 10 years in the field and exclusion criteria was LHW or LHS under 10 years of field experience. Purposive sampling technique was utilized and only LHWs and LHSs were allowed for interview. Interviews were analyzed by deductive analysis methods.

The findings from the FGD, revealed an in-depth understanding of their roles in community-based surveillance (CBS) of deaths and diseases. Despite being deeply embedded in their communities and showing strong commitment, participants expressed several operational, structural, and emotional challenges that limit their effectiveness. All respondents strongly disagreed with the notion that their current salary compensation was sufficient, especially considering the expectation of additional responsibilities such as mortality and disease surveillance. While they showed readiness to support CBS, they emphasized that financial incentives and logistical support must accompany these expectations. Both LHWs and LHSs expressed that they cannot take on additional tasks without corresponding benefits or recognition. Despite this, many reported continuing to perform CBS-related duties informally, driven by monetary and community need. The role of LHWs was described as respected within the community but less acknowledged within the health system, particularly by administrative authorities

Table: Comparison of community vs. health system responses regarding LHWs and LHSs roles in community-based surveillance.

<i>Aspect</i>	<i>Community Response</i>	<i>Health System Response</i>
Trust and Respect	LHWs/LHSs are trusted, especially for maternal care and family planning.	Their role is respected less within the formal healthcare structure.
Information Sharing	Communities report deaths/diseases frequently and feel heard.	No proper reporting tools: workers rely on self-made registers.
Decision-Making Inclusion	Community often engages with workers openly.	LHWs/LHSs are excluded from planning or decision-making.
Support and Incentives	The community appreciates their visits and presence.	Inconsistent medical supply, outdated equipment, and no extra pay or incentives.
Training and communication	Urdu-based communication and education are effective locally.	Minimal refresher training and weak device/network access.

(Table). Most participants reported that their opinions were not considered in decision-making, particularly around health reporting protocols or policy changes. This lack of involvement, despite their frontline engagement, was a source of dissatisfaction. Educational backgrounds ranged from secondary-level education to higher degrees, highlighting a capacity for more formal roles in data reporting and disease detection. However, respondents noted that training was limited, often confined to Urdu booklets, with refreshers rarely provided. Symptom recognition is part of their informal training, yet no standard digital (or structured methods; defined methods exist) were introduced. Most respondents preferred working 4-6 hours per day, citing challenges in balancing work responsibilities with family life, especially due to limited family support and the time spent away from children. Operational barriers emerged strongly across interviews. LHWs and LHSs reported that transportation and digital network issues significantly hinder timely reporting. Additionally, the absence of equipment, such as thermometers, weight machines, baby weighing scales, and first aid kits, reduced their functional capacity. Items were often expected to last 2-4 years, despite being intended for short-term use. Furthermore, no formal tools were provided for death or disease documentation, compelling workers to create their own manual registers to track community health events which compromises standard reporting. All the LHWs expressed a negative experience after the integration of LHW and LHS into the RHC mainly due to reduced authority in decision making and increase in workload. A few enablers were consistently reported. The trust and accessibility LHWs enjoyed in their communities allowed people to frequently report deaths and diseases directly to them. In situations where disease patterns changed (emerged) or unusual symptoms were observed, LHWs preferred to report immediately to their supervisors (LHSs) or, in the case of LHSs, directly

to District Health Officers (DHOs). While public health systems lacked standardized reporting tools, this informal network of trust-based communication acted as a substitute. Additionally, many LHWs mentioned that community members often felt emotionally validated when asked about deaths and diseases. The LHWs' consistent involvement in prenatal, postnatal care education, and family planning services has further solidified their presence and importance at the grassroots level. Finally, participants called for salary systems to be restructured based on merit, citing disparities and inconsistencies that demotivate workers despite their continued commitment to serve.

Comments

These findings underscore the critical but under recognized role of Lady Health Workers (LHWs) and Supervisors (LHSs) in grass root surveillance. Embedded within communities, they consistently report health-related issues, caregiving trust, and emotional validation. Their work is impacted by system limitations such as inadequate infrastructure and the lack of a formal reporting system. Comparable research in Pakistan affirms that trusted social standing alone does not compensate for systemic dysfunction. In Thatta district, stakeholders reported fragmented governance, paper-based reporting, and underutilization of surveillance data⁴⁻⁵ shows that LHWs in Sindh promoted the idea of Healthcare insurance and Food packages as an alternative to cash salary however in our findings they strongly rejected this, this may be due to changes in current financial landscape. These parallel constraints corroborate our participants' experiences, particularly regarding poor connectivity, resource gaps, and lack of institutional responsiveness. This study at a single site limits generalizability. Still, thematic saturation suggests relevance across similar contexts.

The healthcare system is different in all the provinces and federation, for complete assessment of current infrastructural situation LHWs and LHSs from other provinces should also be interviewed. This study is limited to experienced LHWs having more than 15 years of experience, hence problems associated with novice LHWs and LHSs have not been documented. Given evolving health challenges, future research should examine pilot integration of digital registers, merit-linked incentives, and community feedback loops in diverse provincial settings to assess scalability. For policy and practice, strengthening CBS through LHWs/LHSs requires reform at multiple levels: Provide standardized reporting tools and digitized platforms, ensure regular refresher training and functional supervision, implement performance-based incentives linked to service delivery and data quality and consider revisiting the previous independent working model for LHWs, as all interviewees found it more effective than the current RHU-linked system. Such measures would help transition from one-way community engagement to a responsive, two-way surveillance ecosystem.

Funding: None.

Availability of Data: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethical Approval: Exempted, as per the institutional policies and guidelines.

Conflict of Interest: None declared.

References

1. Hafeez A, Mohamud BK, Shiekh MR, Shah SA, Joona R. Lady health workers programme in Pakistan: Challenges, achievements and the way forward. *J Pak Med Assoc* 2011; 61(3): 210-5.
2. Mumtaz Z, Salway S, Bhatti A, McIntyre L. Improving maternal health in Pakistan: Toward a deeper understanding of the social determinants of poor women's access to maternal health services. *Am J Public Health* 2013; 103(1): 17-23.
3. Khalid F, Hussain S, Aftab W, Saleem S, Ahmed A, Zaidi S, et al. Perspectives on community health worker integration into health systems in low- and middle-income countries: A qualitative study from Pakistan. *PLoS One* 2022; 17(3): e0265015.
4. Naeem I, Siddiqi S, Siddiqui AR, Hasan R. Exploring stakeholders' experiences and perceptions regarding barriers to effective surveillance of communicable diseases in a rural district of Pakistan: A qualitative study. *BMJ Open* 2022; 12(11): e067031.
5. Khan MS, Mehboob N, Rahman Shepherd A, Naureen F, Rashid A, Buzdar N, et al. What can motivate Lady Health Workers in Pakistan to engage more actively in tuberculosis case finding? *BMC Public Health* 2019; 19(1): 999.