Understanding the role of lady health workers in improving access to eye health services in Khyber Pakhtunkhwa (KPK) Province of Pakistan

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List of acronyms

BHU	Basic Health Unit
DHQ	District Headquarters
DPIU	District Programme Implementation Unit
FGD	Focus Group Discussion
FHF	Fred Hollows Foundation
KPK	Khyber Pakhtunkhwa
LHW	Lady Health Worker
LHS	Lady Health Supervisor
LRBT	Lytton Rahmatulla Benevolent Trust
PEC	Primary Eye Care
PICO	Pakistan Institute of Community Ophthalmology
RAAB	Rapid Assessment of Avoidable Blindness
WHO	World Health Organization

Executive summary

Background and objectives

In 1994, the Lady Health Workers (LHWs) Programme was established in Pakistan to increase access to essential primary care services and support health systems at the household and community levels. LHWs are salaried, fully recognised members of the public sector health workforce. In Khyber Pakhtunkhwa (KPK) province in northern Pakistan, eye care is among the many unmet needs that LHWs were trained to address, including screening and referral of people with eye conditions to health facilities. However, compliance with referrals, especially among women in KPK, has been very low. We explored the role of LHWs in patient referral and the barriers to patient compliance with referrals.

Methods

Between April and June 2019, we conducted a qualitative study in KPK. We captured a range of experiences and opinions from a diverse group of 73 participants that included patients, LHWs and their supervisors, district managers and other stakeholders across two different sites through eight focus group discussions and nine in-depth interviews. Participants were interviewed about the organisation and delivery of eye care services as well as the challenges patients face in accessing services. Data were analysed thematically using NVivo software version 12.

Key findings

Findings showed that LHWs have a broad understanding of basic health care and are responsible for a wide range of activities at the community level. LHWs felt that the training in primary eye care (PEC) had equipped them with the skills to identify and refer eye patients. However, they reported that access to care was hampered when referred patients reached hospitals, where disorganised services and poor quality of care created significant barriers to access to eye services. LHWs felt that this had a negative impact on their credibility, trust and respect they receive from the community, which, coupled with low eye health awareness, influenced patients' decisions about whether to comply with a referral. They further expressed frustrations with the insufficient supply of consumables, lack of refresher training, being overburdened and overworked and fixed salaries with no monetary or non-monetary compensation for additional programmes, such as eye care. The majority of patients interviewed prefer visiting charitable eye hospitals or other private facilities to seek eye health care services. There was a lack of trust in the health care services provided by public sector hospitals. Limited information, health care staff attitude, poverty, deep-rooted gender inequities and transportation were the other reported main drivers of non-adherence to referrals.

Conclusions

Results from this study have shown that the training of community health workers in eye care was well received. However, training alone is not enough and does not result in improved access for patients to specialist services if other parts of the health system are not strengthened. The role of LHWs in eye care in a given programmatic context should be articulated and their responsibilities and competencies should be clearly defined. Pathways for referrals should be agreed and explicitly communicated to both the health care providers and the patients. Attention should be paid to how LHWs are remunerated and supported to prevent their overburden and demotivation. The role of LHWs could be made particularly effective and should be strengthened in providing patients with accurate information about eye diseases and services available and in delivering alternative more gender-focused services tailored specifically to the needs of women.

Chapter 1: Introduction

Background and rationale

In many low- and middle-income countries, including Pakistan, access to health care services is often limited, particularly in remote locations and for disadvantaged population groups. In 1994, as part of a national strategy to increase access to essential primary care services, the Government of Pakistan launched the Lady Health Workers (LHWs) Programme, which aimed to strengthen health systems at the household and community levels and to bridge local communities with hospital-based services [1-3]. Since then, the programme has rolled out across the country with more than 110,000 LHWs recruited, trained and deployed to carry out monthly household visits to advise on health promotion activities, screen, provide basic treatments, refer and encourage the uptake of referrals. One of the key strengths of the programme is that LHWs are salaried and fully recognised as part of the health care workforce. They are also recruited from the local communities and thus can deliver services in a culturally integrated manner [4-6].

Lady health workers serve the whole community, but they play a particularly important role in maternal and child health in rural and urban slum communities by coordinating efforts with traditional birth attendants and midwives, and by ensuring that all mothers and children receive adequate care [7, 8]. LHWs conduct home visits to monitor vital signs (body temperature, blood pressure, pulse and breathing rate) and provide health education, health promotion and referrals to other services. Support to immunisation, nutrition, family planning and polio eradication is also a major focus of their work.

Each LHW is assigned to one or two villages (usually where they live) with a population of approximately 1,500 people. The LHWs' office is her house. A lady health supervisor (LHS) oversees the work of 20–25 LHWs on a semi-monthly basis, with her office typically located within a Basic Health Unit (BHU) or a Rural Health Centre (RHC), which are the first-level health care facilities in Pakistan. A District Programme Implementation Unit (DPIU) coordinator oversees the work of all LHSs and LHWs in a district.

The national blindness and visual impairment survey conducted in Pakistan in 2004 estimated the all age prevalence of blindness at 0.9% [9]. The major causes of avoidable blindness were cataracts (51.5%), corneal opacity (11.8%) and refractive error/aphakia (8.6%). Other common causes of visual impairment were glaucoma, retinitis pigmentosa, optic atrophy, senile changes and retinitis [9-11]. A situational analysis of district health facilities conducted jointly by Sightsavers, Fred Hollows Foundation (FHF) and the Pakistan Institute of Community Ophthalmology (PICO) in 2014 revealed that eye conditions presented at the district facilities were broadly aligned with the findings of the blindness and visual impairment survey [12].

Many international non-governmental organisations are working in partnership with the Government of Pakistan and other national stakeholders to improve eye care services across the country. Sightsavers has been providing support to the National Programme for the Prevention and Control of Blindness with the aim to develop and strengthen the eye health system and improve eye health outcomes for all people in Pakistan.

In collaboration with FHF and PICO, Sightsavers has been implementing a project titled "New Vision for Eye Health in Khyber Pakhtunkhwa (KPK) Province of Pakistan". The 4-year project that started in 2016 is funded by the Standard Chartered Bank under the Seeing is Believing initiative and is being implemented in four districts (Swat, Swabi, Mansehra and Haripur) with the aim to strengthen eye health services and improve the demand for and

supply of eye care. The programme focused on human resources for health, enhanced service delivery, developing referral pathways, strengthening partnerships, awareness raising, advocacy and research.

A Rapid Assessments of Avoidable Blindness (RAAB) survey conducted in Swabi and Mansehra districts estimated prevalence of blindness among people aged 50+ years at 4.5% and 1.8%, respectively [13]. Women, particularly those in Swabi, carried a disproportionately high burden of eye diseases with the prevalence of blindness among women being 6.5% compared to 2.0% among men. Cataract surgical coverage in the district was 75% among women compared to 94.2% among men. The difference was particularly striking in older groups aged 70+ years. Cataract and refractive error were the most common causes of blindness and visual impairment in both districts. The proportion of poor post-surgical visual outcomes in both districts was high (26.6%), well above the World Health Organization (WHO) target of 5% [13].

To address the problem of unmet eye health needs in the programme districts, LHWs were trained to screen and refer people with eye conditions to nearby health facilities. However, the uptake of referrals, especially among women, was recorded as low, estimated at around 15–20%. This study set out to explore the role and experiences of LHWs in eye health screening and referrals and the barriers to the referral uptake among patients, particularly women.

Chapter 2: Methodology

Study design and setting

This study had a qualitative design and used focus group discussions (FGDs) and in-depth interviews (IDIs) to collect data. FGDs were conducted with patients and LHWs from Swabi and Mansehra districts. IDIs were conducted with patients, lady health supervisors (LHSs) and government officials from the LHWs provincial programme and the social welfare departments of the study districts. IDIs were used to explore themes generated from the FGDs in greater depth. Participants were interviewed about the organisation and delivery of eye care services as well as the challenges patients faced in accessing services.

Sampling

A diverse group of participants that included patients, LHWs and government officials was purposively selected to capture a range of opinions and experiences. Patients were selected to ensure diversity in terms of gender, age, geography, and history of referrals. A total of 75 participants were approached and 73 (52 women and 21 men) agreed to participate in eight FGDs and nine IDIs. Two female participants declined participation in the FGDs, as they needed permission from their husbands, which they could not obtain ahead of the interview.

Data collection

Face-to-face interviews and FGDs took place between April and June 2019. All interviews and group discussions were conducted by two (one male and one female) trained qualitative researchers speaking Urdu or Pashto. Interviews took place at the district hospitals, patients' homes or government offices and, on average, lasted one hour. Prior to each interview or group discussion, the researchers introduced themselves and explained the study. Participants had an opportunity to ask questions and all provided consent. The two data collectors met regularly during the fieldwork to discuss emerging themes and receive feedback from the research supervisors.

A topic guide was developed based on the literature to address a broad set of topics (1) LHWs' training experiences; (2) their perceived role in the delivery of eye care; (3) LHWs' capacity and motivation; and (4) community challenges in accessing eye care services. The core questions were the same for all participants, while specific probes were added to explore the themes emerging from the interviews in depth. Data was collected until the point of saturation, that is until no new information or themes could be identified from the interviews.

Data analysis

IDIs and FGDs were audio-recorded, transcribed verbatim and translated into English for data analysis. Two bilingual members of the study team independently reviewed the transcripts against the original audio-recordings to ensure the quality of transcribing and translation.

The transcripts were analysed thematically using both deductive and inductive approaches to explore themes and data patterns [14]. Two researchers coded the first set of transcripts independently, while a senior researcher undertook coding of a subset of transcripts and met with the two main coders to discuss emerging themes and discrepancies. Similarities and differences in the coding were discussed, and the coding framework was refined, agreed and applied to the remaining interviews. All coding and data analysis were conducted using NVivo software version 12 (QSR International).

Ethical considerations

The study was reviewed and approved by the Institutional Review Board of the Pakistan Institute of Community Ophthalmology (PICO) (protocol #073/2019). All participants provided a written informed consent. Participants were served with refreshments and paid an equivalent of US $3.00 to compensate for their time and transport. All identifiable information was excluded from the transcripts and data confidentiality was protected throughout the study.

Chapter 3: Findings

Participant characteristics

Participant characteristics are described in Table 1. Among 73 participants who agreed to take part in the study, 52 were women and 21 were men. Thirty-two participants were LHWs; 35 were patients and six were managers. Participants' age ranged from the early 30s to the early 70s.

Most LHWs and managers were married and had acquired some form of education. Almost 90% of LHWs had been in their role for 10 or more years. For 20 LHWs (62%), their LHW salary was the main source of income and 12 (38%) reported being financially dependent on their husbands or brothers. Managers interviewed had been in their roles for 12–30 years and two worked as LHSs, one was a district welfare officer, two were coordinators of the LHWs programme at the district level and one was a senior manager at another collaborating organisation.

Among 35 patients interviewed, seven women and five men had been previously referred by the LHWs to the district hospital but did not take up the referral.

Table 1. Participant characteristics (n = 73)

Characteristic	LHWs (n = 32)	Patients (n = 35)	Managers (n = 6)
Age in years, mean (range)	41(31–51)	51 (46–70)	45 (34–56)
Sex, n (%)			
Female	32 (100)	17 (49)	3 (50)
Male	0 (0)	18 (51)	3 (50)
Marital status, n (%)			
Married	21 (66)	Not available	4 (66)
Not married	11 (34)	Not available	2 (34)
Education level, n (%)			
Below grade 10	29 (91)	Not available	0
Grade 10 and above	3 (9)	Not available	6 (100)
Main source of income, n (%)			

Salary	20 (62)	Not available	5 (83)
Remittances (husband, brother)	12 (38)	Not available	1 (17)
Other	0 (0)	Not available	0 (0)
Time spent as LHW, n (%)			
Less than 10 years	2 (6)	Not applicable	Not applicable
10–20 years	21 (66)	Not applicable	Not applicable
Above 20 years	9 (28)	Not applicable	Not applicable
Years in role, mean (range)	-	Not applicable	18 (12–30)

Emerging themes

Two overarching themes have been used to organise findings emerging from the data analysis (1) Training and integration of LHWs in the eye health workforce, and (2) Patient health-seeking behaviour and barriers to the referral uptake. The first overarching theme describes the nature of the training and the health system context in which LHWs are being deployed. The second theme captures a range of factors and challenges affecting the pathways through which patients access specialist eye care services.

Training and integration of LHWs in the eye health workforce

The PEC training for LHWs was delivered in each district in two stages. The first stage focused on skills of 124 LHSs, as master trainers in eye care programming. A training of trainers workshop was delivered over 3 days by a community ophthalmologist contracted by the project, with the support of officials from relevant departments at each district. The purpose of the training programme was to create a pool of 'experts' that could provide training on eye care at the community level. The expectation was that this pool of 'experts' would be used to support the scale up of PEC interventions in focus districts. At the second stage, one-day training sessions comprising 20–25 LHWs were delivered by the trained LHSs to a total of 3,009 LHWs across the four project districts. All LHWs under a given LHS were brought together for the training in one location. During the training, LHWs were told about the training objectives and the nature of their role and responsibilities in the project.

Content and scope of training

Lady health workers and their supervisors described the training they had received as focused on common eye ailments like allergies, red eyes, watery eyes, trachoma, cataracts, squint and glaucoma. They were also trained in preventive measures, such as personal hygiene and how to refer patients with complex eye diseases to hospitals.

Both LHSs and LHWs described their training as impactful and transformational for their practice. Prior to the training, LHWs could only listen to the complaints of people with eye issues; they were unable to take any action. The training had improved their knowledge and skills and they could now identify eye conditions and either manage them at the community level or refer patients to the hospital, as one. LHW explained:

> *"…[they] explained [during the training] different parts of the eye, symptoms of different diseases … and what can be done before the patient is referred to the doctor. It was also explained how to … diagnose an issue, how to clean... [the eye] and how to bandage it, if required. The use of Polyfax [eye ointment] was also explained." [Lady Health Worker 08, Swabi]*

Another LHW said:

> *"I learnt about … the eyelid, when children rub their eyes, eye lids get damaged, since they are very sensitive. We also learnt different methods for its management". [Lady Health Worker 22, Mansehra]*

LHWs also said that they had learnt about cataracts – introduced to general signs and symptoms' checklist for the detection of cataracts in eyes – and that it should be treated immediately. They further explained that they often observed patients delaying seeking treatment for cataracts, but the training had equipped them with the skills to talk to the patients and encourage them to seek treatment as a matter of urgency.

A number of LHWs, however, said that during the training, they had limited opportunities to share their experiences, clarify project expectations or learn from each other. Some LHWs also felt that their supervisors trained as master trainers lacked direct experiences of eye care programming and could not adapt the content of the training to the LHWs' working environment in the community. In the words of one LHW:

> *"Madam there is a difference of learning from a trained professional doctor and a LHS. An eye doctor has more experience and can guide us better. We would want an eye specialist to educate us … a LHS tells us the management of the problem whereas a doctor would tell us the treatment … LHS tells what to suggest, doctor will tell what to do. We believe a doctor can guide us better step by step. … The message does not remain the same when it rotates among different people. A direct source and an indirect source are two different things." [Lady Health Worker 04, Mansehra]*

Senior managers, on the other hand, felt that LHSs were best placed to train LHWs. They saw LHWs as people with limited education, which may make it difficult for them to follow or benefit from training by medical doctors. Arguably, it was in the managers 'interests' to portray the situation that way so as to maintain control, but the stance could also be explained by deep-rooted gendered norms and status hierarchies in this society. One manager further argued that although doctors are 'naturally' best placed to explain the nature of different eye diseases and treatments, they were not good trainers for people with minimal education (eight to ten years of schooling in the case of LHWs).

One other issue highlighted by the LHWs interviewed was refresher courses. They recommended that the refresher training for eye care should be carried out on a regular basis in the same way as the refresher training for other conditions managed by LHWs:

> *"We get refresher trainings for other disease programmes … [every] 6 months to 2 years. Knowledge is updated, motivation is enhanced. [We] are learning new things and get involved in the field level activities. It is a good way of reminding our duties." [Lady Health Worker 11, Swabi]*

These refreshers are reportedly supported by the national LHWs programme and executed by district health offices. The districts organise the refreshers whenever there is a new campaign on any of the subjects covered by LHWs such as: polio vaccination, mother and child health, dengue etc. It is, however, unclear as to whether these refreshers are paid for by the individual disease programmes or if there is a centralised pot of funds to support refresher training. Primary eye care (PEC) is included in the curriculum for LHWs, but without sustained funding for refreshers, it will be difficult to maintain the skills and gains made in eye health.

LHWs also recommended that the refresher courses should cover the topic of compliance with referrals because at present they were only trained to refer patients and not to ensure the referral uptake. LHWs also wanted more information about the adverse consequences of poor eye health or untreated eye conditions. They explained that the training covered well various eye diseases and how to prevent them but paid little attention to the consequences of non-compliance.

> *"Previously we were not sending this high number of patients to the hospital. After the training, we refer most … people to the hospital, even patients with minor problems are being referred." [Lady Health Worker 05, Mansehra]*

Equipment and supplies

Following the training, all LHWs were given a PEC kit, which included a PEC manual, an E card to test visual acuity, a measuring tape, a flashlight or a torch with batteries, bandages, eye ointment and referral slips. There were two types of vision testing charts available to the LHWs, a small chart to carry with them in the community and a large chart to use in their office/house. The small (3-metre) chart was provided by the project; the large (6-metre) Snellen chart was provided in some districts by the national programme.

> *"We keep the E card in our … house and check those patients who visit us, we do not carry it along. There is a lot of work in the field. We use the small card." [Lady Health Worker 13, Mansehra]*

Most LHWs found the PEC manual practical and useful for the assessment of eye health issues at the community level and specifically, identification of people with uncorrected refractive errors (UREs):

> *"When we have this book [primary eye care manual] with us, then we compare different conditions with those mentioned in the book and can guide people properly... If there is something that we can deal with, then we take care of it. Otherwise we refer them for a proper treatment." [Lady Health Worker 04, Mansehra]*

Several LHWs, however, said that they had not used their PEC kit for at least 2 years; and some kept their kits unopened as they had never used them. There was no explanation during the interviews with the LHWs why this was the case, but the district managers interviewed attributed it to the gaps in the training and the lack of clarity about the LHWs' role and what was expected from them.

The LHWs who used their kits complained about the shortage of referral slips, flashlights/torches, batteries, eye ointment and pads. In some kits received during the training, the flashlight was missing or damaged. The consumables were difficult to replace, as LHWs were provided with them only once at the beginning of the project and in limited quantity. LHWs suggested that the procurement of eye care consumables should be integrated within the LHW programme procurement systems to ensure an uninterrupted supply.

Application of new knowledge and skills in practice

Most LHWs talked about the skills and knowledge they had acquired during the training with only a few referring to the application of their competencies in practice. For those who shared their experiences, there were some apparent tensions between the desire of LHWs to identify and treat minor eye issues and the need for referrals to the upper level facilities. Some LHWs for example, wanted to be supplied with basic consumables and drugs to manage minor eye cases in the community. Others, however, referred all patients irrespective of how minor their condition was:

> *"Previously we were not sending this high number of patients to the hospital. After the training, we refer most … people to the hospital, even patients with minor problems are being referred." [Lady Health Worker 05, Mansehra]*

Although many LHWs were generally happy about their new competencies in eye health, in practice, most of them paid more attention to other duties and other conditions they addressed, i.e. maternal and child health or polio eradication campaigns because these were the diseases prioritised by the government.

At the community level, the majority of community members praised LHWs for their work in maternal and child health and polio eradication. Their work in eye health, however, raised doubts because eye health was thought to be complex and some people were hesitant as to whether LHWs were competent enough to correctly identify, manage or refer patients with eye diseases.

Referral process

The LHWs interviewed explained the process of referrals they made, as part of the project. After the training, all LHWs were provided with referral slips, which they were explicitly instructed to issue to all individuals with vision or eye health problems. The referrals could be made to the facilities at the primary and secondary level and in the public or private not-for-profit sectors. Each referral slip contained a serial number and space to enter the date of the referral, name of the patient, address and contact number of the patient, the type of the eye problem identified, name of the referring LHW and the referral facility. There were three copies of each referral slip, one for the patient, one for the health facility and one for the LHW. Each LHW maintained the record of the patients referred.

The key concern expressed by the LHWs during the interviews was that their referral slip was not recognised or accepted by many facilities they referred patients to. Patients who had been referred and visited a hospital with the slip explained how the hospital staff tore off their referral slip and put it in the trash. LHWs felt that the hospital staff had no respect for LHWs and the patients they referred. They also felt that this type of behaviour damaged their reputation and the trust community members had in their work. Many found it demotivating. This is how one LHW explained her frustration:

“[…] they would put our referral … into the dust bin... Patients do not feel good when our referrals …are put into the dust bin before their eyes...” [Lady Health Worker 20, Swabi]

An LHW in the other district had similar experiences:

“They say there is no value of your slip. They do not check it well … Moreover, they don’t give medicines.” [Lady Health Worker 19, Mansehra]

The same views were shared by one LHS:

“They do not give any importance to the referral slip; many times, our workers accompany their patients, but they [the hospital] say that we do not need this piece of paper.” [Lady Health Supervisor]

It was explained that to change the situation the project had to talk to the referral hospitals as well as to a partner not-for-profit hospital, who would sign the referral slips on behalf of the LHWs:

“They [health care workers at the hospital] never valued the slip. [After that] we were given a training session [and] our seniors talked to LRBT [a private not-for-profit hospital]. So, now they sign the referral slip.” [Lady Health Worker 26, Mansehra]

LHWs further reported that they had believed that the patients referred by them would get some privileges at the hospital, for example they could be prioritised in the hospital queue. They believed that as LHWs were highly respected in their communities, their referral slip would carry a special value at the secondary-level facility. It appears that the patients referred by the LHWs also had these impressions. However, when they visited a hospital, they did not receive any special privileges. They had to wait in a queue in the same way, as any other patient. This was disappointing and discouraging. Some patients shared their frustrations with other community members and discouraged them to take up LHWs’ referrals. It was unclear from the interviews whether the expectations of ‘special treatment’ by hospitals were due to the role the LHWs played in the communities with limited access to services or because their eye care work was supported by an international development project.

Remuneration and working conditions

Managers at the district level described the role of LHWs as a ‘bridge’ linking patients with health care facilities. They praised LHWs for their commitment and hard work, where they had to move from house to house daily:

“LHWs are such an asset that we can utilise them anywhere. They help us in campaigns, different problems of the eye, polio, in everything.” [Manager at the district, Mansehra]

However, study participants also recognised that the LHWs’ capacities were stretched; they were often overburdened and overworked. Most LHWs felt that any health problem in the community was ‘dumped’ on them and the same fixed number of LHWs was expected to do them all with no additional compensation or operational support.

“[…] what is Rs 18,000 [US $112] per month and we remain in the field till late; and when we return home, it takes us many more hours to prepare the report and then people would come to our homes for check-ups, examinations. So, we have long hours of working and look at what we get.” [Lady Health Worker 30, Swabi]

Some LHWs argued that the eye care programme increased their paperwork and required additional visits to the villages to remind people about hospital referrals. Some said that the monitoring visits organised specifically by the project to boost the uptake of referrals was particularly stressful for them.

Many LHWs expressed frustrations about their fixed salaries with no monetary or non-monetary compensation for additional programmes, such as eye care. In addition, their standard salary was often delayed with no communication or explanation of the reasons. As a result, they had to find other ways to feed their families and, in these circumstances, they could not do extra visits to the patients to encourage them to take up referrals. There were also frustrations about hard working conditions and inability to receive medical supplies or replace damaged kits used in eye care.

Patients' health-seeking behaviour and barriers to referral uptake

Perception of eye health

The main driver of patient health-seeking behaviour was their perception of eye health problems. Many participants believed that minor issues were self-limiting or could be treated at home. Many preferred to wait and would only get to the hospital when the situation got worse. The same attitudes were found in relation to poor eyesight, watery eyes and even cataracts. Poor eyesight was perceived as part of the ageing process and many older people simply tried to adjust their lifestyle to accommodate visual impairments. For example, they tried to work in the daylight, read the Quran with large font and avoid activities involving near vision. Participants with poor vision tried to accommodate their impairment, usually until they have lost the ability to recognise their family members or faces. Often it is at this point, that they would seek help. Even LHWs and LHSs themselves believed many eye-related problems were minor and could be addressed at any time:

> *"…I know I have weak eyesight and I will get it checked [but] not today … after a few days. What is the worst that could happen? I would get to wear glasses. That is fine. This is the thinking that we people have, that we won't be greatly affected by something so minor." [Lady Health Supervisor]*

Information about eye diseases and services

It was also reported that patients had little knowledge of adverse consequences of delaying treatment, which contributed to their laid-back attitudes towards eye care. Several participants emphasised a need for repeated messages about risks of not attending eye examinations and referrals:

> *"… they [LHWs] should make people understand, which they don't do … Few people … care for themselves and there are many who don't. That is not an issue for them. If [LHWs] provide awareness that this may lead to blindness and you may become disabled, then one would care." [Patient, Male, Non-adherent to Referral, Mansehra]*

Another important factor was the lack of information about the costs and services at the referral facilities. Many patients did not know what to expect at the secondary-level hospitals. Some had bad experiences in the past, where patients would be turned away because they could not pay for medicines or surgical procedures. These experiences resulted in negative views and rumours circulating in the communities:

"They [hospitals] have all the required facilities for testing vision, but no medicines are provided free of charge. I had referred an old man who needed an operation for cornea, and he had the Sehat Insaf Card [health insurance for the poor]. But he was not satisfied with the attitudes of the staff and returned without an operation. And this is causing dismay to many." [Lady Health Worker 16, Swabi]

Most LHWs and LHSs themselves were unaware of how eye care hospitals work, many had never visited an eye care department and did not know how much time patients needed for their referral or how much money the hospitals would charge:

"… are there any charges in the DHQ [district hospital]?... I have no clue about their charges." [Lady Health Supervisor]

Financial constraints

One of the key factors mentioned during the interviews with both patients and LHWs was the lack of financial resources to cover the costs of specialist eye care services and transport; and this was the reason for not taking up the referrals for many patients. Patients argued that many of them were small-scale farmers, small-scale shopkeepers, daily wagers and casual labourers and they could not afford fees charged by the hospitals coupled with the loss of their wages:

"You know that if you came here [to the hospital], expenses are almost Rs1,000–1,200 and the loss of daily wages is 1,000 as well. So, the cumulative loss is more, which is unbearable for a person working on daily wages, how to make bread at home?" [Patient, Male, Non-adherent to Referral, Mansehra]

As a result, the only way to address an eye problem for many patients was to use home remedies. For example, the use of surma, kagal, arqu-e gulab [rose water] was frequently mentioned during the interviews as remedies to keep the eyes healthy and to treat eye allergies. However, this rose water could potentially be harmful for eyes.

Lack of trust in public sector hospitals

Several patients said that they did not trust the quality of services provided in public hospitals. Many had a view that eye surgeries carried out in a government hospital were of poor quality and that patients can go blind after the surgery in these public facilities, as one patient explained his fears:

"We have heard that they [public hospitals] did not operate successfully, people turned blind. Government hospitals take patients eyes out and patients become blind. Therefore, we avoid going to the government hospital." [Patient, Female, Non-adherent, Mansehra]

Another patient expressed similar views:

"People these days visit private hospitals more frequently. Anyone who is doing better monetarily prefers private hospitals because they take better care of patients in private hospitals." [Patient, Female, Adherent to referral, Swabi]

Sometimes, patients had fears of public hospitals irrespective of whether they personally had visited them or not. It seems that patients were more driven by their expectations of poor services rather than the actual experiences of these services:

"… I got an accident at Karachi and … I had to bear 3–4 lakh. [US $1,875–2,500] in medical costs … If I go to Civil or Jinnah hospitals [public sector hospitals] they might have cut down my arm, because they do not have too much time. I got an operation

[in a private hospital] for five hours; they removed body tissues from my leg and applied on the arm." [Patient, Male, Non-adherent to referral, Mansehra]

A number of patients said that they preferred visiting private hospitals because they could get all services in one place. Government hospitals were often lacking diagnostic equipment or laboratory services and had to send patients to private facilities, as one female patient explained:

"… at the hospital, they send you to Major Sb [a retired military doctor running a private clinic], so it is better to go Major directly." [Patient, Female, Non-adherent to referral, Mansehra]

Patients further reported that public sector hospitals did not provide medicines, eyeglasses and they were not sure about the availability of doctors. At private not-for-profit hospitals, doctors and medicines were always available; surgeries were successful and free and even lenses were provided free for certain categories of vulnerable patients. LHWs also noted that some government hospitals did not have staff with the right attitudes, many hospitals were busy and lacking essential personnel, and patients – particularly old and vulnerable patients – did not feel comfortable in such facilities:

"It is the attitude of staff and doctors. We feel that facilities … [should] test vision, prescribe medicines there and if he or she needs an operation, the doctor should properly guide them and refer them … and then at the … hospitals, these referred patients [should] be treated humanely and with good manners." [Lady Health Worker, 15 Swabi]

Distance to hospitals and difficulties in travel

Another challenge reported by a number of patients was the distance to the health care facilities. Many patients found it very difficult to cover long distances to reach the main cities, where public health care facilities were located. This was particularly frequently reported in Mansehra district, where health care facilities were located in the city centre. They were difficult to reach for patients coming from far away areas with challenging terrain.

Travel appeared to be a particular challenge for older female patients, who had to find time, financial resources and get a permission from the husband or the son, who often did not take women's health issues seriously. Female patients had to find money to cover the costs of her own transport and that of a family member to accompany her on the journey to the hospital. This was a major barrier for many female patients. Often, family members were not available to take them to the hospital. For these patients, the only care options were homemade remedies or a visit to a general doctor practising in the community, who they could visit with a female neighbour. One woman captured well this challenge:

"Sir, they [husbands] say as it is not a serious disease we are not permitted [to travel]. If they are not travelling with us, obviously alone women cannot go." [Lady Health Worker 29, Mansehra]

Chapter 4: Discussion

This study set out to assess the role of LHWs in improving access to eye health services in remote locations of Pakistan and specifically the uptake of referrals by patients with eye diseases. The study also explored the main drivers of patients' eye health-seeking behaviour and barriers to eye care services.

The study provides insights into the experiences of LHWs as the first points of contact for eye health. The findings draw on previous research on the nature and role of community health systems in facilitating the access to health care services for disadvantaged populations [15-18] and addresses specifically the cadre of community health workers that, to date, has received relatively little attention.

There are a number of key findings that have policy and programme implications. Overall, results show that LHWs and their supervisors were enthusiastic about the opportunities to be trained in primary eye care and be involved in providing eye care services to the underserved populations in their communities. However, similar to other research [19], our study demonstrates that training of primary eye care workers alone is not sufficient to increase patients' access to specialist services. There are other elements of the health system that need to be adjusted to make the integration of the new function within the system a success. For example, in this context, the procurement of the LHW programme has not been changed to integrate the supply of basic ophthalmic equipment, such as torches or simple medicines, such as eye drops. The trained LHWs received their eye care kits only once, immediately after the training, and there was no provision for re-stocking or replacing the supplies. Similar problems were highlighted by Jolley et al. in Tanzania, where primary health care workers were trained in eye care but the primary care facilities, where they worked, made no provisions for ophthalmic equipment or medicines in their procurement systems [19]. As a result, many stopped delivering eye care services, when their torches got broken or when they ran out of eye drops.

The training itself was generally well received, although there are questions as to whether the model of training of trainers (who themselves are not familiar with eye care) over three days followed by a one-day training for LHWs is sufficient to acquire the necessary knowledge and skills. The presence of an eye care specialist during the LHW training by their supervisors could potentially improve their understanding of eye care and particularly how secondary eye care facilities work. Another aspect of the training programme that will require attention is the lack of refresher courses for LHWs to update their knowledge and share their experiences with others. On the positive side, training of LHWs by their supervisors has possibly ensured a good level of supervision of their eye care work, as in contrast to other studies [19, 20], the issue of the lack of supervision has not been raised in this project. This effective approach can be replicated in other programmes, which involve primary or community level workers in eye care.

Another important factor raised during the interviews was the lack of clarity about LHWs' responsibilities and what was expected from them. It seems that the LHWs were confused whether they were expected to treat patients with minor illnesses in the community or they were expected to refer everyone with an eye issue irrespective of how minor it was. It seems that the LHWs interviewed had different opinions about it and their practice varied. In this study we did not review any formal policies on the role of LHWs in eye care or what their responsibilities and competencies were. If the LHW programme continues to integrate the eye care function and is to be rolled out across the country, it would be critical to clearly articulate what LHWs could and could not do in eye care. It is also essential that they are sufficiently trained to distinguish between the conditions that do and do not require a referral

because a large number of referred patients with minor or self-limiting conditions can overwhelm already overcrowded and overstretched eye care hospitals [21]. It can also undermine patients' trust in the LHW programme, as patients will be unnecessarily travelling to faraway and expensive facilities.

It is also interesting that this task shifting programme was introduced in the districts with relatively high coverage for cataract services, which means that patients do get to hospitals for at least serious sight threatening conditions such as cataracts. The problem highlighted in the recent RAABs was gender inequality with a significantly lower cataract coverage among women. In this context one would expect that the primary purpose of the LHW's role would be to identify female patients with cataracts and help them to receive the service. But this potential focus on women did not come out strongly in the interviews and it remains unclear whether LHWs have been specifically encouraged to find women with cataracts or not.

A number of factors affected the uptake of referrals by LHWs in this project. First, although the role of LHWs in maternal and child health and polio eradication campaigns has been well appreciated by their communities, some community members had doubts whether LHWs can be as effective in addressing more complex issues, such as eye diseases. It is possible, therefore, that some patients did not take seriously the LHWs' advice to go to distant secondary facilities, where they will be expected to pay and wait for long hours. Second, there seemed to be a misunderstanding of what a LHW's referral means for hospital services. It appears that both the LHWs and the patients expected a 'special' treatment at the hospital for those referred by the LHWs. It remains unclear whether this information was wrongly communicated to the LHWs during the training or it was their own interpretation of what their referral slip meant. It appears that many secondary-level providers were unaware of the LHW programme and the referral slip, which LHWs spent time to complete, did not have a required level of authority. As advocated by several participants in this study, improved engagement and communication between LHWs and hospital-based health care providers is required to ensure that the referral pathways work effectively, and the referred patients receive the care they need.

In addition, many barriers to the uptake of referrals identified in this study were system-related and could not be addressed by the LHW referral programme alone. Similarly to other rural contexts in South Asia[22, 23, 24], we identified user fees and long distances to the facilities as major factors affecting patients' decision-making. Also, in this specific context, the perceived poor quality and dissatisfaction with services in government hospitals were a major barrier. The finding is consistent with previous research that showed that overcrowded facilities with busy and unfriendly staff created significant barriers to the uptake of referrals by LHWS [21, 25].

Two types of barriers, however, could be potentially addressed by this programme, the lack of information about eye diseases and eye care services and inability of women to negotiate their travel and financial payments with their husbands or sons. Gender inequities in particular is an area where LHWs can be very effective and their role in addressing these should be strengthened in future programmes. Pakistan is a society with extremely salient cultural dynamics and sensitivities. Gender inequities are deep-rooted, and the broader society is unwilling to facilitate access to women's empowerment opportunities. The underlying gender structures which offer men numerous material benefits and decision-making authority contribute to women's relatively lower uptake of health services [23, 26]. Previous studies in the country have shown that even those who have some source of income to facilitate travel to the hospital often choose not to – reflecting the values and ideals of being a good wife and putting the family first [24, 26, 27]. The government is aware of the problem and recognises that gender inequity is a key determinant of negative health outcomes among women [24, 28]. Indeed, the government recognises that more innovative

service delivery models are required to improve women's access to health care services[21, 28] but progress towards addressing the problem has, been slow [29]. Using LHWs as case finders to identify women with cataracts and organising services closer to the communities, where women do not have to travel far, could be potentially an effective strategy to increase coverage with cataract services among women in these districts.

Finally, our findings suggest that the eye care programme in KPK increased pressures on LHWs who already had heavy workloads and grievances such as late pay to deal with. While training and deploying LHWs to identify and refer patients appeared to be acceptable, it also represented a significant challenge to the community health system, as some LHWs perceived this additional responsibility as a burden, which did not come with additional pay or support. In resource-limited contexts with overstretched and often inefficient health systems, adding more responsibilities to the workload of a fixed number of overworked and underpaid community workers should be very carefully managed, as this could potentially do more harm than good[8, 30].

This study has a number of limitations. First, the study was conducted in only two purposively selected districts of KPK province. The range of patients, LHW and manager experiences may not be exhaustive when considering referral pathways and experiences in other parts of the province. Second, our data on LHW's role were based on what we learnt from our study participants rather than on an objective measure of performance. Third, while we selected participants to ensure that the different community health system configurations were included, we do not know to what extent the included LHWs and their supervisors are representative of others in the same district.

In conclusion, results from this study have shown that the training of community health workers in eye care was well received. However, training alone is not enough and does not result in improved access of patients to specialist services if other parts of the health system are not strengthened. The role of LHWs in eye care in a given programmatic context should be articulated, and their responsibilities and competencies should be clearly defined. Pathways for referrals should be agreed and explicitly communicated to both the health care providers and the patients. Attention should be paid to how LHWs are remunerated and supported to prevent their overburden and demotivation. The role of LHWs could be made particularly effective and should be strengthened in providing patients with accurate information about eye diseases and services available and in delivering alternative more gender-focused services tailored specifically to the needs of women.

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