

Lady Health Workers (LHWs) as Flag Bearers for Children with Disabilities in Pakistan

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ABSTRACT

Purpose: *This study explores the perceptions, knowledge and attitudes of LHWs towards children with disabilities in Pakistan. It considers the feasibility of utilising the LHWs for prevention, early identification and management of disabilities for these children in the community.*

Methods: *Two Focus Group Discussions (FGDs) were conducted with 15 Lady Health Workers (LHWs), and two In Depth Interviews (IDIs) with LHWs of both a semi-urban and a rural community of Pakistan.*

Results: *LHWs were found to have major concerns and strong emotions regarding children with disabilities. They also revealed the insensitive attitude of community members towards these children. While they understood the major types and magnitude of disabilities better than lay persons, they lacked the knowledge to manage these disabilities. Consanguineous marriages were identified as the main cause of disabilities. LHWs reported that education and health facilities were lacking in semi-urban and rural areas, and demanded that the government provide these facilities for the children. They also expressed their willingness to work for these children, provided they had the approval of higher authorities and were given proper training.*

Conclusions: *This qualitative exploratory study recommends that the existing primary health system be reviewed, and the possibility of introducing community based rehabilitation services, utilising LHWs' services for children with disabilities, be examined. In this regard, it is imperative to assess the existing training modules of LHWs and to introduce modules on prevention, early*

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identification, and management of children with disabilities. It is also necessary to employ mass media to spread awareness about persons with disabilities.

Key words: *Rehabilitation, Community workers, Inclusive education, Primary health care (PHC) services*

INTRODUCTION

According to global estimates, people with disabilities comprise 10 % of the population (WHO, 1981), and 80 % of them live in developing countries (United Nations, 2006). In 62 countries around the world there is a complete lack of rehabilitation services for people with disabilities (UN Special Rapporteur on Disability, 2009).

Millennium Development Goals (MDGs) do not address issues regarding disability directly; however, MDGs cannot be achieved without paying due attention to disability (International Disability and Development Consortium, 2009). According to research studies, children with disabilities are less likely to attend schools than their counterparts without disabilities. The United Nation's Economic and Social Commission for Asia and Pacific Survey (ESCAP Fact Sheet, 2007) indicated that the school enrolment rate of children with disabilities is 2 % in the Philippines and 4 % in Bangladesh and Pakistan.

According to the Pakistan Census (1998), the prevalence of major disability is 2.49 % (3.2 million are affected), with 66 % of the population with disabilities living in rural areas. Among the major disabilities identified, 19 % had physical disabilities, 14 % had intellectual disabilities, 8 % had multiple disabilities, 7 % had hearing impairments, 9 % had vision impairments and 43% had unknown causes. Among the population with disabilities, 33% were children up to 14 years of age.

Disability specific data for Pakistan, as reported by Japan International Cooperation Agency (JICA), provided the following statistics: 40% had physical disabilities, 20% had mental disabilities, 20% had visual impairments, 10% had hearing impairments and 10% had multiple disabilities (Japan International Cooperation Agency, 2002).

To serve the needs of the population with disabilities, WHO has recommended Community Based Rehabilitation (CBR); an approach that makes optimal use of primary health care and community resources for the benefit of people with

disabilities. The CBR approach has been successfully implemented in many developing countries, including Iran, Mongolia, India, South Africa and Vietnam. In these countries primary health care personnel, along with the community, are involved in taking care of persons with disabilities. According to WHO (1981), 80% of children with disabilities can be helped through the coordinated use of community resources. Apart from this, WHO also recommends early detection of disabilities, within the first few days or months of life, and early intervention for better results as compared to delayed diagnosis.

The healthcare system in Pakistan mainly comprises primary, secondary and tertiary healthcare facilities. Pakistan is a resource-poor country with regard to public spending on health and education. Annual spending on healthcare is only 0.75 % of the GDP (Ministry of Finance, 2006-07). With minimal healthcare resources, limited availability of healthcare facilities and no separate programme to cater to their needs, Primary Health Care (PHC) can be explored as a promising option for the population with disabilities in Pakistan.

The primary health care (PHC) system in Pakistan includes Maternal and Child Health Centres (MCH), Family Welfare Centres (FWC), Basic Health Units (BHUs) and Rural Health Centres (RHCs), assisted by over 100,000 Lady Healthcare Workers (LHW), catering to the needs of more than 90 million of the population. Lady Health Workers deliver a range of services related to maternal and child health, including promoting childhood immunisation, growth monitoring, family planning and health promotion. They treat minor ailments and injuries, and are trained to identify and refer serious cases. They serve around 1000 individuals, comprising about 150 households in their catchment area. At present LHWs cover about 55% of Pakistan's population, close to 65% of which resides in rural areas.

Based on the already established PHC system, LHWs may prove to be a strong bridge between health systems and the community, with some additional knowledge on prevention, early identification and management of disabilities incorporated in their training modules.

A number of research studies were done in Pakistan during the 90s, to explore various perspectives regarding children with disabilities and their families (Shahzadi, 1992). However this is the first time that the perceptions of LHWs are being considered.

With this premise, the study explores the perceptions, knowledge and attitude of LHWs regarding children with disabilities in the community. The findings would

aid in understanding the feasibility of utilising this workforce for prevention, early identification and management of disabilities for community children in Pakistan.

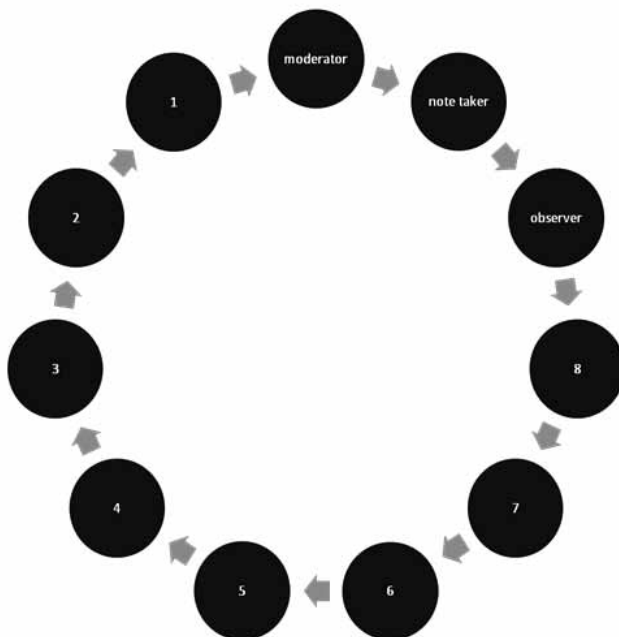
METHOD

A qualitative descriptive exploratory study design was employed. The study settings were a rural community in the Province of Baluchistan and a semi-urban community in Sind. This qualitative research with LHWs was unintended and came about while conducting focus group discussions (FGD) with teachers and mothers as part of a larger research study to assess the effectiveness of the WHO Training Manual for persons with disabilities. The need for induction of LHWs was felt strongly, as they are the key stakeholders to ensure that health needs of community children are met. Community members have a lot of respect and high regard for their work, especially in the rural areas. LHWs working in both areas were invited to take part in the study. Methods of data collection were FGDs and In Depth Interviews (IDIs). Semi-structured FGD and IDI guidelines were developed based on literature reviews and past experiences. Two FGDs and two IDIs were conducted, one in each community. Two moderators, who were qualified psychologists and experts in the local languages, were given training in conducting qualitative research, FGDs and IDIs, and regarding common disabilities in children. The duration of the training was three days: two days for theoretical background and the third day for practicals at the field site.

Before conducting FGDs, informed consent was taken from each study participant. Each FGD began with introduction of the participants and the FGD facilitators, followed by an informal discussion on the reasons for holding the FGDs and how this information will be used for the betterment of children with disabilities. These informal discussions served two purposes: first, to break the ice and enable the participants to express their views more effectively and second, to build rapport with them. Each FGD lasted for 50 – 55 minutes. Seven LHWs from the rural community and eight from the semi-urban community participated. Almost all the LHWs from both the communities showed up to take part in the FGDs. The study was approved by the Ethical Review Committee of Aga Khan University.

The team which conducted FGDs involved a moderator, a note taker and an observer. All the discussions were tape-recorded, and notes were taken down as well. The participants were seated in a circle on the floor with the moderator in

front, to enable her to connect well with all of them. A diagrammatic representation of the seating arrangement is shared here:



In Depth Interviews were conducted by the psychologists. They were tape-recorded and notes were documented. Data analysis was performed manually. Transcripts were entered in MS Word and were reviewed many times to identify major themes regarding LHWs' perceptions on disability, the common causes, and concerns about the availability of healthcare and education. Vocational training and rehabilitation facilities for children with disabilities were explored. LHWs were also assessed for their knowledge about the rights of children with disabilities. Content analysis was performed to quantify the responses in each category. While irrelevant information was discarded, new and emerging themes were identified. The information provided by FGDs was also triangulated with IDIs to bring more richness.

RESULTS

Findings on all the major themes are presented here:

Perceptions regarding 'What is Disability'

While exploring perceptions regarding disability, the participants (LHWs from

here on), not only shared their own perceptions but also exchanged information on community perceptions regarding childhood disability.

One of the LHWs quoted with great emotion:

“Disability means being worthless all through his/her life.”

The LHWs were well aware of the presence of children with disabilities in their own catchment areas, and had very good knowledge and understanding of the major physical and intellectual disabilities found among them. One LHW stated very convincingly that if a child suffered from physical disability, it did not necessarily mean he /she also had intellectual disability. Only one LHW regarded physical disability as the only form of disability.

LHWs revealed that children with disabilities are often unable to perform age-appropriate daily functional activities, such as feeding, walking, drinking and toilet functions and need the help of others. However, some LHWs cited the examples of very short-statured females who are leading a normal life. Contradictory statements were found regarding the management of physical and intellectual disabilities. Some LHWs thought that managing physical disability was difficult, while some were of the view that intellectual disabilities were the most difficult to handle.

Attitude of Community People towards Children with Disabilities

“People have wrong perceptions about disabled children; they do not pay attention to them and think they are useless and psycho” (LHW).

In response to this theme, LHWs observed that the attitude of family members was generally very loving and caring, but community people normally tease and make fun of these children. For this reason, mothers do not allow their children to socialise and participate in community gatherings. LHWs underscored the importance of encouraging these children with love and care. They also emphasised the need to create mass awareness and to conduct sessions whereby people would change their attitudes and behaviour towards children with disabilities.

Knowledge about the Cause of Disability among Communities

According to LHWs, mothers regard the following as the main causes of disability among children:

1. No / incomplete immunisation during early childhood.

2. Inadequate care during antenatal period, including non provision of pregnancy related vaccination (Tetanus Vaccine).
3. An effort to abort unwanted pregnancy using home remedies / medicines, in spite of which the pregnancy persists and the child is born with disability.
4. Mothers' ill health.
5. Mothers giving birth to pre-term babies.
6. Mothers giving birth without spacing.

LHWs also shared their own perceptions regarding the cause of disability. A few viewed consanguineous marriages as the main cause of disability as they had observed a particular disability running in certain families.

One of the LHWs expressed her opinion,

"No parents want their children to be disabled, it's all in God's hand".

Availability of Educational Facilities for Children with Disabilities

LHWs asserted that parents' education was of utmost importance for children's upbringing. They emphasised that it was necessary to guide and build capacity of illiterate mothers about managing the needs of their children with disabilities.

Regarding the availability of educational activities in the neighbourhoods, LHWs provided the information that special schools are only available in big cities. In rural and semi-rural communities there is a total lack of educational facilities for these children. Stating that the government was not doing anything to improve the situation, the LHWs demanded separate schools and parks where these children could get education and enjoy play activities.

LHWs reiterated that education can completely transform the lives of these children. To back up this statement, they gave the example of a blind girl who did her matriculation with family support and is now leading a 'normal' life.

Training Required to Improve the Lives of Children with Disabilities

LHWs suggested that mothers should be trained to take care of their children with disabilities in such a way that the children would be able to manage their own basic needs independently. LHWs reiterated that programmes should be organised to develop the skills of mothers, in order to gain maximum benefits.

Perceptions about the Availability of Inclusive Education for Children with Disabilities

“Disabled children cannot be left just to stay at home lying on bed all the time, they should at least be taught how to read and write their names” (LHW).

Most of the LHWs were not aware of the term “inclusive education”, when used in English as well as the national language. After the moderator explained the meaning of the terminology, they opened up and participated very actively in the discussion.

The majority of the LHWs were of the view that children with disabilities should be sent to regular schools as they would benefit from peer learning and wider exposure. They cited the example of a boy who had completed engineering from university despite his physical disability.

They also reiterated that it was necessary to send children with disabilities to school and to support them for education. They asserted that these children should not be left at home.

One LHW stated that though children with disabilities could be accommodated in regular schools, there was a strong need for special schools, as only teachers in special schools would be able to teach them properly.

Information on Government Facilities to serve Persons with Disabilities

LHWs felt that there should be proper institutes for these children, with schools also providing vocational training. Hospitals and parks should be built for them. They added that the government needed to do something about these facilities because the people were very poor and could not afford to provide for their children with disabilities.

Rights of Children with Disabilities

LHWs stated that children with disabilities should at least be given the following rights:

- They should be well taken care of; they should be loved and cared for.
- Facilities for physiotherapy should be available for children with physical disabilities.
- They should be provided with adequate nutrition and attention.

- Playing games with these children will help them learn new things and inspire them to do much better in life.
- They should be taught how to eat and use the lavatory independently; this will help them gain self- confidence.
- The children should be provided with proper education.
- They should be given freedom of choice for everything, including choosing their profession.

LHWs as Flag Bearers to work with Children with Disabilities in the Community

“These children always stare at us as if we brought something for them” (LHW).

“We (LHWs) talk and shake hands with these children. They also talk to us but we understand only few words and that too with the help of their mothers” (LHW).

“We (LHWs) can work with mothers to bring change in the lives of these children” (LHW).

“If government will initiate programmes for these children they will have our (LHWs) full support” (LHW).

LHWs also explained that they come across many children with disabilities while making visits in the community. In many cases, they do not feel comfortable while interacting with them (probably due to the lack of training in managing these children). They reiterated that there is a great demand from parents that they work with these children.

Challenges Faced by LHWs

LHWs revealed that initially there were myths among community people that polio drops were the cause of disabilities among children. With time these perceptions have minimised, but there are still some families who refuse to administer polio drops to their children.

EMERGING THEMES

Psychological Repercussions of Disability

LHWs expressed the opinion that children with disabilities usually suffer from an inferiority complex. They also felt that the parents of these children suffer from severe stress, as taking care of their wards is quite difficult. According to

them, the major reason for stress among parents is the worry about what will happen to these children and who will look after them after the parents' death.

Observations of Non-Verbal Gestures

The LHWS were very enthusiastic about doing something for these children, mainly because they were meeting the children and their parents regularly, and could feel the pain and stress that they were all going through. They were quite confident while sharing information regarding children with disabilities and their families, and showed great excitement and willingness to work with them.

DISCUSSION AND RECOMMENDATIONS

Working for children with disabilities requires a multi-pronged and integrated approach involving well-coordinated interventions from all sectors.

It was very encouraging to know that the LHWs were well informed about the statistics and specific details of the disabilities that the children were suffering from, in their communities.

It can be assumed from the above findings that these LHWs are able to identify major physical and mental disabilities among community children. This seems to be due to their ongoing and regular interactions with their communities.

While LHWs appeared to have a very deep understanding of the magnitude and the different types of disabilities among children in their communities, information regarding management of these disabilities was found to be completely lacking. Involvement of community workers to work for the population with disabilities at community level is not new; this has already been in place in various countries including Iran and India (Mathur et al, 1995; Chopra et al, 1999). A study done in Karachi during the 1980s also identified the need to work with families of children with disabilities in close coordination with the communities (Shahzadi, 1992).

LHWs were well aware of the major causes of disabilities among children and identified consanguineous marriages as a main cause. They were also found to be knowledgeable about community perceptions regarding the major disability causes.

The attitude of community members towards children with disabilities was not very encouraging, according to reports by these LHWs. They suggested

conducting awareness-raising sessions and educational campaigns to change the mind-set of the masses.

As majority of the caregivers in the community were illiterate, LHWs urged that more support be given by training them in managing childhood disabilities. In this context, the WHO Training Manual has been found to be of great help while working in communities with community workers. Another important finding highlighted by this research study is the need for involvement of the government, in collaboration with other stakeholders, to provide educational, sport, leisure and recreational activities and facilities for children with disabilities, in order to fulfil their basic rights and bring change to their lives. These services are particularly required in rural and semi-urban areas which are deficient in the facilities most needed by the population with disability, such as rehabilitation and special education services. After all, the majority of Pakistan's population with disability (66%) lives in rural areas.

All the LHWs strongly recommended greater availability of educational facilities for children with disabilities. They suggested the provision of inclusive education for these children, though a few also supported the setting up of special schools. It was not clear which categories of disability were recommended for regular schools and which for special schools.

Convention of the Rights of the Child (CRC) does touch upon children with disabilities (Article 23). There is also the UN Convention of the Rights of Persons with Disabilities (CRPD), which discusses the rights of children with disabilities (Articles 3,4, 18,23, 24 and 30 touch upon, whereas Article 7 exclusively talks about, children with disabilities).. There is an urgent need to develop an additional international document to highlight and promote the rights of children with disabilities. Participants emphasised that children with disabilities not only require fulfilment of their basic human rights, but should also have their special needs taken care of.

LHWs expressed their willingness to provide full support if the government commences any work with these children. A few of them, who already visit households where children with disabilities reside, urged provision for educating LHWs to manage these children. They revealed that there is a great demand for them to work with children with disabilities from mothers / caregivers. LHWs claimed that they are already involved in some prevention activities, such as polio prevention. However they still face many challenges, including parents' refusal

to permit immunisations due to the belief that vaccinations cause disabilities among children.

Induction of LHWs to work for people with disabilities has many advantages. Firstly, LHWs have a network system which takes care of the healthcare needs of majority of the population. Secondly, in rural and semi-urban settings, the first contact and interaction for childhood healthcare needs is with LHWs, and it is widely claimed that the earlier the identification of disabilities is done, the better the results. Thirdly, LHWs are already trained in issues concerning child health, including childhood immunisation, growth monitoring, family planning and health promotion. Hence, it would not be difficult to add one more module to their training programme, which deals with prevention, early identification and management of disabilities among children.

Besides the above justifications, while talking about societies promoting and practising social inclusion, this should be a norm rather than an exception. In case a LHW finds a child who is suspected to be at risk of disability, she will simply refer that child to the nearest primary healthcare centre for further investigations and diagnosis. She will be acting as a facilitator as well as a link between the community and the healthcare facility.

According to a report by UNICEF, *“Primary healthcare workers, along with other community workers, have a key role to play in identifying infants and young children with developmental delays and impairments, and in supporting families to help their child to learn and develop”*.

There is an urgent need to establish early intervention services at the level of Primary Health Care, with a referral system for proper diagnosis and rehabilitation of at-risk children. The induction of LHWs can be the first step in this direction.

The findings of this study have been crucially helpful in understanding the perceptions of LHWs and their willingness to work for children with disabilities in the community. In addition, to gain further insights, it would be worthwhile to capture the perceptions of LHWs' supervisors regarding this new role of LHWs.

The findings of this study are timely, as according to the National Plan of Action for Disabled People (2006), Government of Pakistan, Ministry of Social Welfare and Special Education, there is a plan to develop and implement training for LHWs in early detection and identification of developmental delay among early age-group children in 2012 (Ministry of Social Welfare and Special Education, 2006).

Acknowledgment

The authors would like to thank Ms. Nasreen Sulaiman for her review and feedback. This research study was funded by Aga Khan University Research Grant.

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