

Developing partnerships at the community level to promote Community based research in poor urban Lilongwe

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Abstract

This paper highlights the processes of conducting community-based participatory research within an operational research project in Lilongwe under the title of Extending Services to Communities (ESC). The project involves developing partnerships with community leaders, storekeepers and community members to enhance knowledge and effective

referral for TB and malaria. These challenges need further discussion and debate on decentralizing services and developing partnerships with providers close to communities to enhance the poor's access to services. Participatory and community-based research approaches are integral to these partnerships.

Introduction

What do we mean by community based-research or participatory research?

Participation is one of the foundations of equality⁶. Community-based research involves working directly with different community members to try to make a difference in the way people in communities work, think, and relate to others. Its participatory nature supports and contributes to the efforts of individuals, groups and movements that challenge social inequality and work to eliminate exploitation⁷. It strives to play a liberating role in the learning process by promoting the development of a critical understanding of social problems, their structural causes and possibilities for overcoming them (*ibid.*).

Community-based participatory research in Malawi: The role of ESC

In Malawi, community-based research is emerging as a way to encourage meaningful and relevant evidence about practices in communities. The Research on Equity and Community Health (REACH) Trust in Malawi, through its Extending Services to Communities project is currently implementing an intervention in poor urban areas of Lilongwe and is evaluating it using community-based participatory research. The main aim of the ESC project is to assist the National TB and Malaria Programmes to improve the care seeking behaviour and treatment of symptomatic women and men in poor urban areas of Lilongwe.

Poor urban communities have a high burden of TB and malaria in Malawi. In addition they face many barriers to accessing services in the form of social, opportunity and financial costs of care seeking and illness^{3,8,9}. Informal providers have a vital role in ensuring access to health services for poor populations^{10,11,12}. Work conducted by the REACH Trust has shown that storekeepers have an established role in the early treatment of both TB and malaria. However, inappropriate treatment and advice is common¹³. The main thrust of ESC is to improve access to TB and malaria care by strengthening community involvement through training storekeepers, community health committees and volunteers.

The intervention is being implemented in Ngwenya and Kauma. These are squatter settlements, located in the poorest areas in urban Lilongwe. The ESC action research intervention is informed by both participatory and community-based research approaches and involves the active participation of different community groups, namely: chronic coughers who are above the age of 15, carers of under five children, storekeepers, community leaders, TB patients, volunteers and community health

workers. The ESC intervention has a three- year time scale (April 2003 – August 2006) as illustrated in the following table:

Year 1	Initial research and development of intervention: exploring community perceptions of illness, pathways to seeking care and barriers faced in accessing care. Findings were fed back to community members through participatory methods, such as drama, to jointly formulate an intervention to address barriers identified.
Year 2	Implementation of the intervention: capacity building and training of storekeepers, community health committees and community-based organizations to improve their referral, advisory and health promotion skills.
Year 3	Evaluation of the intervention using mixed methods: Quantitative methods included household surveys and a grocery shop survey; qualitative methods included conducting focus group discussions and in-depth interviews.

Working within a participatory development approach: lessons learned by fieldworkers

The importance of dialogue and building trust

Community-based research involves developing positive working relationships with different members in the community. Building rapport, confidence and trust is not always a straightforward process and does not happen over night. Clear interactive discussion about the research - the aims, objectives, roles and responsibilities of different players are key entry points to participatory and community-based research. The working relationships with some of these communities (such as Ngwenya, Area 24), goes back to 1999 with initial work on understanding community perceptions of tuberculosis and HIV/AIDS, livelihood strategies of community members and pathways to seeking care. Since then some of the community leaders have moved out of the community and new leaders elected. Continuous communication and interaction with community leaders and members and clarifying any misconceptions around the objectives of the study helped to address this particular challenge.

The researchers' experience has shown that because much research in Malawi has been conducted in an extractive manner and has not resulted in tangible interventions at the community

level, community members do not initially appreciate the value of research. These concerns, which are often based on lived experience, need to be overcome through a participatory process of listening and discussing the different components of the action research, and adjusting where appropriate to reflect the needs and priorities of different community members.

Incorporating community perspectives throughout the action research intervention

Community based participatory research has enabled people from the intervention sites to participate in defining their health needs and expected outcomes for the intervention. Community members have had a major influence on all aspects of the ESC intervention. For example, the ESC project was initially conceived of as a TB intervention. However, community members requested that the focus should be broadened to include malaria, as this is one of the major illnesses in the area. Community members also shaped the type of intervention through requesting specific training of storekeepers and suggested which issues should be covered in health promotion activities. In this way, participatory community-based research provided a platform for communication and action. Community members fed back to the health providers with suggestions about how to improve the intervention. Research findings were also fed back to community members to verify information collected through role plays conducted by community-based drama groups.

Community members' perceptions of the fieldworkers

Because the intervention focuses on health and improving access to care, most community members had the initial perception that the REACH Trust researchers were health workers. For instance, they explained different types of diseases they were suffering from and other bodily complications, with expectations that we would give them the right medication. They also asked for ideas about how to form health groups; or how to advise their fellow friends, especially neighbours, who lack hygiene in their homes.

Others perceived the researchers as senior bosses who are able to affect change in the health system and briefed them on mal-treatment they had experienced in the formal health sector. This included nurses prescribing drugs before they even finish explaining what they are suffering from; being prescribed drugs contrary to what they are suffering from and without telling them the dosage and being shouted at if they made any delays before reporting to the health facility. It should be mentioned that times of political activity could also confuse understandings of the roles of different players; at times the researchers were perceived as political campaigners.

The researchers also faced challenges when there was confusion between the action research they were involved with and other interventions or research projects that were being conducted in the same areas at the same time. Networking or linking up with other organizations that are also implementing projects within the same catchment area is also important to community-based participatory research.

Continuous interaction and discussion between the researchers and community members, volunteers and health committees provided them with opportunities to clarify their roles – what the researchers were able to do and change, and what they were not.

Working with poor communities: Ethical dilemmas

The research activities involve interviewing TB patients within these poor urban communities. Some of these patients are very

poor to the extent that they depend on ganyu work (day to day employment) to earn a living, and some have inadequate food to eat during TB treatment. This raised a dilemma for the researchers. In Malawian culture it is the norm to carry food-stuffs or gifts to support the family when visiting a patient. Should the researchers follow these cultural norms when visiting and interviewing poor TB patients or would this act as an inducement and mean that TB patients' ability to refuse to participate in the study is compromised? After discussion as a team, the researchers decided that it was ethically appropriate to give to each patient at least two packets of sugar and two tablets of soap. These items were given after the interview so they did not appear as an inducement to participate.

The researchers also discussed how to respond to patients who were ill and in need of health treatment. The researchers were not health workers but do have some health knowledge and felt that it was ethical to use this. Where appropriate, the researchers encouraged sick women and men to go to the health facility and where necessary gave a referral letter. The referral was designed in collaboration with District TB and Malaria coordinators and is an integral part of the intervention.

The implications of working with a stigmatised disease

There is strong TB and HIV co-infection in Malawi; among TB patients, the HIV/AIDS prevalence rate is 77 percent¹⁴. TB and HIV/AIDS are also closely related in community perspectives, as confirmed by a study conducted in urban Lilongwe on community perceptions of TB and HIV/AIDS. This study revealed that community members do not conceptualise differences between TB and HIV/AIDS; people suffering from tuberculosis are perceived to be HIV positive¹⁵. This resulted in challenges to identifying TB patients through the TB registers and following them up in their communities, as many TB patients tried to keep their disease a secret. The easiest way of identifying and accessing TB patients was through the community-based groups who provide support to TB patients. These community groups had established relationships with the patients and act as a social support system for them and their families. Ensuring sensitivity and a guarantee of confidentiality is important in working with these sick and frequently stigmatised individuals.

What are the implications of these lessons?

The need to decentralize service provision is highlighted in the Malawi Health Sector Programme of Work and Essential Health Package¹⁷. Key to this is the need to bring services closer to communities, for example to increase TB case finding, up-take of anti-retrovirals and quick responses to high fever in children. This means developing collaborative partnerships with Health Surveillance Assistants, different community structures that are active in different areas (such as grocery store owners or home based care groups) and women and men in the community. This paper has highlighted some of the challenges faced in developing and sustaining these relationships. Developing relationships takes time and community or field workers need to be patient and willing to interact with different community members through time – to listen, engage with, and respond to their perspectives and dispel any misconceptions about their own roles. If trust can be built there is a strong opportunity of joint action for equity.

This type of participatory community-based research in poor contexts, such as Malawi, involves developing relationships with vulnerable individuals and groups. Those living with TB and/or HIV may also be experiencing stigmatisation, which can increase their vulnerability and isolation. The ethical implica-

tions of how to develop these relationships in ways that are culturally appropriate but also ensure informed consent procedures is a challenge.

Finally, the perspectives, experiences and dilemmas faced by field workers, and in this instance written up by ESC fieldworkers, deserve further debate. Fieldworkers or research assistants are arguably the 'cultural brokers'¹⁹ in research interactions and in development practice. It is fieldworkers who mediate between research aims or development goals and the expectations and priorities of women and men at the community level. These processes of mediation can be complex and contested and field workers may face ethical and other dilemmas on a daily basis. There is a need to hear direct from fieldworkers about their experiences to develop learning and exchange around good practice.

Conclusion

Participatory community-based research involves working with different community members to understand a certain problem and/or develop and evaluate the problem at hand. Such an approach has core strengths as it can enable the development of interventions that reflect the needs and priorities of different community members; this approach arguably enhances ownership and sustainability. It can also provide a platform through which different groups can express their experiences of health service delivery and promote service accountability. This is an important approach with the urgent need to look at ways to further decentralize health services to meet the needs of poor Malawians. This is however, not a straight-forward process, communities are not homogenous entities and establishing rapport and trust with different community groups takes time, patience and continual engagement. Critical to community-based research are fieldworkers—their roles and experiences need further debate and discussion.

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References

1. Bowie C, Mathanga D, Misiri H. Poverty, Access and immunisations in Malawi – an assessment in 2005. *Malawi Med J* 2006;18(1):
2. Makwiza I, Nyirenda L, Bongololo G, Chimzizi R, Theobold S. Synthesis studies on researching the poor in the health sector: counselling and testing and Anti-Retroviral Therapy. *Malawi Med J* 2006;18(1):
3. Nhlema Simwaka B, Nkhonjera P, Sanudi L, Gondwe M, Bello G, Chimzizi R, Theobold S. The Malawi National Tuberculosis Programme: An Equity Analysis. *Malawi Med J* 2006;18(1):
4. Mann G, Bokosi M, Sangala W. Reaching the poor: synthesis studies in the health sector; maternal mortality. *Malawi Med J* 2006;18(1):
5. Mathanga DP, Bowie C. Malaria control in Malawi: are the poor being served? *Malawi Med J* 2006;18(1):
6. Fredman S. *Discrimination Law*. Oxford: Oxford University Press; 2002.
7. Chinman M, Hannah G, Wandersman A, Ebener P, Hunter SB, Imm P, Sheldon J. Developing community science research agenda for building community capacity for effective preventive intervention. *American Journal of Psychology*. 2005; 35:143-157.
8. Kapulula P, Salaniponi FML, Squire SB, Kemp J. The journey towards tuberculosis diagnosis: preferences of the people of Mtsiliza, Lilongwe. *Int J Tuberc Lung Dis*.2001;5(11): Supplement 1, S166.
9. Kemp J, Boxshall M, Nhlema Simwaka B, SalaniponiFML, Squire SB. Application of a geographical information system to assess the relationship between socioeconomic status and access for TB care in urban Lilongwe. *Int J Tuberc Lung Dis*. 2001; 5(11): Supplement 1, S167.
10. Snow RW, Peshu N, Forster D, Mwenesi H, Marsh K. The role of shops in the treatment and prevention of childhood malaria on the coast of Kenya. *Trans R Soc Trop Med Hyg* 1992;86: 237-239.
11. Raynal AL. Use of over-the-counter medications in rural Matabeleland, Zimbabwe: The case for upgrading the skills of rural shopkeepers. *Central Afr J Med* 1985; 31: 92-97.
12. Winch PJ, Wagman JA, Khatib RH, Lynch MC, Massi M. Who should be our partners? Defining the role of the informal health sector in efforts to improve malaria treatment in Kongwa District, central Tanzania. *Bull WHO* 2006;
13. Willetts A. Grocery Shops in Tuberculosis Control in a poor urban community, Lilongwe, Malawi. Dissertation for a Masters Degree in Community Health, Liverpool School of Tropical Medicine, UK; 2001.
14. Kwanjana JH, Harries AD, Gausi F, Nyangulu DS, Salaniponi F M. TB-HIV seroprevalence in patients with tuberculosis in Malawi. *Malawi Med J* 2001;13:7-10.
15. Kabwazi N, Kapulula P, Luhanga T, Gondwe M, Nhlema Simwaka B, Kemp J. Perceptions of patients and community members of TB and HIV/AIDS: a study conducted in urban Lilongwe: Project Report, TB Equity Project; 2001.
16. Sanudi L, Makwiza I, Kemp J, Weiss M. Stigma and discrimination experienced by TB patients – a gender perspective from urban Malawi. Oral Presentation at the European Tropical Medicine Congress, Marseille, France: September 2005.
17. Ministry of Health. A Joint Programme of Work for a Sector Wide Approach 2004-2010. Lilongwe: Government of Malawi; 2004.
18. Cornwall, A. Making a Difference? Gender and Participatory Development. UNRISD. Available from the Institute of Development Studies, University of Sussex; 2000.
19. Molyneux, C. Introductory remarks. Paper presented at Locating the Field: The Ethnography of Medical Research in Africa. Kilifi, Kenya, 5th-9th December, 2005.