Part 0: Preamble

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LEVERAGING COMMUNITY PARTICIPATION THROUGH HEALTH COMMITTEES TO ACHIEVE HEALTH RIGHTS: THE ROLE OF POWER

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DECLARATION

I, Marion Hasson (HSSMAR003), hereby declare that this is my original work and has not been presented before for the award of a Masters' Degree in Public Health.

THESIS ABSTRACT

The concept of health committees has been promoted as an effective mechanism for assisting communities to realize their health rights. These committees tend to be formal structures made up of representatives from local government, health facilities and communities. Much of the attention has focused on identifying strategies and interventions to strengthen health committees as vehicles for achieving the right to health and the focus has been on educating, raising awareness, training and policy advocacy.

However, it is important to understand what participation looks like on the ground and to take in to account the day-to-day challenges and obstacles that health committees as a vehicle for community participation; interacting with stakeholders; and getting support from health facility managers and staff. These factors impact on the health committees' ability to facilitate and support community participation, yet they are driven by power dynamics and human interactions and relationships. Little attention has been paid to these dynamics, which play an important role in meaningful community participation at grass roots.

The PowerCube framework was used to explore the multiple dimensions of power that hinder or enable the health committees' ability to support the community to realize their right to health. The PowerCube framework allowed for an investigation of how power dynamics are perceived by a particular group, as well as providing for the comparison of different social, economic and political context. It enabled a comparison with different contexts where there are policies for supporting the community participation in health but implementation has been difficult it in practice.

The research focused on Khayelitsha, the largest township in the Western Cape, South Africa. Although Khayelitsha is a resource-poor township with a rapidly growing population

and a high burden of disease, there are structures and systems in place to support the health committees. Furthermore, there is an active community that wants to exercise their right to health. Yet the health committees in Khayelitsha face many obstacles on a daily basis as a result of power dynamics that influence where and how decisions are made. However, power is a complex phenomenon.

The health committees operating in the facilities in Khayelitsha reported to the Khayelitsha Health Forum who in turn reported to the Khayelitsha Development Forum. Despite all these organisations being voluntary, they have created a well-structured system in which the health committees functioned. However, the power dynamics were evident in where decisions were made and who had the power to make the decisions.

The Khayelitsha Health Forum had claimed and created spaces to try to influence decision-making, but almost all of the decisions were made in closed spaces where they were not present. Similarly, there were differing forms of power that largely played out in understand where accountability lay. There were many players and stakeholders operating within the facility but there was little clarity about who they were accountable to. As a result, many of these actors had forms of power that were invisible or hidden from the health committee, yet their actions affected the health committees. The tension created by power dynamics affected how the communities perceived the ability of the health committees to help them realise their right to health.

It was evident that as the health committees evolved, developed and gained traction with their community, more attention should be paid to the critical role power can play in their ability to act as a vehicle for participation in order to advance health rights.

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TABLE OF CONTENTS

Part 0: Preamble i
Declaration 1
Thesis Abstract 2
Acknowledgements 4
Table of Contents 5

Part A: Protocol 1
Study Protocol 2
Aims, Background and significance 2
Background 2
South African Context 3
Existing Project 4
Why power matters 5
Rationale 6
Aim 6
Methodology 6
Study design and research question 7
Study setting 7
Conceptual framework 7
Population and sampling 9
Inclusion and exclusion criteria 9
Recruitment 9
Research Procedures 10
Ethics 12
Risks and benefits 12
Consent 12
Privacy and confidentiality 13
Reimbursements 13
Conflicts of interest 13
References 13
Protocol Appendices 14

Part B: Structured Literature Review 1
Literature Review 2
Community Participation in the Primary Health Care Approach 2
Community Participation and Health Committees 4
Health Committees in South Africa 7
Power, Participation and Health Committees 9
Conclusion 12
References 13

Part C: Journal "Ready" Manuscript 1
Abstract 2
Background 2

Health committees and health rights 3
Health committees and community participation in the South African context 4
Why power matters 5
Methods *6*
Study Setting: Khayelitsha 6
Study Design 7
Population and sampling 8
Data collection methods 8
Data analysis 8
Results *9*
Structures supporting health committees in Khayelitsha 9
Participation within the facility: the role of the health committees 11
Participation within Khayelitsha: A Case Study of the Khayelitsha Health Summit 16
Discussion *21*
Conclusion *25*
References *26*

Part D: Appendices 1
Appendix 1: Matrix for Interview Questions 2
Appendix 2: Guide for Interview Questions 4
Appendix 3: Consent form and participant information form 7
Appendix 4: Letter of approval from Research Ethics Committee 10
Appendix 5: Instructions for Author of journal whose format has been used 11
Appendix 6: The Health Committee Structures in Khayelitsha 13
Appendix 7: Breakdown of Health Facilities in Khayelitsha 15

Part A: Protocol

STUDY PROTOCOL

LEVERAGING COMMUNITY PARTICIPATION THROUGH HEALTH COMMITTEES TO ACHIEVE HEALTH RIGHTS: THE ROLE OF POWER

Note to Reviewers

The original protocol for the project is included here to give reviewers a sense of the fuller planned methodology. In general, the protocol is left in the future tense and revisions are not made to its content during the course of research and thesis process. However, minor changes have been made to capture the smaller shifts in methodology that occur in the normal course of research.

AIMS, BACKGROUND AND SIGNIFICANCE

Background

A human rights-based approach to health "aims to support better and more sustainable development outcomes by analysing and addressing the inequalities, discriminatory practices… and unjust power relations which are often at the heart of the development problem" [1]. However, the "implementation of human rights can go well beyond legislation" [2]. A rights-based approach "must seek to give voice to those who are vulnerable and enable them decision-making scope to change their conditions of vulnerability" [2].

Thus, community participation is viewed as an integral part of a rights-based approach to health. It encourages the community to engage with policymakers in setting the agenda, developing and implementing health policies, and monitoring policy effectiveness that address the local needs. Meaningful participation involves dynamic and purposeful interactions between government, health care workers and communities, in order to develop sustainable health services that address local needs.

Yet meaningful community participation remains difficult. Many health systems have not established the mechanisms or structures necessary to promote effective community

participation. Where policies have resulted in mechanisms or structures for community participation, many policy actors have struggled to mobilize communities.

The concept of Health Committees (HCs) has been promoted as an effective mechanism for assisting community participation in order to realize their right to health. HCs tend to be formal structures that are made up of representatives from local government, health facilities and communities. They are "intended to serve as a link between the health services and the communities they serve" [3].

International evidence suggests that HCs may help to improve the quality of and access to health care under certain conditions. These conditions include positive health facility attributes such as receptive staff attitudes and appropriate skills; supportive social, political, cultural and economic environments; clear roles, functions and mandates for HCs; processes to facilitate community mobilization; and capacitation and support for HCs. However these conditions are not just technical and they are influenced and affected by power dynamics and human interactions and relationships.

South African Context

Within the South African (SA) context there is a legal and constitutional environment that is conducive for communities to participate in the realization of the right to health. However this has not been reflected at a provincial level and has had a significant impact on the functioning of HCs; it has left the HCs to operate without clear direction and undermined the community's capacity to hold health services accountable.

The South African Constitution contains provisions that are consistent with international human rights law for the right to health, as well as other provisions related to social determinants of health. Within the SA Constitution the right of access to health care is subject to progressive realization. Furthermore, the National Health Act makes provision for the establishment of HCs in order to bring together all the stakeholders who have an

interested in the community's health [4]. Thus the HC structures are intended to encourage community participation.

However, the Act did not provide guidance on the roles and powers of the HCs, leaving these decisions to provincial legislatures to finalise. This has resulted in an uneven implementation of mechanisms, structures and systems to support community participation in health in SA; currently only two out of nine provinces have policies and none have legislated for HCs.

In the Western Cape a draft policy has been stalled since 2008. The vision of the draft policy was for HCs to be functional in all facilities and to exercise governance, oversight and planning functions. However, given the void of the policy environment, the HCs have acted as auxiliary services to the health services and done little to promote community participation. This left the HCs without direction and undermining the community's capacity to hold the services accountable.

Existing Project

Over the last three years, the Learning Network for Health and Human Rights (LN) has focused on identifying strategies and interventions to strengthen HCs as vehicles for community participation. However, it has not covered the complicated role that power plays in HCs ability to achieve this.

The LN is a network of four universities (including UCT) and five South African civil society organisations (including Cape Metro Health Forum) whose mission is to empower CSOs to become agents for realising their right to health and to promote functional HCs [5]. Their approach is based on the premise that the right to health cannot be realized without the active participation of civil society to support a responsive and accountable health system.

One of the LN's projects has focused on understanding the potential role HCs can play in realizing the right to health and developing a training and advocacy platform to support health participation**.** The focus has been on educating, raising awareness, training and policy

advocacy though activities such as a national appraisal of the state of health committee legislation and policy; facilitating dialogue with department officials to clarify the roles and functions of health committees; developing a training package including curriculum, manuals, case studies and other media. However, it has not focused on how power can influence and affect interactions and engagements.

This project aims to add to current work of the LN by providing an insight into the ways that various forms of power can influence the functioning of HCs and the crucial role that power can play role in the design and establishment of HCs.

Why power matters

Much of the health rights approach is aimed at mitigating the impact of power differences and identifying abuses of power. However, power is a complex phenomenon - more complex than the more obvious human rights violations that are often the focus of discussion.

Given the range of socio-economic factors being addressed by a human rights approach, it requires a multi strategy approach to bring about change. But in order to operationalize the right to health, it is critical to take a broader approach to understand both the technical challenges as well as the power dynamics that influence the relationships and the environment.

In the PowerCube framework, Gavanta argues that to achieve transformative change, all the dimensions of power must be challenged through multiple and linked strategies aimed to realign the power dimensions [6]. Therefore it is necessary to understand the role that power plays in community participation – but more specifically the role that power plays in HCs ability to mobilize the community to participate in realizing the right to health.

Rationale

The rationale of the project is to use the PowerCube framework to gain a better understanding of the role that power can play in HCs ability to mobilize the community to participate in realizing the right to health.. This will help inform the strategies designed by the LN to strengthen HCs to enable them to become more effective vehicle for the realization of health rights.

Aim

The project will examine the multiple levels of power that influence and affect the HCs in order to gain an insight into the critical role that power can play in hindering or enabling transformative change. This will include looking at the day-to-day ways in which power is gathered, exercised, contested, transformed, and put to use in the process of health participation.

It will also test the PowerCube framework as a tool for understanding the aspects power that need to be challenged and realigned in order to bring about transformational change. In addition it may provide insights as to how to amend the framework to make it more effective for this kind of analysis.

It will help inform the LN's strategies for strengthening HCs as a vehicle for to support community participation in order to realize the right to health.

Finally it will form part of a broader comparative research project that aims to draw lessons about the daily practice of power in health participation from collaborators in other contexts.

METHODOLOGY

The case study of the Khayelitsha Health Forum (KHF), and the underlying health committees who make up the KHF, will form part of broader comparative case study project with research partners in Uganda, Guatemala and the US. Although these countries may

have policies for supporting the community participation in health, they have struggled to implement it in practice. By examining multiple levels of power in community participation, it aims to provide insights into what obstacles the role of power can play and to help inform strategies to address this.

Study design and research question

This case study of the KHF will look at the role power plays in its ability to facilitate community participation in order to realize the right to health. It will use the PowerCube framework to understand the critical dimensions of power that are necessary to achieve transformative change. This in turn will to inform the development of linked strategies to realign the dimensions of power.

The research question is: What role does power play in the health committee's ability to serve as a vehicle for community participation and contribute to the realization of the right to health?

Study setting

The subject of case study is the KHF, which is an umbrella organization that represents all the HCs in the Khayelitsha sub-district of Cape Town. The KHF has been recognized by the community as the representative of the HCs in Khayelitsha; however it had no formal legal status. For this reason it provides a useful context in which to explore the role that power can play in facilitating community participation in order to realize the right to health.

Conceptual framework

The PowerCube was developed in the UK by Gaventa and colleagues [7] [8]. It is widely used in the development field to inform change actions for citizen participation. The premise of the framework is that transformative, fundamental change happens when social movements or actors are able to work effectively across each dimension simultaneously. The PowerCube seeks to describe the multiple levels of power in community participation

by focusing on three dimensions/elements of power that need to be understood as separated entities as well as interrelated concepts:

- Space, i.e. difference spaces where power is exercised
- Levels, i.e. different levels in which power emerges
- Forms, i.e. different forms of power that actors use

Spaces of power

Spaces of power include the opportunities, moments and channels where people can act potentially to influence policies, decisions and relationships. The power that shapes these spaces has the ability to restrict people who may participate and the topics and interests that may be discussed.

- Closed spaces: Decisions are made behind closed doors by a set of actors. These actors are the elites (bureaucrats, experts or elected representatives) who make decisions and provide services to "the people," and do not see the need for broader consultation or involvement from the people receiving the services or influenced by the decisions made;
- Invited spaces: "Non-elites" (service users, citizens or beneficiaries) are invited by the elites or other authorities to participate in varying degrees in decision-making;
- Claimed/created spaces: Less powerful actors claim spaces from or against the power holders. These spaces often emerge out of common concerns and often consist of like-minded people joining together in common pursuits [6].

Levels of power

There are local, national, and global dimensions of participation, which should be seen as a flexible continuum instead of a fixed set of categories [6].

Forms of power

In such spaces and at such level, power is exercised on the basis of:

- "Visible power: observable decision-making", including the organizations, processes and procedures, and formal rules that structure decision-making;

- “Hidden power: setting the political agenda”, including how influence is maintained by controlling who gets a seat at the decision making table and what makes it on to the agenda;
- “Invisible power: shaping meaning and what is acceptable”, including the power to keep significant problems both off the table and far from the minds of key role players involved [6].

Population and sampling

The study population will consist of KHF and its underlying health committees. It is anticipated that sample size will be 10-15 people from the study population. If necessary, more people will be interviewed until the research team believes that saturation has been reached and no more themes have emerged.

Purposive sampling will be used to identify the interviewees from the leadership of the KHF and general members of HCs. The main criteria for the purposive sampling will be experience of working with HCs; capture a broad range of roles or function carried out as part of a HC; and gender so as to ensure that both males and females are represented even if it is not equal or balanced.

Inclusion and exclusion criteria

Any person working for or with the KHF over the last three years will be a possible study participant. Patients and users of health services who are not members of HCs will not be included in the study.

Recruitment

Once local government, LN and the KHF have given their overarching consent for the study, they will be asked to identify which health committees they believe should participate in the study. The researchers will approach these people to participate in the study and each participant will be asked if they are willing to participate and to give their consent in writing.

RESEARCH PROCEDURES

This case study will use three qualitative methods of data collection: semi-structured interviews; document analysis; and participant observation of meetings and fora.

Semi-structured interviews

The interviews will aim to examine activities in terms of the space for participation; the levels in which decisions are made; and how power is exercised within the space. This will focus on the activities of the KHF in relation to:

- Policy interventions and how successful they have been
- The practice of generating, accessing and disseminating information, success or otherwise in community mobilization and capacity building
- Opportunities used to redress grievances and how such processes have worked, and the extent to which the former has been institutionalised
- The way in which governance plays out, with a view to understanding the limitations in the system and opportunities to enhance governance roles

The interviews are expected to be 1-2 hours long and will be recorded and later transcribed by the researcher. The interview will take place at interviewee's place of work or any other place that is appropriate and conducive for the interview to take place and convenient for the interviewee.

Document analysis

The documents reviewed will include internal KHF documents such as meeting notes and correspondence, internal reports and operating policies or guidelines. It will also include any training manuals (whether developed internally or externally) and public reports. The review will also take into account any policy guidelines or legislation. This will focus on the same issues as the semi-structured interviews, namely policy interventions; practices of generating, accessing and disseminating information; redressing grievances; and the way in which governance plays out.

Observations

Where appropriate the researchers will attend meetings of the KHF and public or internal meetings where the research teams' presence will not be disruptive. The intention is to gain insights into the day-to-day ways in which power is gathered, exercised, contested, transformed, and put to use. It will also provide an opportunity to observe the human interactions and relationships as well as the interaction between the different organisations.

Storage of data

All recordings, transcripts and researcher notes will be kept in a locked cabinet in the PI and/or researcher's office. Only members of the research team will have access to these documents and recordings

Data analysis

The methods of data analysis will focus on identifying key themes that emerge from the interviews. The PowerCube framework will guide the identification of the themes. The data will provide multiple perspectives and the accuracy and explanations of the data tested through triangulation.

What happens at the end of the study

Key findings will be shared with the KHF, LN and DoH. The KHF will be encouraged to use the key findings to meet with DoH to guide future discussions about the role of HCs and identify areas for strengthening and capacitating HCs.

Results

Some of the anticipated outputs include: a tool for mapping power in terms of the PowerCube; a report on the findings presented to key stakeholders; a journal article based on the case study report; and a methodology for use of the PowerCube by CSOs to strengthen action for change.

ETHICS

Risks and benefits

The research team is aware that the people interviewed for the case study are likely to hold key positions and, given the political nature of the organisations, they are likely to have strong views and opinions on issues. This makes them easily identifiable despite every effort to protect their anonymity in the writing up of the case study.

Furthermore, given the political nature of the organization and the work they do, it is likely that there will be areas of tensions and disagreement. These tensions will be within organization itself as well as between the different organizations and between the organizations and government. They will reflect the many different perspectives, views and interpretations of the issues under discussions.

It will be imperative for all information to be reported evenly, fairly and sensitively. In addition, to protect anonymity of the participants, they will be asked to identify those issues that are off the record or need to be addressed less directly and where necessary minor details may be amended solely for the purpose of protecting the person's identity.

Despite these risk, the benefits of understanding the power factors that enable and hinder the role of HCs is vital if they are to be used as a mechanism for mobilizing communities to realize their right to health.

Consent

It will be necessary to secure the overarching consent and buy-in from KHF, Provincial DoH and LN. Once the details of the study have been explained to the stakeholders, their consent will be required in writing.

Standard consent forms will be use for the individuals who participate in the study. The consent form will explain the aims and purposes of the study as well as the research methodology and processes. Each individual will required to complete and sign the consent

For any external or internal meetings or for a which the researcher attends as a participant to observer, the research will not secure written consent but will secure permission from the organisers to attend the meeting and will ask for oral consent from the group.

Privacy and confidentiality

The researchers will follow the principles of confidentiality and access to the data (including transcripts and recordings) captured will be limited to the research team. All participants will remain anonymous.

Reimbursements

The interviewees will not be reimbursed for their time but they will be reimbursed for any travel costs incurred in order to attend the interviews. Where appropriate, they will also be provided with light refreshments during the interview.

Conflicts of interest

The research team does not believe there are any conflicts of interest.

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PROTOCOL APPENDICES

This has been moved to the Appendices of the Thesis Document to avoid repetition

Part B: Structured Literature Review

LITERATURE REVIEW

COMMUNITY PARTICIPATION IN THE PRIMARY HEALTH CARE APPROACH

Although most people associate the concept of the 'primary health care (PHC) approach' with the 1978 Alma-Ata Declaration, it was not a new concept at the time of the International Health Conference on Primary Health that produced the Declaration. Fleck writes that the concept of primary health care can be traced back to at least the intergovernmental conference held in 1937 by the health arm of League of Nations [1]. Whatever its origins, however, advocates of primary health care approach have always agreed on one goal: the attainment of 'Health for All'. And a comprehensive idea of 'primary health care' was the strategy to achieve this [2].

The Declaration defined primary health care as "health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation" (WHO, Declaration of Alma-Ata 1978). The PHC approach also includes a focus on the social determinants of health and the forms of intersectoral collaboration necessary to address these upstream determinants of health. Finally, the Declaration stated that primary health care "requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care" [3].

Since the Declaration, much attention has focused on to trying to implementing and actualising this "call for action" using the core principles of PHC, namely universal access and coverage; health equity; community participation; and intersectoral approaches to health [4].

Walley et al argue that primary health care includes "the wider goal of universal access to health through acceptable, accessible, appropriate and affordable health care" [5]. This notion of universal access to healthcare is much more than just the presence of health

facilities in a community. Walley et al include under 'access' the physical availability of health services; the user's ability to cover the expenses related to the services; the user's "willingness" to look for the services; and the user's decision to take up services [6]. Others have noted the importance of a fifth 'A' of access: accommodation (having services available when they are needed) [7].

Ensuring the success of this complex model of access to basic health care is a challenge, particularly in resource-poor settings. Factors that hinder or enable access to services range from financial constraints such as transport and user fees to poor quality services and a lack of infrastructure or shortage of skilled health care workers. Furthermore, there are also cultural and social factors that affect how health services are perceived by the user and would influence the appropriateness and acceptability of the services to the users.

As noted above, the framers of the Declaration believed that community participation and engagement was a critical tool in tackling barriers to the goal of Health for All. Zakus and Lysack define community participation as the ability for the users to assume greater responsibility for their health by assessing their needs; planning, implementing and sustaining their interventions; and evaluating and monitoring the effectiveness [8]. Rifkin offered an insight into reasons why key stakeholders like WHO and UNICEF believed community participation was critical to primary health care. The reasons presented were:-

1. "People are more likely to use and respond positively to health services if they have been involved in decisions about how these services are delivered, thus helping to make the services sustainable;
2. People have individual and collective resources (time, money, materials and energy) to contribute to activities for health improvements in the community;
3. People are more likely to change risky health behaviours when they have been involved in deciding how that change might take place;
4. People gain information, skills and experience in community involvement that help them take control over their own lives and challenge" [9].

But the Alma-Ata Declaration went further than just identifying primary health care as a core strategy. It also reaffirmed health as a fundamental human right and acknowledged the role that social determinants play in health. Thus, it played a critical role in trying to address social and health inequalities. In doing so, it adopted a rights-based approach that aimed "to give voice to those who are vulnerable and enable them decision-making scope to change their conditions of vulnerability" [10].

COMMUNITY PARTICIPATION AND HEALTH COMMITTEES

Community participation in health is thus a key strategy of PHC and the aim of community participation is to provide a mechanism for the community to engage with policymakers and service providers in setting the agenda, developing and implementing policies and programmes, as well as monitoring and evaluating their effectiveness to address the local needs [11]. At the implementation level, community participation can be achieved through a variety of different mechanisms ranging community consultations, community involvement in annual planning and budget cycles, health committees, community-based participatory research, and community advocacy and mobilisation.

Health committees are an interesting mechanism for promoting community participation in health for a number of reasons. They tend to be formal structures and in some countries, like South Africa, national policies make provision for the establishment of health committees. Health committee members are usually meant to represent a wide range of stakeholders and can include representatives from the community at large, from sectorial interest groups (e.g. the youth, the disabled, the unemployed), from community-based organisations as well as from the management team at local health facilities and representatives from local government.

The goal of health committees is to "serve as a link between the health services and the communities they serve" [12]. In creating this link, they aim to facilitate the role of community participation in developing health services that are sustainable and appropriate for their community's needs. To this end, McCoy et al point out that health committees

have the potential to play a role in strengthening health systems [13]. Furthermore, health committees provide a mechanism that can allow for marginalised and vulnerable communities to have a say in how health services are provided to their community. Thus, in contexts like South Africa where health inequality remains a persistent issue, health committees have come to be viewed as an integral part of a right-based approach to health because they have the potential to help communities realise their right to health.

Zakus and Lysack point out that after the Alma-Ata Declaration many countries incorporated community participation into their health planning. However, the strategy of community participation that was "originally conceived as a common and straightforward approach" has come to be recognized as "fundamentally more complex" [8]. It is this complexity that has concerned much of the subsequent literature on health committees as a vehicle for community participation.

McCoy et al conducted a systematic review of literature for evidence for the effectiveness of health committees in low-and-middle income countries. Their findings showed a very limited number of studies that provided empirical evidence of the impact of health committees and the majority of the literature simply "assumed that CPH [community participation in health] is beneficial, either to participating community members, the community more generally or the health systems itself" [13]. Rifkin conducted a literature review to explore the direct link between community participation and health outcomes and described the link as weak [14].

Writing about health committees as a vehicle for community participation in South Africa, Glattstein-Young and London argue, "community participation through health committees can advance the right to health" [15]. Loewenson et al's report on the Equinet's regional meeting of people working with health centre committees in the broader context of Eastern and Southern Africa also concluded that there is evidence of the "positive impact of HCCs [health clinic committees] on the performance and outcomes of PHC systems" [16]. However, Haricharan's study of factors that impacted on health committees in South Africa found that health committees' contribution to realizing the right to health was largely

through “supporting and assisting the health services, rather than through participation” [12].

The literature on health committees does point to some of challenges they face in supporting community participation. At the core of these challenges is that fact that health committees are not a homogenous entity. They operate in varying social, economic and political contexts and the needs and challenges facing their communities will differ significantly as a result. Nor do health committees have the same structure, roles and responsibilities, or mandates across settings [17]. In their report Loewenson et al described health committees as “a heterogeneous set of entities, with composition, roles and functions that vary across ESA countries” [16]. This complexity is important to remember in the context of debates over whether ‘health committees’ (in the abstract) can act as effective vehicles for community participation and realising the right to health.

While Rifkin’s recent contribution to the literature has focused on community participation in health as a whole, her findings provide valuable insights for understanding the challenges that health committees face as a vehicle for community participation. These include the lack of a standard definitions for ‘community’ and ‘participation’ i.e. who should represent the community and what their roles and responsibilities are; an inability to separate out the contributions made by the community participation to health outcomes from other developmental outcomes; and a failure to take into account the social, political, economic and historical contexts in which the communities function [14]. Rifkin calls for a “holistic analysis” of the situation and encourages us to consider community participation as a process that can evolve over time rather than an intervention to support a particular programme or outcome [14].

This debate has helped to push the thinking about health committees beyond the technicalities of establishing, developing and training health committees and takes into account the contextual factors in which health committees function [17]. It encourages the exploration of the dynamic, inter-related factors that are influenced by power dynamics and human interactions and relationships that can hinder or enable effective community

participation. As Rifkin writes, “effective participation encounters issues of power and control over decisions” [9].

HEALTH COMMITTEES IN SOUTH AFRICA

South Africa provides an interesting context in which to explore the role health committees can play in helping communities to realise their right to health. The apartheid system of race and gender discrimination “permeated” the political, social and economic structures of the country [18]. It left behind significant economic and social divisions. For the vast majority of South Africans, the legacy of apartheid continues to shape their daily lives, where poverty and inadequate access to education, employment, housing, food or health remain hugely challenging.

The South African Constitution, which was drafted and passed in the newly democratic South Africa in 1996, aimed to address these inequalities and injustices [19]. Section 27 of the Constitution enshrines the right of all South Africans to access health services, which is subject to progressive realization. In addition, the Constitution includes other provisions that relate to social determinants of health such as access to water and food.

It is this context that there was a drive to implement policies and interventions that would try to rectify past injustices and inequalities. In terms of public health, The Constitution made it possible to start addressing the issue of how to provide access to health services for all South Africans and to incorporate the international support for community participation in planning and providing for health services [20]. Furthermore, it created a context that was conducive to a human rights approach that focused on reaching marginalised, vulnerable and under-served groups.

In line with the Constitution, the National Health Act of 2003 called for the establishment of clinic and community health centre committees to bring together stakeholders who have an interest in the community’s health. The Act stipulated that every province should provide for health committees in the provincial legislation; every clinic should be linked to a

committee; and the committees should include representatives from the communities, facilities and local government [21]. But more critically, the Act stipulated that the provinces would be responsible for defining the functions of the health committees. This has resulted in an uneven implementation of the health committees across the nine provinces of South Africa. Padarath and Friedman's study found that 57% of clinics in South Africa had clinic committees and there were a higher number of clinics in those provinces where there was explicit political support for them [9].

In the Western Cape, the draft policy, which aimed for functional health committees in all facilities to exercise governance, oversight and planning facility functions, has been stalled since 2008. In 2015, the Western Cape Provincial Government presented the Western Cape Health Facilities and Committees Bill for comment. The Bill aimed to provide a framework for the role of community participation in PHC in the province. However, there has been resistance from the community, health committees and NGOs who are concerned that the Bill hinder rather than enable community participation. The on-going policy uncertainty in the Western Cape raises questions about the provincial Government's commitment to creating frameworks to enable meaningful community participation at all levels. Without this support, there is a growing recognition from advocacy organisations, like the People's Health Movement (PHM), that the health system will not meet the needs of the people [22].

Despite this, health committees have continued to operate within many clinics. However, they have often focussed on "problem solving between the community and the health facility, health education and volunteering their services" [9]. The lack of a clear framework or policy environment has exacerbated the challenges that health committees faced on a daily basis, including a lack of resources; lack of clarity around their roles, responsibilities and level of authority; and resistance from facility managers and healthcare workers [12] [15] [20] .

Glattstein-Young's identifies "limited communication and contestations over power" as key barriers for community participation through health committees in her study of the Cape Metropolitan area [15]. In her study, power was a barrier in terms of how and where

decisions were made but also she noted the sense of powerlessness felt by the committee members who were unable to effect change due to the challenges they faced [15].

POWER, PARTICIPATION AND HEALTH COMMITTEES

As seen above, community participation is a complex phenomenon. It has been almost 40 years since the Alma-Ata Declaration endorsed PHC as the strategy to achieve 'Health for All'. However, this has proved to be far more difficult than originally envisaged, largely due to social, economic and political contexts in which health services are operate.

From her research on community participation post Alma-Ata, Rifkin has distilled four lessons that can help unpack some of the main complexity of community participation. They are:

1. "It was neither useful nor possible to have a standard definition of the term 'community participation;
2. It was not possible to consider participation outside a political context. Effective participation encounters issues of power and control over decisions, particularly those related to resource utilization;
3. It was not possible to create broad, self-sustaining community participation through health services alone. People and communities had other priorities, such as food, shelter, education and income;
4. It was not realistic to define or pursue a standard model for creating community participation in health programmes. History and culture were strong defining elements of the value, structure and sustainability of any community health programme" [9]

Of particular interest is Rifkin's lesson above about power. Power is complex; it is dynamic and can vary significantly from community to community and province to province. But irrespective of the context in which power is exercised, when it is unfairly or inappropriately applied it has the potential to lead to significant injustices, discrimination and abuses. A human rights-based approach to health "aims to support better and more sustainable

development outcomes by analysing and addressing the inequalities, discriminatory practices… and unjust power relations which are often at the heart of the development problem" [23].

In their systematic review that explores the extent, nature and quality of community participation, George et al point out that "there remains a lack of common understanding of concepts, motivations and social processes underpinning community participation" [24]. Thus Rifkin argues that treating community participation as a process rather than an intervention may led to stronger community participation but this requires a holistic approach that addresses the issues of context around empowerment, sustainability and ownership of health outcomes [14]. In a similar vein, Gaventa argues that creating new structures may not necessarily result in greater community participation because of the dynamics created by power relations [25].

Furthermore, Rifkin argues that the weak link between community participation and health outcomes can become a barrier to securing funding for promote community participation [14]. Gaventa argues that the transformative change can only come about when all dimensions of power are challenged [25]. Yet, there is a lack of literature that explores the role of power in community participation [24]. It is therefore imperative that policymakers, funders and activists understand how to engage with the "changing configurations of power" [25].

However, power is difficult to define and hard to measure. The Oxford Dictionary defines power as "the ability or capacity to do something or act in a particular way" or "the capacity or ability to direct or influence the behaviour of others or the course of events" [26]. Thus Gaventa, building on the work of other colleagues [27] [28], developed a framework called the PowerCube to explore the different forms and types of power being encountered in community participation and/or citizen engagement research in order to explore how they interact.

The PowerCube framework is widely used in the development field to inform change actions for citizen participation. The premise of the framework is that transformative, fundamental change happens when social movements or actors are able to work effectively across each power dimension simultaneously [25]. The PowerCube seeks to describe and explore the multiple levels of power in community participation by focusing on three dimensions/elements of power that need to be understood as separated entities as well as interrelated concepts of spaces where power is exercised; levels in which power emerges; and forms of power that actors use.

Spaces of power include the opportunities, moments and channels where people can act potentially to influence policies, decisions and relationships. The power that shapes these spaces has the ability to restrict people who may participate and the topics and interests that may be discussed. Below is a summary of Gaventa's list of the different spaces in which power operates:

- Closed spaces: Decisions are made behind closed doors by a set of actors. These actors are the elites (bureaucrats, experts or elected representatives) who make decisions and provide services to "the people". They do not see the need for broader consultation or involvement of those utilising the services or those influenced by the decisions made;
- Invited spaces: "Non-elites" (service users, citizens or beneficiaries) are invited by the elites or other authorities to participate in varying degrees in decision-making;
- Claimed/created spaces: Less powerful actors claim spaces from or against the power holders. These spaces often emerge out of common concerns and often consist of like-minded people joining together in common pursuits [25].

Levels of power are local, national, and global dimensions of participation, which should be seen as a flexible continuum instead of a fixed set of categories [25].

Forms of power can include:

- Visible power: the observable decision-making, including formal rules, structures, authorities, institutions and procedures;

- Hidden power: how powerful people maintain their influence by controlling who is allowed to be at the decision making table and what gets on the agenda;
- Invisible power: the power to keep significant problems and issues not only from the decision-making table, but also from the minds and consciousness of the different players involved. Invisible power influences how people think about their place in the world, and shapes their beliefs, sense of self and acceptance of the status quo [25].

Thus using the PowerCube framework to offers a way of thinking about the different types of power in a way that captures the contextual nuances in which community participation operates. By exploring the different levels and spaces, it provides an opportunity to explore participation as a process that is influence by external factors such as politics, socio-economic factors, culture and history. It also creates space for vulnerable and marginalised groups to be heard.

CONCLUSION

Such research can build on the existing body of literature and can add valuable insights to our understanding of power dynamics in participation; historical, political and cultural contexts and socio-economic disparities that enable or hinder health committees to mobilize their communities. It offers way of focusing on a specific context and exploring what opportunities for community participation emerge as well as the threats and obstacles that arise. Finally it can provide insights into the multitude of factors that influence where and how decisions are made that influence how health committees function at the grassroots level. The study that follows aims to address some of these broader questions about the ways power operates in health committees to enable community participation, taking into account a human rights approach.

Gaventa recalls from his early experience of researching power: “There was something about power which had led not only to defeat where voices had been raised, but also, somehow, over time, the voices had been silenced altogether” [25].

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LEVERAGING COMMUNITY PARTICIPATION THROUGH HEALTH COMMITTEES TO ACHIEVE HEALTH RIGHTS: THE ROLE OF POWER

ABSTRACT

Health committees have been promoted as an effective mechanism for promoting community participation in order to realize the right to health. These committees tend to be formal structures made up of representatives from local government, health facilities and communities. Much of the focus on health committees has been on technical issues such as how to establish and structure health committees as well as how to capacitate, train and support its members. However, the functioning of health committees is also influenced by interpersonal relationships, social contexts and broader power dynamics. While little attention has been paid to the latter, they can potentially determine the success or failure of health committees as vehicles for promoting community participation. In Khayelitsha, the largest township in the Western Cape, South Africa, there is structures and systems in place to support the existing health committees. Although it is a resource-poor township with a rapidly growing population and a high burden of disease, there is an active community that is keen to exercise their right to health. Yet the health committees in Khayelitsha continue to face obstacles on a daily basis many of which are a result of local and regional power dynamics. This study used the PowerCube framework [1] to explore how multiple dimensions of power that can influence, enable or hinder the health committees' ability to support community participation and effect change. As health committees evolve, develop and gain traction with their communities, more attention should be paid to the critical role power plays in their ability to bring about transformative change for their communities.

BACKGROUND

The Alma Ata Declaration of 1978 called for 'Health for All' and adopted primary health care as its key strategy to achieve this [2]. Furthermore, the Declaration reaffirmed health as a fundamental human right. It was in this context that the democratic government of South Africa began to address the huge inequalities in the public health system they inherited. However, the high burden of disease in South Africa has and continues to place huge

pressure on an already weak health system; in particular communicable disease such as TB and HIV and non-communicable disease such as cardiovascular disease and cancers [3]. In addition, the Apartheid legacy has and continues to impact on the social determinants of health. Together these factors have presented significant and on-going challenges to addressing the inequalities in access and coverage of health services in South Africa. Thus, the focus in South Africa has been on addressing these inequalities in access to and coverage of health services through primary health care.

A core principle of primary health care is community participation, which provides communities with the opportunity to become actively involved in how services are provided in their community to ensure they meet the needs of their community. Furthermore, the South African context lends itself to adopting a human-rights approach to health not only to address past violations human rights and growing inequalities in health outcomes but also to ensure that due attention is paid to marginalised and vulnerable groups.

Health committees and health rights

There are many vehicles and mechanisms for facilitating community participation which aims to enable communities to engage with policymakers and service providers in setting the agenda, developing and implementing policies and programmes, as well as monitoring and evaluating their effectiveness to address local needs [4]). Zakus and Lysack argue that for community participation to be sustainable and effective it cannot be imposed onto the community but needs to be seen as an integral part of it [5]. In the context of health services, examples of these mechanisms include lay counsellors, community healthcare workers, community support groups and health committees.

Health committees are a particularly interesting mechanism of community participation to explore because they tend to be formal structures made up of representatives from the community, health facilities and local government. Health committees are “intended to serve as a link between the health services and the communities they serve” [6]. Thus the goal of health committees is to promote and facilitate community participation in order to effect changes in health services provided.

In light of this, there has been a shift towards talking about “meaningful” community participation, which Meier et al [4] describes as being “dynamic and purposeful interactions between government, health care workers and communities, in order to develop sustainable health services that address local needs”. To achieve this, a human rights approach is integral to community participation because it aims to reduce the vulnerability of marginalised groups as well as addressing “unjust power relations which are often at the heart of the development problem”[6].

Health committees and community participation in the South African context

The South African Constitution recognizes health as a fundamental human right as well as providing for social determinants of health [7]. The National Health Act requires the establishment of health committees in health clinics to facilitate the engagement of all stakeholders, including communities [8]. However, the Act does not provide guidance on the roles and powers of the health committees and left this to the provincial legislatures to determine. This has resulted in an uneven establishment of health committees in South Africa. Padarath and Friedman’s study in 2008 found 57% of all health facilities had clinic committees in South Africa; Free State had the highest percentage of health committees while Mpumalanga had the lowest. In the Western Cape just under 60% of facilities had health committees [9].

In the Western Cape a draft policy has been stalled since 2008. A revised policy was presented 2015 but received little support from the communities, health committees and NGOs, who felt the policy did not effectively support the role of health committees in community participation. Despite the on-going policy vacuum, health committees have been established in many clinics and continue to operate without clear direction about their roles and responsibilities or clarity about whom they are accountable to. Padarath and Friedman’s argued that the “lack of provincial guidelines, inadequate resource allocation, and the limited capacity of committees constrain their abilities to actively fulfil their intended roles and responsibilities” [9].

Why power matters

There is evidence to suggest that health committees can make a positive impact on primary health care [10] [11]. However, the literature points out that the compositions of health committees will vary from province to province and country to country and these variances reflect the different social, political and economic contexts in which they function [10] [12] [11]. These contextual factors, which are influenced by power dynamics, can affect the functioning of the health committees at grassroots. Thus these power dynamics need to be taken into account when looking at the role of health committees to facilitate community participation in health.

There are many definitions of power. For the purpose of this case study, the power dynamics being explored are those that influence or affect the community's ability to be voice their concerns and be heard. Furthermore, the intention is to view power with a human rights lens. Thus, the Oxford Dictionary provides a useful definition of power: "the capacity or ability to direct or influence the behaviour of others or the course of events" [13]. However, power is a complex phenomenon and made more complex in environments where there are significant socio-economic inequalities. A human rights approach aims to address these power imbalances and abuses.

Gaventa developed the PowerCube framework to describe and explore the different facets of power that influence citizen/community participation. He argued that to achieve transformative change, all the dimensions of power must be recognized, challenged and realigned [1]. The PowerCube focuses on three key distinct, but inter-related, dimensions of power:

- The spaces where power is exercised, such as closed spaces, invited spaces and claimed/created spaces. This explores where and how decisions are made and who has the power to influence who can be in that space;
- The levels in which power emerges such as local, community and district levels or local, national or global levels;
- The forms in which power is exercised. This aspect examines how actors use their power to influence decision-making. It considers whether their influence is

visible (i.e. their power is transparent and observable), invisible (i.e. their power exercised through influence or control) or hidden (i.e. their influence is used to exclude issues) [1].

Looking at the PowerCube framework through a human rights lens, this article aims to provide insights into the role that power (in its various forms) can play in enabling, hindering or influencing the role health committees as a vehicle for community participation. Based on this case study of health committees in Khayelitsha, it presents various examples of how these power dynamics play out at a grassroots level and in the context of persisting socio-economic inequalities and urgent health problems.

The PowerCube is a useful framework to compare and contrast power dynamics in different social, political and economic contexts. It allows for an investigation of how power dynamics are perceived and how they impact on health committees' ability to act as a vehicle for community participation. This study will form part of broader comparative case study project with research partners in Uganda, Guatemala and the US. Although these countries may have policies for supporting the community participation in health, they have struggled to implement it in practice.

METHODS

Study Setting: Khayelitsha

Established in the early 1980s, Khayelitsha means "new home" in isiXhosa [14] and falls under the City of Cape Town Metropolitan Municipality. It is difficult to capture the exact number of people living in Khayelitsha due to the large influx of migrants from other parts of South Africa and Africa. Yet Khayelitsha is regarded as the fastest growing township in South Africa with an estimated population of over 800,000 residents [15].

Khayelitsha has been described as a "zone of poverty and unemployment" [16]. It has overcrowded living conditions, crime, food insecurity and poor access to basic services like water and electricity. Concerns around sanitation and hygiene are on-going, highlighted by

continued service delivery protests [17]. Unemployment and poor education continue to contribute to income poverty in Khayelitsha; the majority of households live on R3,200 per month [18]. The burden of infectious and non-communicable diseases is considerable; Khayelitsha has the highest HIV prevalence area in the Western Cape, which also contributes to the burden of TB infection in the area [19].

Given its' close proximity to Cape Town, Khayelitsha is also home to many local and international non-governmental organisations (NGOs), community based organisations (CBOs) and faith based organisations (FBOs) that provide services and support to the community. The history of Khayelitsha is embedded in the Apartheid era and together with a strong presence of NGOs and a burgeoning informal sector run by the residents, this has contributed to building a spirit of community participation and activism.

Study Design

Khayelitsha is a complex setting with a wide range of socio-economic factors that impact on health and health systems interventions such as health committees. The manner in which power dynamics play out is complex, multi-facetted and specific to context. The study aims to understand the role power plays in the health committee's ability to serve as a vehicle for community participation and contribute to the realization of the right to health. Furthermore, it aimed to provide an insight into how socio, political and economic factors, particular at the grass roots level, influence the power dynamics.

To achieve this, a qualitative case study approach was chosen. The case study methodology allowed for an in-depth study of the context - social, political and economic dynamics – in which health committees are expected to operate and function. Furthermore, it provided an opportunity to explore how the committee members viewed, understood and participated the role power plays in the processes, systems and structures in which they operate [20]. Finally, a qualitative case study approach would allow for an exploration of how situations were perceived and why they were perceived in that manner.

Population and sampling

The focus of the study was to gain an insight into how the power dynamics were perceived, experienced and addressed by the health committee members. As a result, the population was restricted to active health committee members living in Khayelitsha. Eight active members from six different health committees in Khayelitsha were purposively sampled. The participants were all residents of Khayelitsha and the health committees were established and functioning. The participants represented a range of roles within the health committees, including positions of leadership as well as general committee members. Furthermore, two of the eight members interviewed were also members of the overarching community structures that supported the health committees. A mixture of male and female participants was included to ensure that a diversity of perspectives would be captured.

Data collection methods

The primary source of data collection was in-depth semi-structured interviews, which explored the role power plays in the health committees' ability to mobilize communities to realize the right to health. Several unstructured interviews offered the opportunity to further explore issues and themes that came out of the initial interviews. Observations from various meetings and public forums were recorded in the form of field notes. The individual interviewees gave consent. Unfortunately it was not possible to include a document review of the health committees' internal documents, such as meeting notes and correspondence, internal reports and operating policies or guidelines, as they were not made available to the research team.

Data analysis

All semi-structured interviews were audio recorded and then transcribed verbatim by the author. The interview transcripts and field notes were initially analysed for core themes based on the PowerCube framework. Data was coded using an initial codebook, which was then further refined. The emerging themes were continuously discussed with some of the participants in order test the strength of the data and formed the basis subsequent informal and semi-structured interviews. The themes were further explored using an ecological

approach, looking at relationships between individuals within health committees; relationships between different health committees; and relationships within the overarching community structures such as development and health forums. Finally, the data and themes were tested against the notes made from observations of the meetings and incorporated into the analysis of the data.

RESULTS

The results are divided into three sections. The first section looks at the structures in place in the community that supported and governed the health committees. The second section focuses on the role that the health committees play within the health facilities and explores the power dynamics between health committees, facility managers/staff and residents. Looking from a health committee's perspective, it tries to understand the factors that enable or hinder them in helping community members realise their right to health. The second section takes a broader view and looks at the collective role of health committees within Khayelitsha. Here the focus is on the Khayelitsha Health Forum (KHF), an umbrella organisation that represents the health committees in Khayelitsha. It explores power dynamics between KHF, the community and key stakeholders such as government, NGOs and other community structures such as the Khayelitsha Development Forum (KDF).

Structures supporting health committees in Khayelitsha

The overarching structure under which health committees operate is the KDF. Launched in 1995, it aims to provide a vehicle for community participation and support community development initiatives in Khayelitsha. It has and continues to play a critical role in facilitating and supporting the development of community forums, ranging from health and education to social welfare and youth. In addition, it provides a critical platform for these forums to interact, raise and address concerns relating the Khayelitsha community, such as sanitation, environmental issue, infrastructure and housing.

One of the community forums under the auspices of KDF is the KHF, who reports to the KDF and has two members who represent it at the KDF level. Each health committee represents a health facility in Khayelitsha and they report to the KHF, with the exception of the

Khayelitsha District Hospital (KDH) which has a board appointed by Provincial Minister for Health. However, the CEO of KDH attends all the KHF meetings. The KHF has been active in establishing and supporting the health committees in Khayelitsha. Currently there are 8 health facilities with established health committees and approximately 6 health facilities that need to establish a health committee.

In accordance with draft policy for health committees, each facility must have a health committee. The health committees are made up of 14 members, including a chairperson; deputy chairperson; general secretary; deputy secretary; treasurer; organiser/administrator and four additional members. Each health committee elects its members at their annual general meeting (AGM). The proposed candidates are selected from civil society organisations (CSOs), non-governmental organisations (NGOs) and community based organisations (CBOs) working in the catchment area for that health facility and as well traditional healers and local leaders. Ward councillors attend health committee meetings to assist, advise and provide a link to the Department of Health (DoH) yet they do not have any voting rights.

However KDF and KHF are community created structures created to represent the community and are accountable to the community members. They meet regularly with the community, however it is difficult to ascertain what formal mechanisms are available to hold them accountable by the community, and/or the health committees due to the fact that they rely on voluntary membership and lack resources. The same applies to health committees. Thus any discussion around their engagement, accountability, responsiveness and impact is based on individuals' experiences.

According to health committee members, KHF enables the health committee members to engage with and learn from each other and in doing so they have been able to develop good working relationships with other health committees. But more importantly, there is a strong sense from the health committee members that the KHF helps them to solve problems. Their perception is that they can take their problems to the KHF who will help them access the right people in order to find solutions and answers. As one health committee member said: "they [KHF] have the power to call a facility manager. If the facility manager can't

come, they will [call someone] who is more senior to that manager and that person will be able to call the facility manger to say 'go and account'."

The support provided by KHF was highlighted in an example relayed by a health committee member at one of the local clinics. In 2014 a patient and her family laid a complaint at her local clinic of being mistreated at KDH and wanted to sue the hospital. In order to properly investigate the case, the health committee needed to access the patient's file but KDH would not oblige. They referred the matter to the KHF who engaged with the CEO of KDH. When the KHF got the patient's file, it transpired that the incident had happened at a different hospital. The health committee, with the crucial help of the KHF, was able to provide the patient and her family with the correct information in order to properly address their situation. Their approach of engagement was very different to that other NGOs working in Khayelitsha who wanted to organize a community protest in response to the incident.

Another health committee member spoke about how the KHF helped them to access the City and Provincial Departments of Health (DoH). He said that representatives from the KHF often accompanied the committee members to meetings with DoH to address issues and pointed out that there have times when KHF had briefed DoH prior to their meetings.

Participation within the facility: the role of the health committees

Dynamics between health committees, facility managers and staff, and other stakeholders

The KDF, through the KHF, supported the establishment of health committees as a means of providing a direct link between the clinic and the community to facilitate the community's participation. A KHF representative pointed out that the community "needed to be involved and assisting management in the facility and not just coming to complain to the manager. Therefore, manager of any facility is part of the health committee", as are members of the community who make up the health committees.

The representative also believes the support of the facility manager is critical to the functioning of the health committees because “everything that comes through the clinic comes through the facility manager”. However, the engagement of the facility managers with the health committees varied from site to site; some managers see the health committees as a support and others feel that facility managers have been “forced” on them by the Government.

From the health committees’ perspective, the common challenges were finding time to meet with the facility manager and having access to budgets and expenditure plans for the facility and the sub-district. The facility managers require meetings during working hours while the health committee members prefer meetings after hours. However, health committee members are volunteers do not always available during working hours.

The health committees also want to be part of the expenditure planning for the clinic while the KHF want to understand how the City and Provincial DoH budgets are allocated to the community clinics in Khayelitsha. For example, at one facility the health committee member reported that they were told that the facility was to be renovated, however the committee was not consulted. The committee members objected to the renovation on the basis that they believed it was too expensive and not a priority, and had concerns about the tendering process and appointment of contractors. The health committee members felt that this had created tension between them and the facility management who felt challenged.

Another health committee member commented on the tension created between the health committees and facility staff when issues around the service provision were raised. A committee member reported that health care workers felt they were being monitored by the health committee. According to the committee member, a facility staff member said to a health committee member: “You are not employed here and you cannot tell me to do this and this.” But the committee members argue that they are monitoring the process and not the facility staff. As one committee member said: “If I see anything that isn’t right, I don’t report it to the staff I just report it to the manager and the manager has a right to go and talk to the staff… I must not take anybody’s responsibility but I must make sure that everything is going fine”. For example, in one of the clinics, a nurse was selling infant

formula that belonged to the clinic. The health committee intervened with the intention of holding the facility accountable and ensuring the matter was properly dealt with. As the health committee member said: “the community stood firm and she [the nurse] was removed and suspended.”

The main mechanism available to the community to report concerns about the service delivery is the complaints and compliments box (or the suggestion box) located in every facility. The community members are encouraged to make use of the box. The contents are reviewed on a monthly basis by both the facility manager/management and the health committee.

One of the main concerns consistently raised through the suggestion or complaints and compliments boxes is the attitude of the clinic staff and the community towards each other. The staff feels the community “has attitude” and the community feels the staff “have attitude”. By “attitude” the committee members are referring to some people who can come across as arrogant, unhelpful, rude or dismissive. Many of the committee members attributed the community’s “attitude” to a lack of understanding about the processes and procedures within the facility, while they attributed the staff’s “attitude” to a lack of understanding about the issues the community face in trying to access the facility. To address this, health committees raise awareness about how the clinic works in order to manage the community’s expectations. They advise the community about staff shortages which could lead to longer waiting times; educate them about the clinic systems e.g. the triage systems which fast tracks the critical patients; and, at some sites, use a health promoter to announce and advise the patients of the procedures for the day. From the clinic’s perspective, they are trying to keep the health committee’s informed on a daily basis of factors, such as shortage of staff or renovations that would affect service delivery.

A good example of where health committees have intervened to address such misunderstandings is the long queues of patients that form outside the clinic from the very early hours of the morning. The community perception is that clinics will only see a set number of patients in one day so they need to be at the front of the queue. However, in the early hours of the morning they are vulnerable to attacks and theft. To address this, the

health committees encourage the community to start queuing an hour before the clinic opens and they have requested that the clinic staff ensure that services are continuously provided during the clinic hours.

The health committee members also raised concerns about some of the NGOs who operate out the health facilities. According to one health committee member, these NGOs are reluctant to work with the health committees because "they [health committees] are not employed here. They are going to give us [the NGO] their [the health committee's] problems". Furthermore, there is a feeling that some NGOs have a different approach to addressing concerns within the health facilities and this can affect how the health committee operates. For example, two health committee members referred to an advocacy NGO who wanted to mobilize the community to protest about poor service delivery in Khayelitsha. The health committee members felt that the NGO's strategy is in direct conflict with their strategy of consultation and engagement with the facility to resolve issues. Another committee member said, the NGO "doesn't engage they just organised a protest and wanted to disturb the whole process…. They didn't consult or engage. They only do mobilisation and protest. They only engage after protest." The perception of the health committee members is that the NGO "influence[s] people to have an attitude around services" and they didn't "advise people as to how to how they can work together as a community and coming up with a strategy of better service for all".

Another example presented by a health committee member was the strikes in Khayelitsha called by SAMWU (South African Municipal Workers Union) about the grievances of the facility staff with the management of City of Cape Town's DoH. From the health committee's perspective, they voiced their concerns that the strikes were disrupting health services and preventing community members from accessing services in the City's facilities. According the committee member, SAMWU told them the "community must stay outside" and this created tension between the facility staff and health committee. According to a health committee member, "even today some of the facility staff are not seeing eye to eye with health committees because we [the health committee] are seen as people that sided with management but what we wanted was a service."

Lack of resources for health committees and their members

The health committees are run as voluntary organisations and their members do not receive any payment for their services. As one committee member said: "There is a problem in that health committees don't receive any stipend or salaries. They working very hard and they have no resources. KHF approach the MEC [Member of the Executive Council] about this and there was a general discussion around this and she has promised she would help somewhere somehow." Another committee member felt that health committees should get a "token of appreciation because the work we do we have to use our own resource. We are assisting the government that has resources. We are asking for a stipend not a salary."

Given that the health committee members' role is voluntary, many are elected without a thorough understanding of how a health facility operates. Most health committee members believed training would be beneficial and suggested subjects such as budgeting and expenditure; leadership and how to treat people; and understanding their role and responsibilities. However, the lack of resources affects the ability for the health committees to organise training for their members and they remain dependent on other NGOs to provide such training.

While a lack of resources was commonly cited as a challenge, only one member talked about an initiative to raise resources for their health committee. The facility manager allowed the health committee to sell off the building rumble (furniture, old windows and doors) from a recent renovation at the facility to raise funds for themselves. The money raised will cover transport and food for a team building session to be held in the facility. But this was only made possible by the very good working relationship between the facility manger and the health committee.

The lack of resources also impacts on the ability of the health committees to meet in order to plan, prepare and operate. Most of the members talked about the need to have a desk, a computer, internet access and a telephone line. Some clinics are small and there is no space to accommodate the health committees. In one clinic the health committee raised these issues facility manager and it was agreed "it was fine for them [health committee] to use the

clinic's computer but they can only do it when facility staff aren't using it". For the health committee member, their hope is that "when they extend the clinic there will be space for health committee". Whether limited space was shared with health committees was also dependent on the relationships between the different committees and facility managers, with some offering more space than others.

Participation within Khayelitsha: A Case Study of the Khayelitsha Health Summit

The findings thus far have focused on the dynamics within the health facilities i.e. between health committees, facility managers/staff and community. Yet these dynamics needs to be seen within the wider context of the Khayelitsha community and the structures that support the health committees such as the KDF and KHF. In Khayelitsha, there is a strong sense of community that has enabled the active engagement between KDF, KHF, health committees and the community on issues relating to the access and provision of quality health services. As a long-standing community leader in Khayelitsha said: "In the black community people are active. They don't want to be at home doing nothing. That is why Khayelitsha is so organised that they can have a KDF because people came together to form a structure and that structure includes all sectors. If you want to get support you get them there [KDF]; if you want social development you can get it there [KDF] …. Political parties and civic [organisations] and NGOs are part of that structure."

Motivations for calling the Health Summit

It in this context that in 2015 the KHF called for a Health Summit which aimed to create a platform where the community, service providers, stakeholders and local Government could engage on health matters. In terms of the community, the KHF wanted to inform them about the burden of disease; strengthen the connection between them and the community health facilities; and help them identify key partner NGOs and CBOs that offer services in the community. Their intention was to provide the community information that would empower them to better understand their health and the services available to them.

The KHF's vision was to hold a three-day event for approximately 500 community activities, community leaders and NGOs, CBOs, and FBOs working in Khayelitsha as well as key stakeholders such as DoH. Over the three days, various organisations would present to the community on different aspects of health in Khayelitsha. They wanted National DoH to share their vision for how pending health system reforms would affect health services provided in Khayelitsha; Provincial and City DoH to provide statistics on the burden of disease; Provincial and City DoH to present budgets and expenditure plans for health care services; and the Minister of the Executive Council (MEC) for Health in the Western Cape to talk about the health programmes she was planning for the province. In addition, there would be facilitated breakout sessions where community members could interact with key players and provide insights on the challenges they were facing with the health services delivery.

The end goal was for the key players and the community to jointly identify major health issues that needed to be addressed and the organisations working in Khayelitsha who could provide services and support. The intention was to hold a health 'indaba' [consultative and decision-making meeting] in the true sense of the word and in doing they would devise a plan of action to take this forward.

Initially KHF wanted to hold the Health Summit in May 2015 but it was postponed on numerous occasions in 2015; first to June, then July, then Oct and finally to November. Unfortunately, KHF's lack of resources and failure to secure sponsorship or funding meant that the Summit as they envisaged never took place in 2015 and was once again postponed to March 2016.

Resources and party politics

On the surface, the main reason for the numerous delays was a lack of resources. The KHF, like the health committees and KDF, is a voluntary organisation that receives no funding for their work. To hold the Health Summit, they required resources to cover the costs of invitations, transport, catering, and supplies (including stationery, t-shirts, caps, marquees and furniture). For some of the costs they could use their networks to provide services for

free; they could find a venue in Khayelitsha, ask the women in the community to do the cooking and request the local radio station to advertise the Summit. However, the KHF felt the event, as they envisaged it, could not go ahead without secure funding or specific donations to cover the cost of food, general supplies and transport for community members.

KHF managed to secure some funding from a local NGO that provides support and training to health committees. They also managed to secure some funding from a key stakeholder and had a number of substantial offers of funding from local businesses. The politics and conditions surround these donations were, however, a minefield for KHF to navigate.

The stakeholder money could only be utilised if specific vendors were used and these vendors had to be approved by the stakeholder. Thus KHF could not apply the funding as they wanted e.g. buying groceries or organising transport. In order to secure funding from the NGOs, the KHF had to side step another NGO, which created tension. But the bigger issue was that the KHF felt that this other NGO was acting like a gatekeeper. One KHF member said: “we didn’t want to waste our time taking our programme to [this NGO] knowing that [they] are not going to move with it” and having no follow up mechanism for them to follow up with them on the status of the funding requests.

The leads from local businesses resulted in naught for the KHF, which they attributed to party politics. A KHF member felt that the politicians were influencing local business leaders. One of the potential business sponsors had made it clear that their funding was dependent on which political parties were allowed present at the Summit. According to KHF, one of local Government’s departments was interested in sponsoring the event, provided that the political opposition was not invited; they did not want it to look like the opposition’s event in their Province.

The result was a huge sense of frustration for the KHF. As one KHF member expressed their frustration. They felt that their potential sponsors had “played” with them; they had asked for meeting after meeting and often the sponsors played “hard to get”. But more significant was that the KHF felt the sponsors had been insensitive to the fact that they personally

covered all the costs of attending the meeting e.g. transport, emails, and phone calls. As a KHF member adamantly said: “they should have told us from day one that they were not interested. They should not have played with us…. Not played hide and seek with resources we don’t have”. They argued that the party politics missed that this was a “community driven programme… it is **not** the government proposing the programme to the community”.

Information and accountability

Another core theme for the Health Summit was the idea of accountability. The community wanted to create a mechanism to understand what services should be provided and how they can hold the providers to account. This includes government, NGOs, CBOs, and FBOs working in the community. As one KHF member said: there are “organisations working in Khayelitsha and the community doesn’t know who they are and what they do. They are not held to account”.

If the community’s representatives – i.e. health committees and KHF – are to hold service providers to account, they felt the need for access to information. They want access to information from DoH at City and Province about budgets, expenditure and plans for health services in Khayelitsha. They want clarity and transparency on the deliverables of NGOs and CBOs working in Khayelitsha and the funding available to achieve this. They want to be consulted about new community initiatives and programmes being launched in Khayelitsha.

Yet many members of the KHF felt that could not easily access such information. Some members claimed they could only access information from City and Province via senior people working at NGOs in Khayelitsha. KHF cited examples of receiving information only because they had asked the NGOs to request the information on their behalf. Thus KHF’s perception was that the NGOs had direct access to City and Province’s DoH staff and information that they did not have.

Some KHF members raised specific concerns about foreign, donor-funded organisations that they felt were actively hindering their access to the decision makers and funders. This was frustrating for the KHF, who felt they represented the community and were best placed to

mobilise the community, yet they were unable to get the necessary support to mobilize community.

This highlights a greater and on-going concern for KHF about accountability, in particular understanding who is accountable to the community and how do you hold them accountable. This task is so much harder without resources. It also begs the question of who are the KDF and KHF (and by association the health committees) accountable to and how is this managed. While the KDF and KHF believe they are accountable to the community, it is not clear what mechanism are in place to enable this and what power dynamics exist between them and the community.

Working with other stakeholders

Another challenge for the KHF was the role played by stakeholders operating in Khayelitsha whose focus was on development issues such as housing, sanitation, education and environmental concerns. While many of these stakeholders did not appear to have a direct role in the provision of health services, their actions often had unintended consequences for the community's health. As a DoH representative said in a public presentation: "Health is the collective responsibility of several providers. It is not only the [responsibility of] DoH. DoH is a care provider".

One such example is the issue of rats in Khayelitsha. The rats are attracted to the waste left by the food vendors who prepare and sell food on the streets. The community complained to KHF, who raised it with KDH and the City. Together with Department of Public Works (DPW), the City implemented a programme that distributed rat cages for the community to use. Due to budget constraints, the DPW would collect the rats and then dispose of them by drowning them. The system worked for the community; it was poison-free and effective. However, the programme was suspended because an animal welfare organisation took legal action against the City on the grounds of cruelty. The community responded by refusing to return the cages to the City.

DISCUSSION

Even though there are functioning structures and a conducive legislative environment to support and assist the health committees in Khayelitsha, the results indicate that they still face significant obstacles that hinders their ability to facilitate community participation and effect change. These obstacles often reflect underlying power dynamics that are multi-dimensional and play out at the different levels of interaction. These are the interpersonal relationships, social contexts, and broader socio-economic and political dynamics which Gaventa describes as having the power to "not only to defeat where voices had been raised, but also, somehow, over time, the voices had been silenced altogether" [1].

The PowerCube framework enables the interpretation of the power dynamics that affect the community's ability to mobilize itself in order to realize their health rights and effect a transformative change for itself. In this context, the community is represented by health committees and the frameworks asks whether they "recovered a sense of their capacity to act and how they mobilised to get their issues heard and responded to in the public agenda" [1]. Ultimately it aims to explore what influence the power dynamics influenced the health committees' ability to act as a vehicle for community participation in order to be an active part of transformative change. Furthermore, it allows for an It allows for an investigation of how power dynamics are perceived by health committee members who are trying to work within a particular socio-economic and political context. Using the PowerCube framework, the discussion below focuses on the inter-relationship of the levels, spaces and forms of power [1].

Spaces of power

Gaventa describes this as the opportunities and channels where people can act to influence policies, decisions and relationships. The power that shapes these spaces has the ability to restrict or invite people to participate in discussions and decision-making. In Khayelitsha there is an active community that wants to participate in dealing with issues that relate to them. In terms of health service there is a policy environment that promotes a rights-based approach where community participation is an integral factor.

It is in this context that there was a conscious move by DoH service providers to invite the health committees into their decision-making space as the representatives of the community using their services. Previously, these decision-making spaces were closed to the local DoH representatives, health care workers and other service providers.

Yet this invitation came at time when the Khayelitsha community was actively mobilizing itself through community structures like the KDF and KHF. They were looking to consultation and engagement as a means of addressing their issues and concerns. As one community leader said: KHF is “the voice of the people” and wanted to represent those who “cannot stand themselves down there, raising their voice [and] unhappiness” and to balance it with “those people that are doing good” because without community structures “like KHF you get more people that are protesting for things that can be solved. It’s a long walk to freedom.”

However, it can be argued that the health committees, with the support from the KHF and KDF, wanted more than just to be invited by those in power. They wanted to claim and create a space where the community had a powerful voice in deciding how their concerns were addressed. Thus, building on the invited space offered to the health committees, they constructed a hybrid space that allowed them to claim more power than the invited space offered.

Part of the complexity relates to the fact that the community, NGOs and donors perceive the community structures, like KHF and KDF, as important stakeholders who have power. This perception has encouraged them to claim spaces of power even though they do not have formal legal status and neither has Provincial Government formally recognized them. For example, building on the power that they have claimed, one of KHF members spoke of their plans to create area committees and street committees. They would be the first port of call for residents needing help or support on any issue and direct them to the appropriate community structure to assist. It would also make it easier to communicate critical information down at grassroots.

Another factor to be considered in the context of Khayelitsha is the multiple, and sometimes conflicting, numbers of claimants wanting to access spaces of power. Furthermore, some of these claimants are not health focused yet they too want to claim spaces of power that relate to health. The strikes, protests and the rat problem mentioned above provide examples of non-health organisations that wanted to claim spaces of power to exercise their influence and in doing so they came up against health committees. But more importantly, this reflects the complexity and intersectoral nature of public health, which is affected by upstream factors such as issues like housing, sanitation, nutrition, education etc.

Levels of power

Gaventa argues that the discussions around the spaces for participation naturally intersects with where power lies and should be seen as a flexible continuum instead of a fixed set of categories [1]. In the case of the KHF and their associated health committees, the levels of power were particularly complex. In terms of this case study, the highest level of power sits with the DoH, which is ultimately responsible for the provision of health services in Khayelitsha.

However, there are two separate DoHs that provide services within Khayelitsha. The majority of the clinics in Khayelitsha are run by the City of Cape Town municipality, while a few clinics and the district hospital are run by Western Cape's Provincial Government. The two DoHs are separate entities, with their own budgets and workforces, even though they are providing services to the same communities. Thus, at the top level of power there are two independent players who are not always aligned.

At the lowest level of power is the health facility. At this level, the facility manager has the power to influence and affect the role the health committees can play in their clinics. In the middle are the community structures like the KHF and KDF, who have created a space where they can participate.

These levels of power are complex and, given the existence of two DoHs and the fact that the community structures are not fully legally or formally recognized, the boundaries of

where levels of power start and end and how they intersect are often unclear and confusing. However, the socio-economic status of health committee members (including the KDF and KHF) makes navigating and accessing these levels of power so much harder. The committees are generally untrained volunteers who rely on their very limited personal resources to cover their transport and communication costs. This is a very tangible and frustrating obstacle for them.

Forms of power

This section explores how power is used, exercised or acted out by the players – what Gaventa calls "dynamics of power" - within these spaces and levels of power [1]. In this case study, the forms of power that came to light were often subtle and implied. In many cases, analysis of the power at work relies of people's accounts of how situations were perceived and understood by the health committees and there often were multiple forms of power at play at the same time.

The most visible form of power exercised by the health committees was their drive to hold the health providers accountable for the services provided to the community. To a lesser extent, this also applies to the committees' need to understand what services and support are being provided health NGOs to the community and how these services were funded.

While the health committees tried to exercise visible power in holding facilities and DoH (and sometimes NGOs) to account, facility managers, DoH and other donors responded with other forms of power, often less visible ones. For example, in order for the health committees to be able to hold providers accountable, they need access to information and to be part of the consultation process. The health committees sought access to budgets and funding plans; planned expenditure; current and future programme plans as well as information about health of community i.e. burden of disease, mortality rates etc. However, a lack of resources makes it difficult for them to gain access to this information. Even the costs of basic expenses like transport to attend meetings, telephones/emails to communicate, and the internet to do research serve as powerful barriers. Furthermore, they

don't have the resources to access training to assist them in understanding how the health system works and guiding them on the important questions to consider.

From the health committee's perspective, the problem of stipends (and to some extent lack of training) was seen as form of power used against them. The lack of stipends for health committees to cover basic costs of transport and communication resulted in obstacles to health committees accessing consultation processes and information. It can be argued that the government and donors had exercised a hidden form of power because they were thereby able to effectively determine who was part of the decision making process.

Furthermore, from the health committees' point of view, the failure of DoH to actively advocate for stipends had in fact disempowered them. Not only did it create a significant obstacle to being part of the decision-making process, it also prevented them from raising general awareness of their problems in the minds of other key decision makers or influential actors. This points to forms of invisible power, ones that include the on-going policy uncertainty in the Western Cape for health committees.

Like the issue of stipends, which forms of power should be considered invisible or hidden depends on context. Political party politics, for example, had a significant impact on the health committees' ability to facilitate community participation through the Health Summit. This played out in the long and painful attempt by KHF to secure sponsorship for the Summit from local businesses and local government. Some members of the KHF were explicitly concerned that any decision to provide sponsorship depended on which political parties were present at the Health Summit. Members of the local health committees, however, were not aware of the ways party politics was shaping the prospects for the Summit. Whether hidden or invisible, though, it was evident that party politics played a critical role in the failure of the KHF hold the Health Summit.

CONCLUSION

The health committees operating in Khayelitsha, under the leadership of the KHF, are fortunate to work in a context that is well structured, functioning and supportive of them.

Despite this, it remains difficult for them to meaningfully participate in the decision-making processes relating to the health of their community. Furthermore, they face on-going obstacles to effectively and constructively mobilize their community. There were other significant factors contributing to the challenges and obstacles they faced.

Using the PowerCube framework, this article has considered the role of power to see if and how it shaped the health committees' ability to facilitate community participation in order to effect change. It is evident that there were many power dynamics at work that played out through working relationships, access to information and resources, local and party politics. The many obstacles that the KHF faced in trying to organise the Health Summit highlights just how forceful the power dynamics can be in hindering community mobilization.

As the health committees evolve, develop and gain traction with their communities, more attention should be paid to the critical role power plays in their ability to bring about transformative change for their communities.

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Part D: Appendices

APPENDIX 1: MATRIX FOR INTERVIEW QUESTIONS

Presented as an appendix in the Protocol, this matrix was adapted from the working notes of the broader PowerCube case study project led by Meier, London, Flores et al

Describing spaces for participation	**Describing the different levels (geography/government) in which decision-making occurs**	**Describing how power is exercised within spaces for participation**
What are the different types of spaces that are available (mapping spaces)	What are the different levels of government with authority over allocation and/or use of resources (i.e. National, provincial, municipal, etc.) and how is authority constituted within these different levels?	Who sets the agenda and defines the terms of reference for participation?
Who created the space? Is there a legal mandate for the space to exist or is the result of the leadership of an authority? Are claimed/created spaces the product of interests with a broad mandate or legitimacy?	How do these levels of government relate to each other? In what directions and on what terms does power flow between levels?	Who sits around the table? I.e., who is included and excluded in the space and how is this determined? Are participants elected or appointed and/or do they force their way in?
Are there formal rules, structures, authorities, institutions, and procedures that guide the work of the space?	What are the non-governmental spaces that are important on various levels and how do they interact with the governmental spaces on various levels?	How are visible and hidden forms of power enacted in the practice of participation? How is invisible power exercised (through the shaping of what is considered possible or necessary within spaces)?
What is the mandate of the space? i.e. just advising local healthcare services or the planning and allocating of public resources?	Are there bottlenecks, leverage points, etc., between different levels? Do relations between levels happen in a linear fashion (i.e. from one level to the next) or there jumps across scales?	What mechanisms exist to ensure information is accessible and accountability is maintained? How are violations of procedure addressed?

What is the relationship between spaces? Do some serve as entry points, leverage points, bottlenecks, etc.? Does access to one spaces open up (or close down) access to another?		What are the effective strategies for countering and reshaping the exercise of power within a space?
What "skills, strategies and resources" are required to operate in this space?		

APPENDIX 2: GUIDE FOR INTERVIEW QUESTIONS

Questionnaire used in the semi-structure interviews

Consent

Go through the consent form?

Ask interviewee to sign

What is their role in the health committee? Why did they choose to get involved?

- How long have you been involved with health committee?
- What made you want to become a member of health committee
- What are your views/thoughts about the current legislation for Health Committees
- Does it enable you to function better? Examples
- Does it hinder you?

How does the health committee operate? Internally and in relation to other stakeholders / organisations e.g. Government, CSO

- How is it made up? Please describe the structure
- What is the purpose of the forum?
- What are the issues?
- How are the committee members elected? Who is represented on the health committees
- How often does it meet? Who sets the agenda?
- Is there an overlap of members?

How does the health committee interact with the community and other stakeholders?

- Examples of how it interacts and what it is trying to achieve
- Who sets up the meeting and where are they held?
- Who sets the agenda?

Who does the health committee meet with (outside of community members) and how often

- What re the outcome of these meetings
- What would make these meetings more successful in terms of outcome for the KHF
- What prevents these meetings from being helping health committee to achieve what they need

What have been the achievements of Khayelitsha Health Forum (KHF) and what have been the challenges and why

- What do they regard as the success of the KHF?
- Examples and reasons why
- What helped them to achieve these successes
- Where do they think that KHF could improve?
- Examples and reasons why
- What hinder them as an organisation
- What has enabled them; what could be done to further enable them?
- What has hindered them; why are these blockages?
- Who or what do they regard as challenges to achieving their goals?

The Health Summit - What was your experience of setting up the Health Summit

- How did they manage to get the other groups on board?
- How did they secure the groups?
- What was their intentions?
- Who is driving it?
- What have been the obstacles and challenges to setting up the Health Summit?

What do they view "meaningful community participation" and why is it important

- What does participation mean to you
- Why do they think participation is important?
- How do they represent their communities?

- What mechanisms/ structures do they use to engage with/mobilise their community? Examples of what they have done
- Examples of how they have mobilized their communities
- Where have they succeed and where have they done less well?

APPENDIX 3: CONSENT FORM AND PARTICIPANT INFORMATION FORM

University of Cape Town

CONSENT TO PARTICIPATE IN RESEARCH (PARTICIPANTS)

Leveraging Community Participation through Health Committees to Achieve Health Rights: The Role of Power

1. **WHO IS DOING THIS STUDY AND WHY?**
   You are being asked to participate in a research project Dr Christopher J. Colvin from the School of Public Health and Family Medicine at the University of Cape Town.

   The project is a case study of the Cape Metro Health Forum (CMHF) which will form part of broader comparative case study project with research partners in Uganda, Guatemala and the US. The aim of the research project is to examine multiple levels of power in community participation and to provide insights into what obstacles the role of power can play and to help inform strategies to address this.

   If you agree to participate in this project, you will be asked to speak with Marion Hasson, one of Dr Colvin's students, who will use your responses as part of her thesis.

2. **WHAT WILL YOU DO IN THIS STUDY?**
   If you volunteer to participate in this study, we would ask you to answer some questions and talk about your experiences of working with and/or in CMHF. If you feel uncomfortable about talking about any of these experiences, feel free not to participate or not to answer a particular question.

   At the start of the interview the researcher will ask for your permission to record the interview. The recordings will be safely stored in a locked cabinet and only the researchers will have access to them. Please tell the researcher if you would not like a particular question or response to be recorded or if you would not like the entire interview to be recorded and hand written notes will be taken.

   Interviews will last between 1.5 and 2 hours. Please tell the researcher if you have any time limits or if you need to leave at any time. Nothing will happen if you do not wish to participate or if you decide to withdraw from the study before its conclusion.

3. **ARE THERE ANY RISKS IN THIS RESEARCH?**

You may feel uncomfortable speaking about some aspects of role or interaction with CMHF. If at any time you do not want to answer a particular question, please tell the researcher and you will not be asked to answer. You are free to not answer any question or speak about any subject that you do not want to. If you feel upset during or after the interview, please tell the researchers.

4. ARE THERE ANY BENEFITS OF PARTICIPATING FOR ME?

There are no direct benefits to you for participating in this study.

5. WILL I BE PAID TO PARTICIPATE?

Participants will receive no payment for participating in this study.

6. WILL MY NAME BE SHARED WITH ANYONE?

The researchers will not share your name with anyone and when they write about the research, they will not use your name. All the information from this project will kept by the principal investigator (Dr Colvin) in a safe place. No one outside the research team will have access to your information. Extracts from your interviews or coursework may be published in research reports but any direct information that could identify who you are will be removed.

7. WHO ARE THE RESEARCHERS?

The Principle Investigator is Rd. Colvin from the School of Public Health and Family Medicine at the University of Cape Town. If you have any questions or concerns about the research, please feel free to contact

Rd. Christopher J. Colvin

Tel: 021 447 7605

E-mail: cj.colvin@uct.ac.za

or

Marion Bloch

Tel: 021 650 1487

Email: marion.bloch@uct.ac.za

8. WHAT ARE MY RIGHTS AS A RESEARCH PARTICIPANT?

You may withdraw your consent to participate in this study at any time and stop participating without any penalty. When you participate in this study, you are not giving up any legal claims, rights or remedies that you may have. If you have questions about your rights as a research participant, contact the HREC at the Faculty of Health Sciences at the University of Cape Town on 021 406 6338

SIGNATURE OF THE RESEARCH PARTICIPANT

The information above was described to me by _____. I was given the opportunity to ask questions and these questions were answered to *my* satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

_____

Name of Participant

_____ _____

Signature of Participant **Date**

SIGNATURE OF THE INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the participant]. [H*e/she] was encouraged and given ample time to ask me any questions.

APPENDIX 4: LETTER OF APPROVAL FROM RESEARCH ETHICS COMMITTEE

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

30 October 2014

HREC REF: 728/2014

Dr C Colvin
Public Health & Family Medicine
Room 3.46, level 3
Falmouth Building

Dear Dr Colvin

PROJECT TITLE: LEVERAGING COMMUNITY PARTICIPATION THROUGH HEALTH COMMITTEES TO ACHIEVE HEALTH RIGHTS: THE ROLE OF POWER (MPH-candidate-M Hasson)

Thank you for your response to the Faculty of Health Sciences Human Research Ethics Committee dated 29 October 2014.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th October 2015.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

We acknowledge that the student, Marion Hasson will also be involved in this study.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

APPENDIX 5: INSTRUCTIONS FOR AUTHOR OF JOURNAL WHOSE FORMAT HAS BEEN USED

HHR
Health and Human Rights Journal
A GLOBAL MOVEMENT TOWARD HEALTH EQUITY

Submissions

Health and Human Rights: Submissions

girls at door

Health and Human Rights Journal, a peer-reviewed open access journal under the editorship of Partners in Health co-founder Paul Farmer, is published twice a year, with new issues in June and December. Selected papers in press are made available prior to issue publication, thereby fast-tracking access to new research and enabling authors to cite their work early. Submissions are welcome at any time.

Types of Submissions

Full papers

Perspective Essays

Letters to the Editor

Blogs

Full papers

Full papers are original academic articles (research, commentary, operationalization of human rights-based approaches to health, and analysis) which contribute to, and advance, health and human rights literature. These manuscripts must be 3500-7000 words (including references), and if selected by the editorial committee, will undergo external for peer review by at least two peers.

*Health and Human Rights Journal*welcomes articles that explore the centrality of the right to health in all social, economic, cultural, and environmental contexts. The Journal publishes a wide range of topics from a health and human rights perspective—please look at our recent issues to get a sense of the range. The editors welcome papers that consider contemporary global health issues as matters of human rights.

Full papers are published in every issue of the Journal and many may be published online ahead of the publication date as a "Paper in Press".

Further detail about style and referencing is included in the Author Guidelines.

Perspective Essays

PAPERS IN PRESS

Opening the Door to Zero New HIV Infections in Closed Settings
(02/03/2016)
Anna Torriente, Alexander Tadion, and Lee-Nah Hsu

An Independent Review and Accountability Mechanism for the Sustainable Development Goals the Possibilities of a Framework Convention on Global Health
(01/20/2016)
Eric A. Friedman

Biosocial Approaches to the 2013-2015 Ebola Pandemic
(12/22/2015)
Eugene T. Richardson, Mohamed Bailor Barrie, J. Daniel Kelly, Yusupha Dibba, Songor Koedoyoma, and Paul Farmer

SUBMIT A MANUSCRIPT

RECENT PERSPECTIVES PIECES

Medical Hostages: Detention of Women and Babies in Hospitals
(01/17/16)
Delan Devakumar and Rob Yates

Extending the Right to Health to the Moment of Death: End of Life Care and the Right to Palliation in Rwanda
(12/04/15)
Agnes Binagwaho, Sardis H. Harward, Theophile Dushime, Jean de Dieu Ngirabega, Parfait Uwaliraye, Cathy Mugeni, Kirstin W. Scott, Marie Aimee Muhimpundu, Jean Pierre Nyemazi

Making Medicines Accessible: Alternatives to the Flawed Patent System
(11/23/15)
Fran Quigley

The editors welcome Perspective Essays which are shorter papers, up to 3000 words, including references. Perspective Essays provide authors with an opportunity to provide a well reasoned and evidence-informed viewpoint, which extends the health and human rights literature. Perspectives often engage with and examine leading edge issues, and are published on the website in advance of each issue, allowing timely responses to current debates. These manuscripts are reviewed by two external peers. They are published in the Perspectives Section of each issue of the Journal.

Further detail about editorial and reference style is included in the Author Guidelines.

Letters to the Editor

Letters to the Editor are welcome. These contributions should be no more than 2000 words in response to an Editorial, Full Paper or Perspective Essay published in the Journal. Letters are internally peer reviewed to check for accuracy and fairness.

Special Themes

Health and Human Rights Journal has a themed section in all issues. Calls for papers for these sections are made well in advance of the deadlines. The forthcoming Special Themes are also included on the website, with the names of the guest editors, information about the theme and author guidelines.

Blogs

Health and Human Rights Blogs are published on the Journal website but are not included in the Journal itself.

Blogs are a less formal and shorter (about 600-800 words) article on a global health topic examined as a human rights issue. The editors frequently run a blog series, for example, SDG SERIES, or COP21 SERIES, to allow contributors to participate in, and shape, an important topical issue.

Blogs can either have hyperlinks or use our normal referencing style. The contributions are internally peer reviewed, for accuracy, relevance, and fairness. We aim for a quick turnaround from receipt to publication which is important for the topical nature of blogs.

General submission information
All manuscripts submitted to *Health and Human Rights Journal* must not be before another publication for consideration.

All submissions are subject to initial assessment by the editorial committee to determine their suitability for publication.

Papers and Perspectives accepted for formal review will be sent to at least two independent referees with all authorship details removed. Typically the authors are advised of the outcome of the peer review phase within three months. The referees and editors may request more than one revision of a manuscript, and alternative referees may also be invited to review the manuscript at any time.

Please submit all manuscripts to HHRSubmissions@hsph.harvard.edu

For specific format details, please see "Author Guidelines."

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SDG SERIES: SDGs and the Importance of Formal Independent Review: An Opportunity for Health to Lead the Way
(09/01/2015)
Paul Hunt

COP21 SERIES: Full list of COP21 SERIES essays and blogs

SDG SERIES: Full list of SDG SERIES essays and blogs

View all Perspectives

BLOG POSTS

Hope for the High-Level Panel on Access to Medicines

Sustaining Underdevelopment: Human Rights Accountability and the Business of Food

Promising the World: Accountability and the SDGs

SDGs, Accountability, and the Right to Health: A New Series

NEW HHRJ SERIES: Calling for blogs on SDGs, Accountability, and the Right to Health

HEALTH AND HUMAN RIGHTS ON TWITTER

Tweets Follow

Health&HumanRights

#HHR Journal deadline for papers on #UHC & #humanrights 28 Feb-don't miss out Guest Ed Prof Audrey Chapman UConn ow.ly/Yh7Lk

Amnesty London

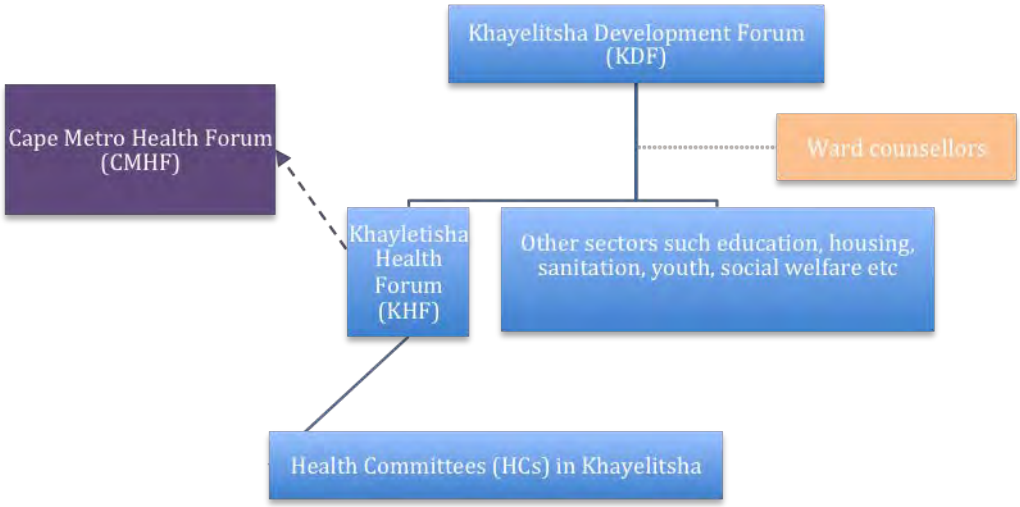
Why we should all love human rights this Valentine's Day amnesty.org.uk/blogs/yes-mini

Tara C. Smith

Downer reminder of the day: much of our chocolate is harvested by child & slave labor. Buy ethically.

ADVERTISEMENT

APPENDIX 6: THE HEALTH COMMITTEE STRUCTURES IN KHAYELITSHA



Within the sub-district of Khayelitsha, the rapidly growing community has access to 12 health facilities and one district hospital. The majority of these sites are run by the City of Cape Town and while Khayelitsha District Hospital (KDH) is run by Province.

In accordance with draft policy for Health Committees, each facility must have a health committee. At the time of this study, there are currently eight health facilities in Khayelitsha with functioning health committees and approximately another six health facilities that still need to establish a health committee. Each health committee is made up of 14 members, which includes a chairperson; deputy chairperson; general secretary; deputy secretary; treasurer; organiser/administrator and four additional members.

Each Health Committee will hold an AGM where members are elected. The candidates, who must be active in the catchment area for the health facility, are recommended from various Civil Society Organisations (CSOs), Non-Governmental Organisations (NGOs) and Community Based Organisations (CBOs) as well traditional healers and local leaders. Ward Councillors also attend Health Committee meetings and are there to assist and advice and to be an important link between the Department of Health (DoH) at City or Province. However, they do not have any rights to vote.

The Health Committees report into the Khayelitsha Health Forum (KHF), which was formed by the Khayelitsha Development (KDF) to address issues relating to health in the area. The KHF is made up of 14 people, who are elected at KHF AGM in accordance stipulations of the KHF constitution. The posts include a chairperson; deputy chairperson; general secretary; deputy secretary; and treasurer. The remaining posts are filled by a representative from the health committee at each health facility. They meet on a quarterly basis and is also attended by the CEO of the Khayelitsha District Hospital (KDH), the City Health Manager for Khayelitsha and Provincial Director for Khayelitsha and Eastern Sub-Structure Office

The Khayelitsha Development (KDH) was launched in 1995 and is a voluntary community organisation that promotes social development within Khayelitsha. It works to support initiatives for community development through citizen/community participation. It has approximately 48 members, which include traditional and political leaders as well as community representatives for health, education, social welfare, housing, youth etc. It meets weekly and is used as a platform to support, assist and communicate with the community representatives, who will then liaise with the community members.

The Khayelitsha District Hospital (KDH) does not have a health committee but rather a board who is appointed by Provincial Government. However, the CEO of the KDH attends all the meetings of the KHF.

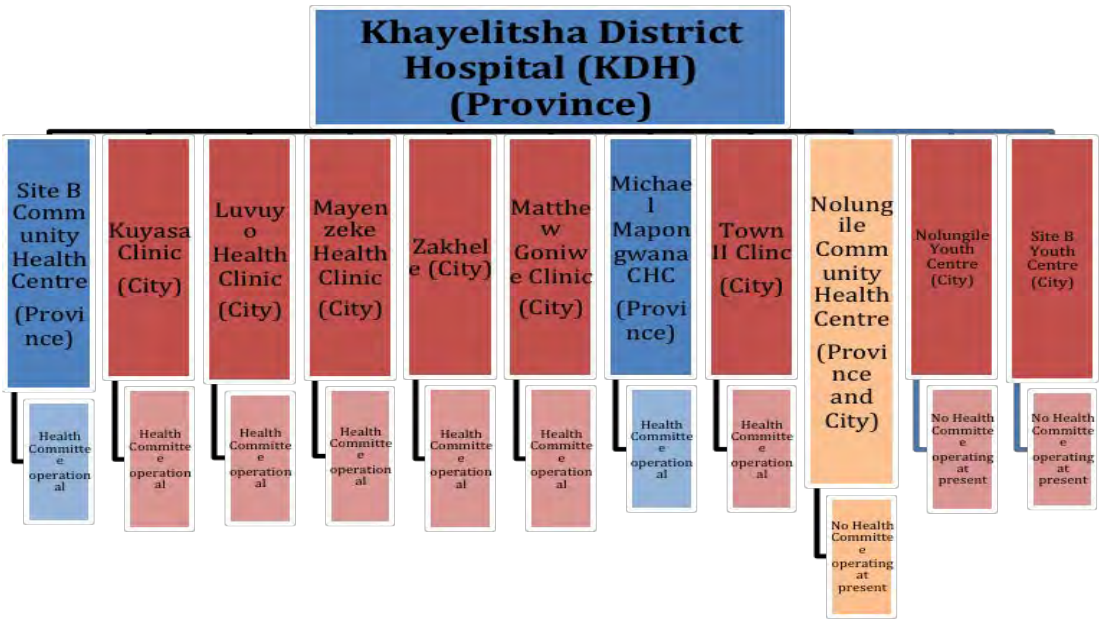
APPENDIX 7: BREAKDOWN OF HEALTH FACILITIES IN KHAYELITSHA

Sites managed by Provincial Government of the Western Cape (referred to as Province) are:

- Khayelitsha District Hospital
- Khayelitsha (Site B) CHC
- Michael Mapongwana CHC

Sites managed by City of Cape Town Municipality (referred to as City) are:

- Kuyasa CDC
- Luvuyo CDC
- Matthew Goniwe CHC
- Mayenzeke Clinic
- Nolungile Youth Centre
- Site B Youth Centre
- Town Two CDC
- Zakhele Clinic

There is one site that is jointly managed by Province and City

- Nolungile CHC