

# Lay Health Worker Programmes as a Public Health Approach in South Africa



Karen Daniels

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## ABSTRACT

**Aim:** The overall aim is to assess the appropriateness of Lay Health Worker (LHW) programmes as a public health intervention in South Africa by considering the effectiveness of LHW programmes across the world and the experience of LHW programme implementation and policy making in South Africa.

**Methods:** This thesis comprises 4 papers that explore the issue of LHWs: (I) A systematic review of randomised controlled trials (RCTs) of LHW interventions in primary and community health care for maternal and child health and the management of infectious diseases; (II) A study of the experiences of farm dwellers trained to be LHWs, as explored through focus group discussions; (III) A study of three LHW supervisors who worked on an intervention to support infant feeding mothers, as explored through individual interviews; and (IV) A study of the process of LHW policy development from the perspective of 11 key informants who were individually interviewed.

**Findings:** LHWs were found to be effective in promoting breastfeeding and in improving pulmonary TB cure rates (I). There was also some indication that LHWs could be effective in reducing child morbidity and child and neonatal mortality, and in increasing the likelihood of caregivers seeking care for childhood illness (I). The experience of LHWs and LHW supervisors suggests that LHW programmes need adequate support and supervision, especially in protecting the LHWs themselves (II, III). The care and protection of LHWs was considered by policy makers (IV), but policy redevelopment processes did not link the need to ensure that LHWs were not exploited to concerns about gender exploitation.

**Conclusions:** LHW interventions can be effective but implementing them in developing countries such as South Africa needs to be approached with caution.

**Key words:** Lay health workers, Lay Health worker programmes, public health, primary health care, gender, intervention effectiveness, intervention experience, policy making, programme supervision.

## ORIGINAL PAPERS INCLUDED IN THESIS

This thesis is based on the following articles, which are referred to in the text by their roman numerals.

- I. Lewin S, Munabi-Babigumira S, Glenton C, **Daniels K**, Bosch-Capblanch X, van Wyk BE, Odgaard-Jensen J, Johansen M, Aja GN, Zwarenstein M, Scheel IB (2010). Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases. *Cochrane Database of Systematic Reviews*, Issue3.Art.No.:CD004015.
- II. **Karen Daniels**, Hendrien Van Zyl, Marina Clarke, Judy Dick, Eva Johansson (2005). Ear to the ground: Listening to farm dwellers talk about the experience of becoming lay healthworkers. *Health Policy*, 73, 92-103.
- III. **Karen Daniels**, Barni Nor, Debra J Jackson, Eva-Charlotte Ekstrom and Tanya Doherty (2010). Supervision of community peer counsellors for infant feeding in South Africa: an exploratory qualitative study, *Human Resources for Health*, 8:6
- IV. **Karen Daniels**, Marina Clarke, Karin C Ringsberg (2012). Developing lay health worker policy in South Africa: a qualitative study. *Health Research Policy and Systems*, 10:8

All articles have been reprinted with the permission of the publishers.

## List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ANC	African National Congress
FGD	Focus Group Discussion
HIV	Human Immunodeficiency Virus
LHW	Lay health worker
NGO	Nongovernmental Organisation
PHC	Primary Health Care
RCT	Randomised Controlled Trial
RCTs	Randomised Controlled Trials
TB	Tuberculosis
WHO	World Health Organisation

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NHV Reports (V)

## INTRODUCTION

I grew up in South Africa under apartheid. During the late 1980s and early 1990s I was a student activist in the struggle against apartheid. My activism during those years has indelibly shaped my view of the world and how I see my place in the world. Since then I carry values such as social justice and equity very strongly. I also believe that the world as it is, is our creation and that it is our responsibility to continuously work towards the creation of a better world in which all people are able to enjoy freedom from poverty, hardship and disease.

The transition from apartheid to democracy was quite amazing for those of us who lived through it. Those of us who had been activists worked tirelessly to bring about the end of apartheid. However, when the end came it caught us by surprise. While I had, with the eternal optimism of youth, always hoped for a better South Africa, it never occurred to me that a switch could come so quickly and in my lifetime. The dawning of democracy brought wondrous hope founded in complete naïveté about what a new government might achieve. I and many of my comrades mistakenly believed (despite warning from thinkers like George Orwell) that the struggle was over. We were wrong; the struggle had only just begun. The African National Congress (ANC) came into government in high spirits on a wave of confidence not matched by actual experience. In the process they tried to reform all aspects of governance and service delivery. In some aspects they have succeeded and in other aspects there is still much work to be done. In the ensuing years since 1994, I have lost my naïveté, but I have not lost my commitment to the creation of a better South Africa. My site of struggle has moved from the streets to policy making and implementation. I believe that we can create knowledge upon which better policies and programmes can be developed through sound research. This PhD is a part of my commitment to transformation in South Africa. Through this work I hope to offer evidence and reflections on Lay Health Worker (LHW) interventions as a public health approach, in the hope of contributing to the continued process of policy making and implementation.

Although I currently work as a public health researcher, I am trained as a historian and I have an undergraduate major in English. As part of my training as a historian I was introduced to qualitative research. In my first job after graduating I was employed as an

intern on a qualitative study which explored caring in health care and hence began my career in public health research. While I have had more experience with qualitative studies, I have worked on quantitative epidemiological studies and I respect the place of both perspectives in public health research.

This PhD started in the early 2000s when I was asked to assist with the process evaluation of a LHW intervention in which farm dwellers were trained to deliver healthcare services to fellow farm dwellers. My task was to research the experiences of the LHWs themselves - Paper II in this thesis is the culmination of that research. As a part of this process I conducted focus group discussions (FGDs) with these LHWs and really listened and took note of what they said. I knew I wanted to come back to this topic, but the time was not right yet. I then did an MPH and in the process strengthened my understanding of public health. My MPH thesis analysed the utilisation of research information (knowledge translation), in policy making and guidelines for the use of magnesium sulphate in the treatment of Eclampsia and Pre-Eclampsia in South Africa. When the opportunity arose to do a PhD I was able to return to the topic of LHWs. At the time I was involved in two pieces of research involving LHWs. The one was a systematic review of evidence of LHW intervention effectiveness. The other was a process evaluation of a LHW intervention. This research is included in the thesis in papers I and III. While engaged in this work the lessons from the research described in paper I, were still with me. What stood out for me was that women were saying that while they enjoyed being LHWs, they found this work increased their caring burden. I started reading other studies in which similar stories were told. Out of this I decided that as a part of this thesis I needed to study how gender concerns were translated into policy-making for LHWs. The outcome of this research is reported in paper IV.

This thesis therefore presents a culmination of my research on LHWs to date. It presents epidemiological evidence for the effectiveness of LHW interventions (I); reflections on the experiences of LHWs and LHW supervisors (II, III) and considerations around how policy making for LHW interventions is developed in South Africa (IV).

Although LHWs interact with clients or patients at an interpersonal level, this thesis focuses on LHW programmes and policies at the population level. Other on-going research focuses

more directly on the interpersonal level, such as that by Sarah Dewing (1) which explores the counselling relationship between LHWs and clients in antiretroviral adherence support.

## **THEORETICAL FRAMEWORK**

### **Public Health**

This PhD adopts a public health perspective. Although the practice of public health dates back to at least the late 19<sup>th</sup> century (2), the definition scope and practice of public health continues to evolve (3). Common to definitions of public health is that it involves some kind of action taken to improve the health of whole populations (2-5). This action has been described as the “process of mobilizing and engaging local, state, national, and international resources to assure the conditions in which people can be healthy” (6, p.3). Public health also encompasses health promotion which is the “process of enabling people to increase control over, and to improve their health” (7). The Ottawa Charter calls for this process of health promotion to be supported by building healthy public policy, creating supportive environments for health, strengthening community action for health, developing personal skills and re-orientating health services (7, 8). Central to these definitions of public health and health promotion therefore is the role of governments in ensuring the health of their citizens. This role is described by Beaglehole et al (3) as a “positive obligation by governments and communities to protect and improve the health of all their communities” (p.2084). It is suggested that individuals are constrained in decision making by environmental and socioeconomic circumstances, thus necessitating government intervention at a population level (3). In the actions they take governments are encouraged to work collaboratively, to ensure that their decisions, policies and interventions are evidence based and to aim towards the reduction of health inequity and inequality (2-5). Action taken towards a reduction in health inequity is particularly important as there is an established link between poor health outcomes and socioeconomic inequity (9). As the commission on Social Determinants of Health has shown, people with the least access to resources are also those with the worst health outcomes (9). Equity in health service delivery is when all citizens are able to access the health services they need for the best attainment of their health within the limitations of the resources of the State (10). Attainment of public health equity by implication then would be when the State is able to

deliver a scientifically sound and fairly distributed service to all its citizens on the basis of need (11).

### **Lay Health Workers (LHWs) as an international public health approach to increase health service access**

A lack of access to healthcare is an internationally recognised problem and many countries in the world are not able to achieve equity in healthcare delivery (9). The World Health Organization (WHO) suggests that “in many places access to healthcare is difficult and there are not enough health workers, and so we need to look at other approaches outside the clinic and hospital setting” (12). In response, one of the internationally (including South Africa) adopted public health approaches to increasing healthcare access has been the development and implementation of LHW programmes (13). LHWs are claimed to serve a critical function in communities in which they work often providing a service to the most marginalized poor communities (14) where none may otherwise have been available.

LHWs have been defined as any health worker carrying out functions related to healthcare delivery; trained in some way in the context of the intervention; and having no formal professional or paraprofessional certificated or degreed tertiary education (15). LHWs may be engaged in a range of activities which include health promotion (such as breastfeeding support) and disease prevention (such as tuberculosis (TB) treatment support) (8, 15). They are known by many names including lay health workers, community health workers, community care givers, treatment supporters/buddies, peer supporters and home/community based carers. For ease of discussion, they will be referred to throughout this thesis as LHWs. Unlike formal health care which requires clients to seek out health services for themselves, LHWs are often engaged in household visits (16), thus taking the service to the doorstep of families. LHWs can be found in some form or other all across the world, including in Nordic countries (e.g. see <http://www.amningsjalpen.se/>).

### **LHWs as part of a Primary Health Care approach to public health**

The concept of LHWs has been around for at least 50 years (13). In particular they were strongly promoted in the years following the International Conference on Primary Health Care (PHC) at Alma-Ata (1978) (17, 18). The contribution of communities to their own

health and the role of LHWs in achieving PHC are both stated in the Declaration of the Alma-Ata (19). In the period immediately following the conference, LHWs were seen as a means to improving PHC in developing countries (18, 20, 21) and reaching the goal of Health for All by the year 2000 (17). The 1980s thus saw the emergence of many such programmes (18, 20, 21), but subsequent failure to produce the expected outcomes led to a decline in enthusiasm for national LHW programmes (18).

Recent years has seen a renewed energy around PHC, with calls for its reorientation and revitalisation (22, 23). In particular support for PHC has come from the WHO itself. When current Director General Margaret Chan took office in 2007 she called for “a return to primary health care as an approach to strengthening health systems” (24). This call was followed by a recommendation from the Commission on the Social Determinants of Health that health systems built on PHC could contribute to the achievement of universal healthcare (25). It was further taken up in the 2008 World Health Report which was dedicated to PHC (22). The call came with recognition that the contemporary organisation of health systems globally, both in poor and rich countries were failing to deliver effective healthcare (22). Furthermore there has been a recognition that the goal of Health for All has not been achieved and this is linked to a growing concern that the Millennium Development Goals are also unlikely to be achieved by the year 2015 (26).

As part of the renewed focus on PHC the concept of community participation and the role of LHWs as contributing to PHC have also come back into focus (26). The role of LHWs and community participation in PHC success has been highlighted (27). Arguments by Global Health Watch however would suggest that the current push for LHWs is within a narrow view of selective PHC in which LHWs are extension workers in vertical (single disease focused) programmes (23). Their arguments further suggest that a more appropriate approach would be comprehensive PHC which looks at both horizontal programmes (across disease) and takes an intersectoral approach, where it is recognised that health is determined by broader political and economic forces which also have to be addressed. Within this approach LHWs would not only have the role of healthcare delivery, but would also have a broader community mobilisation mandate (23, 28).

## **The contribution of LHWs to the reduction of the global burden of disease**

The renewed focus on LHWs within public health and PHC (13) is partly born out of a need to address key contributors to the global burden of disease such as HIV (18) and poor child health (29-32). In child health for example, success has recently been shown in their contribution to exclusive breastfeeding (33). This is an important contribution as poor mothers face particular challenges (34, 35), but formal health workers may find that the need to offer infant feeding counselling competes with the priority of clinical care. LHWs have also been shown to be successful in increasing immunisation rates in their efforts to promote immunisation and in giving the vaccinations themselves (36).

Although LHWs are conventionally thought of in relation to their contribution to infectious disease care, they have been shown to be successful in chronic care such as mental health. As with other areas of healthcare, a great scarcity and inequity exists within human resources for mental health care within developing countries (37-39). The WHO has argued that the limited resources have resulted in a more than 75% treatment gap for mental, neurological and substance use disorders in low and middle income countries (39). Others have suggested an even higher gap of 90% (37). In recognition of the need to close this gap the WHO has been very strongly advocating for task shifting in mental health through its Mental Health Gap Action Programme (39). This argument is supported in the literature (37, 38, 40, 41). In discussing the Mental Health and Development Agenda in sub-Saharan Africa, Jenkins and colleagues (40) argue against the presumption that mental health services can only be delivered by specialists. This argument is supported by evidence for the effectiveness of community based and community health worker interventions in developing countries. These include the treatment of post war depression in Uganda (42), schizophrenia in rural India (43), dementia in India (44), postnatal depression in Pakistan (45), and schizophrenia in China (46).

## **LHWs as part of a public health response to an international human resources crisis**

Developing countries face severe health worker shortages across all levels of healthcare (47). The WHO has estimated that 57 countries face critical health worker shortages (48). Thirty-six of these occur in sub-Saharan Africa (48). While health worker shortages are

exacerbated by increased demands placed on health services by infectious diseases (49-52), they are also contributed to by migration, poor staff morale and incentives (50). The problem is not limited to shortages, but also to inequitable healthcare staff distribution both within countries and between countries thus skewed to the benefit of both wealthy countries and wealthy urban areas within poor countries (37, 50, 53).

As a response to this human resources crisis the concept of task shifting in healthcare services has been advocated, especially since the World Health Report of 2006 (48, 49, 54). The concept of task shifting is not new as in 19<sup>th</sup> century France non-physician healthcare workers were already commonly used (51). When task shifting occurs then medical and health services tasks, which previously were performed by higher level cadres, are shifted or delegated to lower level cadres (50, 54). While this delegation of tasks may be a response to health worker shortages (52), in some instances it may be more efficient and cost effective for lower level cadres to perform the tasks if they can produce the same quality as higher level cadres (54). Proponents of task shifting would argue that this approach should not just be seen as an emergency response since lower level cadres may be as good as or better than those originally trained for the task (52, 55).

Part of the current international focus on LHWs is within this broader consideration of task shifting and health worker shortages. Tasks assigned to LHWs usually involve health promotion or treatment support, but it has been shown that LHWs can successfully take on more clinical tasks such as rapid diagnosis for malaria (52). Thus in many settings LHWs are seen as making a key contribution to the human resource capacity needed for effective healthcare delivery (26, 47).

### **LHW Motivation**

While most research on LHWs has focused on their impact and benefits to public health (56), it is also important to consider what benefits incumbents themselves may derive from becoming LHWs, in other words what motivates them. In a review of the issue Bhattacharyya et al (57) point to monetary (e.g. material incentives), non-monetary (e.g. gaining respect, achieving status, personal growth) and community level (e.g. being selected by the community) factors as acting as incentives and motivators to LHWs. The authors

point out however that these motivators are very context specific. The contextual nature of motivators is supported by other illustrations in the literature. As an example, a study in Nepal found that LHW volunteers were perceived as motivated by a sense of morality, while payment for their services was perceived as being potentially demotivating (187). In contrast, a study in South Africa found that people were motivated to volunteer as LHWs for multiple reasons, including avoiding idleness while unemployed, career opportunities and altruism (58). Research on LHW motivation and LHW attrition are both necessary (56) and on-going (59).

### **LHW programme critiques**

Despite all of this enthusiasm however, over the past 30 years LHWs interventions have also faced critique and failure (18). The oldest explanations for the failure of LHW interventions throughout the world have been the inadequacy of the supervision given to LHWs and the lack of support given to them by formal healthcare staff (17, 21, 60). The lack of support has sometimes been linked to health workers feeling threatened, but this is also premised on questions of scope of practice, and questions raised around who within the health system should be allowed to perform which tasks (55). Effective supervision is however crucial (17, 61).

### **LHWs as care workers**

More recently LHW programmes have also been critiqued by feminist researchers<sup>1</sup> (62-64). These critiques recognise the benefits of LHW programmes, but raise questions around the extent to which these programmes add to the burden of caring for women who become LHWs.

Fisher and Tronto (65, p.103) define care as including:

“everything that we do to maintain, continue and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.”

Within this definition the work that LHWs do, whether it be in promoting health (such as in breastfeeding counselling), supporting treatment (such as encouraging TB patients to

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<sup>1</sup> These critiques are within a broader critique of professionalised and non-professionalised care, which has also been contributed to by sociologist and social work theorists.

complete their course of medication) or palliative care (such as is needed in home based care for very ill AIDS patients), can be described as caring or care work.

Care is increasingly being viewed as an economic activity (66-68). Razavi (64, 67) discusses care as an aspect of social reproduction and a public good. Her arguments suggest that care is a public good because we need care to produce and reproduce labour, i.e. healthy adults and children are the product of adequate care. Despite this importance, some would suggest that care work has remained undervalued and invisible and feminized (66, 67, 69, 70). It is argued that much of the work of care is conducted by women within the context of the home and is unpaid (67, 71). Doyal (72) has suggested that work that takes place in the home, the work of caring and sustaining people is hazardous and demanding. It is also argued that the cost of caring by overburdened poor women is carried by their families (14). Home-based workers also often lack social protection (72). When caring work is required outside of the home, the literature suggests that there is an assumption that women who do the caring work in their families will continue to do the unpaid caring work in their communities (72, 73). Even when caring is taken out of the home it is still more often done by women and continues to be regarded as being of low value:

“Caring seems to be widely devalued, no matter where it takes place and who performs it, the low pay often justified by constructing such work as ‘low-skilled’ and/or as work which carries its own rewards.”(67, p.887)

In an attempt to highlight the value of care one feminist researcher has attempted to measure the contribution of unpaid caring to the gross domestic product (GDP) of both industrialised and developing countries (68). In South Africa she found that this contribution is equivalent to between 11% and 30% of the GDP (68).

The problem of caring work in general being hazardous, gendered and undervalued has not escaped LHW programmes. A gendered analysis has been conducted of human resources internationally, including LHW programmes (62, 63). This review showed how female LHWs throughout the world were burdened by their responsibilities (62, 63). These burdens included challenges to the legitimacy of their work, threats to their personal security and having to take on physically and emotionally demanding tasks. In settings that were poorly serviced this challenge was increased, e.g. having to collect water in buckets for cooking,

cleaning and bathing the sick person. Despite these burdens female LHWs could gain recognition and respect through supportive supervision and management (62).

Care and care work however need not only be burdensome (64). Governments can play a role in creating enabling environments for care and in protecting care workers (64). Tronto (66) points to four phases of care: caring about, giving care, receiving care, and taking care. Caring about refers to the acknowledgement that care is needed, receiving care is what the person being cared for does, giving care refers to the work of caring, and taking care refers to taking on the responsibility for caring. Within this construction governments have the responsibility of taking care by providing resources, policies and environments in which care can be enabled. Part of enabling care would require of governments to take care of those who do the work of caring. Well-resourced countries, such as the Nordic countries are viewed as being caring countries because their strong social welfare policies enable care (64). However research has shown that less well-resourced countries have also been developing and implementing social welfare policies which support caring (64).

Recognising how female LHWs can become burdened by care, and recognising that this situation can be challenged, this PhD is situated within an approach to research which takes a stand not only to understand gender relations, but to challenge gender oppression (74-78). As a researcher I am challenged to consider how care work and women's work as LHWs can be better valued, and whether or not LHW programmes can be considered as effective health care and social reproductive care. Furthermore the emphasis on collective responsibility for caring, including governments' responsibility for taking care suggests that there may be a link between caring and the public health imperative of collective responsibility for ensuring good health care.

## **THE SOUTH AFRICAN HEALTHCARE SETTING**

### **South Africa at a glance**

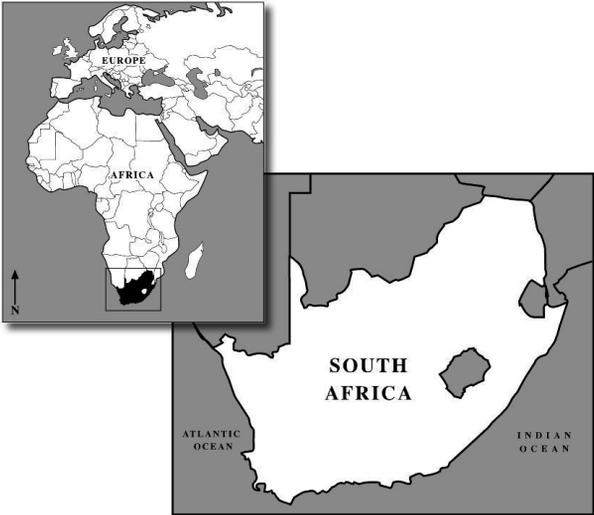
South Africa is a middle income country at the southernmost point of Africa. Since 1994 South Africa has been a constitutional democracy (79). The country is culturally diverse as attested to by its eleven official languages. The Gini coefficient (including salaries, wages

and social grants) of 0.73 as measured in 2006, indicated huge economic disparities within the country. The country’s key indicators are presented in Table 1 below. Issues related to health and health service delivery are described the proceeding paragraphs.

**Table 1: South Africa’s key indicators (80)**

Indicator	Values	
<b>Real GDP (2007)</b>	R1,750 billion	\$248 billion
<b>Real GDP per capita (2007)</b>	R36,461	\$5,168
<b>Population</b>	Total	49,320,500
	Male	23,868,700
	Female	25,451,800
	0-14 years	15,500,700
	15-34 years	18,447,000
<b>Government</b>	Constitutional multiparty, three spheres (local, provincial, national) democracy	
<b>Official languages</b>	English, isiZulu, isiXhosa, isiNdebele, Afrikaans, siSwati, Sepedi, Sesotho, Setswana, Tshivenda, Xitsonga	
<b>Key economic sectors</b>	Mining services, transport, energy, manufacturing, tourism, agriculture	
<b>Adult literacy rate</b>	Male – 87.2	Female – 86.9
<b>Percentage living below poverty line of \$2.50 (purchasing power parity)</b>	42.2 (1.44) [2000]	34.8 (1.60) [2006]

**Map of South Africa in relation to Africa and Europe**



**Figure 1**

### **Public Health reform in South Africa**

South Africa's health system has been impacted upon by its apartheid past during which the health of black South Africans and rural dwellers were particularly neglected and underfunded (53, 81). Since the first democratic elections in 1994, there have been attempts at public health reform aimed at creating a more equitable health system (53, 79, 82-84). This starts at the highest level with a new constitution that now enshrines rights to healthcare and dignity (85). Encompassed in the process of healthcare reform therefore has been the development and implementation of several new healthcare policies (86). The foundation for several of these policies was laid in the African National Congress (ANC) Health Plan and the Reconstruction and Development Programme (87, 88). These documents lay emphasis on public and primary health care approaches (87, 88). This transformation process achieved some success including the provision of free PHC for all, the adoption and implementation of the Choice on Termination of Pregnancy Act, the adoption of anti-tobacco legislation and even better malaria control (84). Despite these successes, major inequities continue to exist in the health status and the health service access of the country's citizens (84, 89).

### **Access to healthcare in South Africa**

South Africa has a health care system which includes both public and private care (53). The general perception is that private care is of a higher quality than public care which is offered by the State, but private care is very expensive (53). Given the huge socioeconomic inequity in the country 64% of the population are entirely dependent on State provided public healthcare services (53). Despite some success in government's attempts at reforming the post-apartheid healthcare system access to care, whether public or private, is still a source of major health inequity within South Africa (84, 89). Poor people use doctors less often than would be expected given their vulnerability to illness (90). Despite a steady process since 1994 of the removal of user fees at State services, particularly for the lowest income groups, service utilization by lower income groups is still constrained (90). Compared to 2007/09 the average utilisation of State funded primary health care services in South Africa in 2008/09 increased from 2.2 to 2.4 visits per person (91). This however is still well below the national target of 3.5 visits per person annually (91). Barriers to utilization include cost

(such as transport costs), socioeconomic status, race, urban-rural location and healthcare insurance status (90, 92). These barriers have been found to be burdensome to poor households (93). Thus despite South Africa placing equity at the heart of its healthcare policies, utilisation and access to public health care remains inequitable (90).

### **The continued burden of disease**

A recent South Africa Series by the Lancet reports that South Africa is on track with only one of the 6 Millennium Development Goals (the promotion of gender equality and empowerment of women) (83). Instead of progressing towards the rest of these goals, some indicators have worsened (89). The series reports that the country has seen an increase in mortality of children under the age 5 and a reversal in the progress of eradicating extreme poverty and hunger (83). There has been no progress in improving maternal health and achieving universal primary education, and combating infectious diseases has been insufficient (83). Contributing to this is a steep escalation in the HIV/AIDS epidemic and difficulties in reducing TB incidence and prevalence (94). South Africa, constituting only 0.7% of the world's population, accounted for 17 % of the global burden of HIV in 2007 (95). South Africa also has one of the most serious TB epidemics in the world (95) with health professionals increasingly having to deal with cases of extreme drug resistant infections (96). Furthermore co-morbidity for HIV and TB is an increasing problem (97).

### **Human resource limitations**

Part of the difficulty in meeting the challenge of this disease burden is an inadequacy in human resource capacity and planning (53). On the face of it South Africa is not short of key healthcare staff with a density of 4.9 physicians, nurses and midwives to 1,000 population (98) [WHO critical threshold is 2.3 =1,000 (48)]. These health professionals are however distributed in favour of private healthcare, well resourced (urban) provinces and hospital care (53). The result is that the number of health professionals in public care fall well below the WHO threshold (84). This shortfall is linked to a combination of factors such as inadequate numbers of professionals being trained, staff demoralisation and staff exodus (99). Even where there are staff, these health workers have historically been ill prepared in their training to provide for primary health care services (53). These poor skills have

compromised the delivery of key programmes including HIV, TB, child health, mental health and maternal health (53).

### **LHWs as part of public health reform in South Africa**

Part of the process of public health reform has included reform of human resources policy and structures. Within this process there has also been continued development of LHW policy and programmes. Although LHW programmes in South Africa have a history dating back to the 1940s, these programmes have almost always remained outside of government (100). Despite support for the concept of PHC, contrary to expectation, LHWs were not incorporated into the health system during the early post-apartheid period (18). However in the wake of HIV, human resources shortages and high unemployment, government is increasingly considering the inclusion of LHWs within the formal health system. As an indication of this LHWs have appeared in government human resource and strategy policies over the past decade, and since 2003 specific LHW policies have been tabled (101). The first two of these policies were the National Community Health Workers Policy Framework, 2003 and The Expanded Public Works Programme Social Sector Plan 2004/5 – 2008/9. Further development, finalisation and implementation of LHW policies were also mentioned in the National Human Resource for Health Planning Framework (2006) and in the National Department of Health's 2009/10- 2011/12 Strategic Plan. In November 2009 a third LHW policy, the Community Care Worker Management Policy Framework (Draft Version 6.0, October 2009), was released for comment. Common to all these documents is recognition of the need for LHWs as part of the national human resources for health capacity.

Historically LHW programmes in South Africa were run by non-Governmental organisations (NGOs) and community based organisations outside of government control and government funding. Since the 2003 policies were tabled, government has been funding the payment of stipends of some LHWs through NGOs (55, 102). Thus while the State funds the stipends of LHW programmes it does not employ LHWs. Instead the funding is directed through the provinces to NGOs who then employ the LHWs. This has however raised some confusion as to whom these LHWs are accountable, and who is responsible for supervising them – the NGOs who pay them or the clinical health staff based in government health facilities in the communities in which LHWs operate (101). This ambiguous position is

reflected on in the commentaries and studies of LHW programmes and policies since 2003 (18, 101, 103). The issue remains unresolved.

A mapping exercise has counted 1636 NGOs employing 38 500 LHWs across the nine provinces of South Africa (55). The authors point out that this should be regarded as a minimum estimate suggesting that the national LHW terrain is overwhelmingly large. Clarke et al (103) raise questions around the sustainability of this model, while Schneider et al (18) point to the fact that this employment arrangement leaves LHWs in an ambiguous position with a lack of employment rights. Part of this ambiguity and confusion around employment rights is linked to the fact that LHWs are seen as organised volunteers, and thus the stipend they receive is regarded as an acknowledgement or reward for volunteerism and not a salary (18, 101). Both Lehmann et al and Schneider et al point out that becoming a LHW is seen by many incumbents as a stepping stone to further employment (18, 101). All of these recent studies have found that LHWs are overwhelmingly female (18, 55, 101, 102). Clarke et al (103) raise questions around the stipulation in the policies that LHWs have to be generalists and not specialists, suggesting that the evidence supporting generalists is not sufficient. Evidence from field studies however suggest that in practice LHWs operate as both specialists and generalists (18, 101).

In August 2011 the Department of Health released an updated human resources policy for comment: Human Resources for Health in South Africa 2030, Draft HR Strategy for the Health Sector 2012/13 – 2016/17. This document makes a shift from previous policies in that it requires that LHWs be incorporated into the formal health system- i.e. become civil servants rather than remain in the employ of NGOs. According to the authors this document is formulated within a broader “re-engineering of the Primary Health Care System” (p.8).

Thus while the place of LHWs within public health is increasingly accepted, policy making and implementation remain continuously evolving processes.

### **Gendered issues around LHWs in South Africa**

Several studies conducted in South Africa have pointed to the majority of LHWs being women (18, 55, 71, 104, 105). Furthermore it is suggested that it is also women who are mostly in need of care (106). When men are involved then they are engaged in physical tasks with women assigned to nurturing tasks (71). Local studies repeatedly point to the difficult and poorly regulated working conditions faced by these female LHWs (105-109). Female LHWs have also been shown to be challenged by physical, emotional, social and economic stress (16, 71, 104, 107). As an example, Akintola (71) explains how from a socio-cultural perspective gender inequalities become entrenched in care work. She argues that due to traditional roles women and young girls are usually chosen as caregivers. However socio-cultural norms make it improper for the caregiver to complain for fear of being seen as insensitive to the plight of the sick.

## **PROBLEMS AND AIMS**

Support for LHW interventions and programmes as a public health approach, particularly in resource constrained settings is increasing internationally, but there are also critical voices raised against such programmes. It has been pointed out that LHW interventions can increase the burden of care for female LHWs in particular. Therefore it is important to make clear how the LHWs are organised. Policy makers need to consider how they might implement such interventions without causing harm to the LHWs themselves. In order that policy makers might make such decisions they need to consider the effectiveness of LHW interventions, and they need to consider the experiences of those who have been working on the ground, implementing LHW interventions. While there is a growing literature on LHWs there are no studies which bring together considerations of effectiveness, implementation experience and policy making experience. All of these perspectives are needed for effective policy decision making (110). While there is a growing literature on how female LHWs are burdened, there are to date no studies which consider how the issue of gender might be taken up in the process of LHW policy development.

The South African health care setting provides an ideal opportunity from which to generate research evidence and knowledge that may feed into such considerations. Firstly, South Africa has a long history of LHW interventions and thus there is much knowledge and experience here of how such interventions work. Secondly, the government is in the process of public health and PHC reform. Part of this reform is the restructuring of human resources for health and within that the incorporation of LHW services into the healthcare delivery efforts. This process allows for the opportunity to study health care reform and it opens up the opportunity to feed into this reform with strong evidence.

### **General aim**

The overall aim is to assess the appropriateness of LHW programmes as a public health intervention in South Africa by considering the effectiveness of LHW programmes across the world and the experience of LHW programme implementation and policy making in South Africa.

## **General questions**

In order to meet this general aim this PhD attempts to answer the following research questions:

- How effective have LHW interventions been in programmes across the world (high, middle and low income countries)? (I)
- What has been the experience of LHWs and LHW supervisors in two separate South African projects? (II, III)
- What lessons can be taken from the experience of contemporary LHW policy development in South Africa to inform future attempts at policy development? What can we learn about the way in which gender was considered in this process? (IV)

## **Specific aims I-IV**

- I. To assess the effects of LHW interventions in primary and community health care on maternal and child health and the management of infectious diseases in high, middle and low income countries.
- II. To explore and describe the self-reported experiences of actively functioning farm LHWs who participated in an intervention to reduce TB on farms in the Western Cape province of South Africa.
- III. To explore and describe the accounts field supervisors who supported LHWs employed in an infant feeding intervention. In particular to describe by the supervisors own account how they viewed their tasks, including the facilitators and challenges they faced in carrying out these tasks.
- IV. To explore the contemporary development of LHW policy in South Africa and to explain if and how gender was considered in this process.

The structure of this thesis is guided by the research questions.

## METHODS

This thesis includes four papers from four independently conducted research projects carried out between 2002 and 2010 (Table 2).

**Table 2: Overview of the papers and the methods applied**

Paper	Approach	Data Collection	Participants
I	Quantitative systematic review	Database search	82 selected studies
II	Qualitative exploratory study of intervention experience. Thematic content analysis	Focus Group Discussions	50 LHWs 48 women 2 men
III	Qualitative exploratory study of intervention experience. Thematic content analysis	Individual interviews	3 LHW supervisors All women
IV	Qualitative exploratory study of policy development. Thematic content analysis	Policy documents Individual interviews	5 policy makers / government officials (3 men, 2 women) 6 policy commentators (5 women, 1 man)

### PhD student's contribution to each of the included papers:

#### Paper (I)

KD joined the review team around September 2006 and was involved in all aspects of the review except the statistical analysis and the initial design. KD's first task was to be engaged in reviewing articles for inclusion and exclusion, then she was engaged in the reviewing and data extraction from the included articles. After this an initial report was written by the two first authors. The review then continued and KD was once again engaged first in abstract and title selection, then in inclusion and exclusion of the articles, and then in data extraction. Once the data extraction and statistical analysis was complete, the first two authors wrote the final manuscript with contributions from each of the authors. The order of the authors reflects the order of contribution. KD's contribution amounted to several months of work which took place between September 2006 and early 2010 when the review was finally published. During this time KD reviewed approximately 2000 titles and abstracts, 70 full text articles for inclusion and exclusion and 35 full text articles for data extraction, of

which she extracted data for twelve. KD has subsequently been leading a separate paper based on the breastfeeding studies included in the review.

#### Paper (II)

KD led all aspects of paper II, first under the supervision of Judy Dick and later Eva Johansson. KD designed the instrument, conducted the interviews and analysis and wrote all drafts of the paper. During the analysis KD worked closely with Hendrien van Zyl, but KD still led the analysis. KD and Hendrien van Zyl then shared the analysis with Marina Clarke and Judy Dick for verification. KD wrote the first draft of the paper, sharing this at first with Hendrien van Zyl and later with Marina Clarke and Judy Dick. Finally KD spent two weeks with Eva Johansson who helped with the very final draft before submission.

This paper is also included in the thesis of Marina Clarke, "Towards cost-effective tuberculosis control in the Western Cape of South Africa: intervention study involving lay health workers on agricultural farms, Karolinska Institute, Stockholm, 2005". The aim of Marina Clarke's thesis was to evaluate the effectiveness of an LHW intervention within a primary health care framework, aimed at improving TB case finding and case holding among permanent farm dwellers, to explore the perceptions of the different stakeholders, and do a cost-effectiveness analysis, in order to contribute to TB control in South Africa.

#### Paper (III)

KD led all aspects of this paper. KD was asked by the PROMISE-EBF team to assist with the qualitative evaluation of the project. Paper III is the outcome of her involvement. Guided by the requirements of the team KD designed the instrument, conducted the interviews, led the analysis and wrote all drafts of the paper. In the analysis stage KD worked closely with Barni Nor, but KD still took the lead as the analysis was her responsibility. The contribution of Barni Nor was primarily around verification and bringing an alternate perspective. KD led the writing, with the rest of the authors contributing through their comments on all of the drafts.

This paper is also included in the thesis of Barni Nor, "Promotion of Exclusive Infant Feeding in South Africa: Community-Based Peer Counselling in high HIV Prevalent Area, Uppsala University, Uppsala, 2010". The aim of Barni Nor's thesis was to identify and describe contextual factors important for the effectiveness of community-based peer counsellors,

with a special focus on the promotion of exclusive breast and formula feeding in areas where HIV is highly prevalent.

#### Paper (IV)

Paper IV is the work of KD, Marina Clarke and Karin Ringsberg exclusively. KD conceived of the idea for the research. She was assisted in the design of the study and the research instruments by Marina Clarke and Karin Ringsberg. KD conducted the interviews and led the analysis and writing under the guidance of Marina Clarke and Karin Ringsberg. This paper is not included in any other thesis.

### **Overall Study Design**

All the papers in this thesis focus on an aspect of LHW interventions and policy.

- Paper I reports on a systematic review of randomised controlled trials (RCTs) conducted in high, middle and low income countries. The included RCTs all evaluated the effectiveness of LHWs in primary and community health care for maternal and child health and the management of infectious diseases.
- Paper II was conducted as part of a broader research evaluation of an intervention which trained farm dwellers to be LHWs (111, 112). These LHWs carried out a range of primary care tasks including TB treatment support. Paper II focuses on the LHWs' experience of the delivery of care and the training they received.
- Paper III was conducted as part of a broader research evaluation of an intervention which trained women as LHWs to deliver infant feeding peer support to mothers in the communities in which they lived (33). This broader evaluation was based in three sub-Saharan countries. Paper III explores the experience of the three women employed to supervise the LHWs in the South African intervention settings. The participants were each responsible for supervising ordinary working class and rural woman who had been trained as LHWs. The LHWs they supervised offered peer counselling and support on infant feeding to new mothers. This was done in the context of HIV where incorrect feeding could increase the possibility of mother to child transmission (113).
- Paper IV reports on a qualitative study which explores the development of LHW policy in South Africa and the place of gender in the discussions which informed policy development. This study emerged out of the questions raised in relation to gender both in the literature and in papers II and III. Using individual key informant interviews the paper explores accounts of the policy making process from the perspective of policy makers, policy developers and policy commentators.

## **Qualitative and Quantitative Approaches**

Each individual paper uses either qualitative or quantitative methods exclusively, but these methods complement each other at the level of the thesis (114). Thus the thesis as a programme of inquiry uses a mixed methods approach (114). Mixed methods research is well established within health research (115). It has been defined as integrating qualitative and quantitative research in a single study or programme of inquiry (114), drawing inferences from both approaches (116). Mixed methods approaches promote comprehensiveness (117). It is argued that in using such an approach, researchers may reach a more complete analysis of the situation as neither qualitative nor quantitative approaches are sufficient on their own (114). This PhD reports on the quantitative and qualitative methods and findings separately, but focuses on their collective meaning in the discussion (114). The quantitative evidence is generated from a systematic review of 82 RCTs of the effectiveness of LHWs in primary and community health care. The qualitative evidence is drawn from the perspectives of people engaged in LHW programme implementation and policy making. These perspectives include the views of LHWs, LHW programme supervisors, policy developers and policy commentators. Through providing different types of evidence and a range of perspectives the thesis comes closer to answering the whole question than if the individual papers were used on their own. Through combining these methods a more holistic picture can be gained.

### **Systematic review (I)**

A systematic review brings together all of the empirical evidence (quantitative, qualitative, or both) related to a specific research question (118-120). While there have been reviews which bring together both qualitative and quantitative studies (such as in a realist review) (121) it is more common to find reviews which focus only on one or the other. Systematic reviews are characterised by the explicitness of their research question, their search strategy and the eligibility criteria with which studies are included and excluded (118, 122). Once the material has been collected, reviewers assess the quality and validity of the evidence before synthesising, interpreting and presenting it (118, 122). Quantitative reviews tend to look at issues of effectiveness while qualitative reviews tend to explore why and how certain options or interventions work or not (120, 122). Systematic reviews, as compared to single studies, are argued as being of particular benefit to decision makers and

policy makers (120, 122). These benefits include efficiency (because the evidence has already been collated) and confidence (because of the transparent and systematic processes) (120, 122).

This thesis includes a quantitative systematic review (I). This review assesses the effectiveness of interventions as tested through RCTs. It was conducted by a team comprised of 12 review authors with a range of public health research experience. The review contributes to the thesis by presenting a collation and synthesis of the best available evidence for LHW interventions in primary care internationally. The review presents quantitative evidence of effectiveness.

#### **FGDs and Individual Interviews (II, III, IV)**

Qualitative research is used in public health research to understand the meaning, processes and context surrounding the experience of health and healthcare (123). Malterud (124, p.398) argues that “the aim of such [qualitative] research is to investigate the meaning of social phenomena as experienced by the people themselves”. In other words, qualitative research attempts to put people’s experience and accounts at the heart of the investigation. These studies therefore aim to understand what happens as well as how and why it happens from the perspective of the people experiencing the health issue or process (125). In order to reach such an understanding qualitative researchers may use a range of data collection techniques including oral, visual and written data sources (125). In this thesis individual qualitative interviewing and FGDs were used, as well as some reflection on policy documents.

Qualitative interviewing allows researchers to explore actors’ own accounts of their experiences. It allows the researcher to clarify and understand in the moment of a thought being expressed through the interview, what the participants really meant (126). Karlberg et al. (123) suggest that data is socially constructed in qualitative interviewing in the interaction between the researcher and the participant. This kind of interaction and its associated potential for depth is simply not possible using any other research tool (e.g. a non-interactive survey).

Both individual interviews and FGDs are techniques used by qualitative researchers in collecting information about people's perceptions, beliefs and experiences by their own account. Individual interviews are used to explore individual experience (125). In contrast FGDs are mostly used to explore group norms by providing an opportunity for interaction between a number of individuals with a common interest (127). This interaction may lead to spontaneity thus encouraging more discussion between the group members. FGDs do not however allow for much attention to specific individual experience. Individual interviews allow researchers to understand in depth the experiences of the individual and the motivations of individuals. It does not necessarily tell us much about what is happening at a community level, yet the individual's experience can be very different from the collective understanding, experience or perspective. In this regard exploring group norms through FGDs is important because it gives an indication as to what behaviour is expected at community level, but it does not tell us much about how individuals themselves respond to these norms. A danger with FGDs is that if an individual feels that their experience is very different to the norm they may not easily share it in the group because of the compromised confidentiality in a group setting (127). A further danger of FGDs is that they can present community level beliefs as if these beliefs are held by each individual member of the community, which is likely not true. Thus there is a place for both FGDs and individual interviews depending on what the qualitative researcher is hoping to establish.

## **Participants**

### **Systematic Review (I)**

The participants in the systematic review were LHWs in interventions intended to improve maternal or child health or the management of infectious diseases and their healthcare provision recipients. For the purposes of inclusion in this review LHWs were defined as any health worker who performed functions related to healthcare delivery, was trained in some way in the context of the intervention, but had received no formal professional or paraprofessional certificate or tertiary education degree. LHWs could be paid or voluntary community health workers, village health workers, birth attendants, peer counsellors, nutrition workers and home visitors. As there were no restrictions on the types of patients or recipients, this group varied widely (e.g. breastfeeding mothers, TB treatment patients).

### **FGDs and Individual Interviews (II, III, IV)**

The qualitative papers each focus on a different set of participants. Each group is described below.

#### *Paper II*

In this study there were 50 participants, two men and 48 women. They participated as LHWs in an intervention which delivered TB treatment and support to farm dwellers in the Winelands area of the Western Cape. The intervention was delivered as part of a research project, but it also received some support from the local municipal health service. Each of the LHWs were farm dwellers themselves, living on farms and within the communities they served voluntarily. They were supported by supervisors employed within the research intervention. The LHWs who participated had different lengths of exposure to the intervention - some had been LHWs for over seven years, while others were with the intervention for just over a year. It was hoped that the research would capture both the experience of those familiar with the intervention and those who had just started out. The participants were sampled by convenience by the research team. In this rural setting it was difficult to bring participants from widely spread farms together and thus the data collection had to fit in with pre-arranged intervention training times. The FGDs were therefore conducted with LHWs who were already gathered together for training purposes, rather than to try and reconvene them outside of their set schedule. The fact that there were only two male participants was reflective of the general gender bias amongst those farm dwellers who became LHWs.

#### *Paper III*

Three persons participated. They were LHW supervisors who were responsible for supporting infant feeding peer counsellors in the three study sites of the Promise Exclusive Breast Feeding RCT in South Africa. The intervention took place in three diverse (rural, urban, peri-urban) settings in South Africa. Since there were only three LHW supervisors, each of them was included as a participant in an attempt to capture their range of perceptions and experiences in the intervention. The participants were similar to the LHWs in terms of ethnic and geographical background (they were all African women residing in proximity to the study area), but not in terms of socio-economic background. One of them had a nursing and research background, another had an administrative background and the third had a counselling background.

#### *Paper IV*

Eleven persons participated. They were purposefully selected by the study authors. These participants were regarded as key informants because of their knowledge and experience in LHW interventions, policy making and research in South Africa. Several of the participants also had an interest in LHW issues outside of South Africa. The group comprised of health managers, government officials (including policy developers), researchers, policy activists and commentators. All of the participants were professionally qualified and tertiary educated. Due to confidentiality no further specific details are given.

### **Data Collection**

#### **Systematic Review (I)**

The review was done within The Cochrane Collaboration and as such adhered to the methods, including data collection methods, for Cochrane Reviews described in the Cochrane Handbook of Systematic Reviews of Interventions (118). The material collected in the review was RCTs of LHW effectiveness in primary and community health care for maternal and child health and the management of infectious diseases.

#### *Search strategy*

Data collection started with a search conducted on multiple electronic databases for primary studies published from 1950 to February 2009 (see Box 1). The search was conducted by a librarian in consultation with the primary investigator and other key review authors. The search strategy incorporated the methodological component of the Cochrane Effective Practice and Organisation of Care Group (EPOC) (128) combined with selected index terms and free text terms relating to LHWs (for example, community health aides, home health aides, or voluntary workers). Reviewer authors also searched the reference lists of included papers and relevant reviews and contacted authors of relevant papers regarding any additional published or unpublished work. As the review progressed the search strategies were revised to reflect the reviewers improved knowledge of terms used in the literature to describe LHW interventions. The full list of search terms used can be found in paper I.

### *Selection of primary studies and extraction of data*

All reviewer authors were involved in the process of selection of studies to be included in the review. Using strictly defined inclusion and exclusion criteria (see paper I for more detail) 9705 titles and abstracts identified from the electronic searches was independently assessed for potential relevance. Thereafter full text copies of the 526 articles identified as potentially relevant were retrieved, read and evaluated against criteria which were predetermined by the review authors. Where appropriate, study authors were contacted for further information and clarification. Out of this process 82 primary studies were selected for inclusion in the review. Using a pre-specified data extraction sheet, data for the following aspects were extracted from each of the 82 selected studies: study design, setting, participants, intervention, control group, and outcome results.

#### **Databases and other resources searched for paper I**

Electronic databases searched for primary studies:

- Cochrane Central Register of Controlled Trials (CENTRAL) which includes citations uploaded from the EPOC and Cochrane Consumers and Communication Group Trial Registers (*The Cochrane Library* 2009, Issue 1) (searched 18 February 2009);MEDLINE, Ovid (1950 to February Week 1 2009, except August 2001 to December 2003 (searched 17 February 2009);
- MEDLINE In-Process & Other Non-Indexed Citations, Ovid (February 13 2009) (searched 17 February 2009);
- EMBASE, Ovid (1980 to 2009 Week 05, except August 2001 to December 2003 (searched 18 February 2009);
- AMED, Ovid (1985 to February 2009) (searched 19 February 2009);
- British Nursing Index and Archive, Ovid (1985 to February 2009) (searched 17 February 2009);
- CINAHL, Ebsco (1982 to present) (searched 07 February 2010);
- POPLINE (searched 25 February 2009);
- WHOLIS (searched 16 April 2009).

Other resources used:

- we searched the reference lists of all included papers and relevant reviews identified;
- we contacted authors of relevant papers regarding any further published or unpublished work;
- we searched the Science Citation Index and Social Sciences Citation Index (ISI Web of Science) from 1975 (searched 10 August 2006 for 55 studies and 10 February 2010 for 16 studies) for papers which cited the studies included in the review.

**Box 1**

#### **Focus Group Discussions (II)**

Three FGDs were conducted with LHWs by KD along with the assistance of a research intern. The FGD approach was chosen because the researchers wanted to know how the LHWs as a group conceptualised their role and experience in the intervention. It was also hoped that

in the group setting they would be encouraged to share their experiences by reflecting on the experiences of their peers.

Although the groups were large, consisting of 17, 12 and 21 participants, there was an endeavour to create an atmosphere in which participants would feel encouraged to express themselves and share their experiences despite the unfamiliarity of the research process. The focus groups were held at the training venue and amongst peers, creating a sense of familiarity and breaking any distinction of hierarchy between the researchers and the participants. The FGDs were conducted in the first language of the participants (Afrikaans). For each FGD the chairs were placed in a circle, so as to encourage the group members to speak to each other rather than to address their comments to the researchers.

The FGDS were conversational and informal in style and lasted approximately 1 hour each. Each FGD started with an explanation to participants about the data collection process (e.g. that a tape recorder would be used). Participants were reassured of the anonymity of their responses, and in particular that their names would not be recorded and thus comments would not be linked to individuals after the FGDs. They were also reassured of the value of their opinions and that there would be no right or wrong answers. Guiding questions ensured that each FGD covered these key areas: experience of being trained as LHWs, the impact of what they were taught and what they practiced (at a personal and community level), their perceptions of the health impact specifically, their perceptions of how their communities received them as LHWs, and general reflections on their individual experience.

#### **Individual interviews (III, IV)**

Individual interviews were chosen (III, IV) so as to explore the depth of each individuals experience and opinions. KD conducted all of the interviews in English, an accepted business language in South Africa. Language did not appear to be a barrier in any of the interviews despite this not being a first language for any of the LHW supervisors (III) and some of the policy actors (IV).

#### *Paper III*

Individual interviews were chosen so as to reflect on the depth of each LHW supervisor's experience of the intervention implementation process. Each of them was contacted in advance of the interview via telephone and email, so as to explain the nature of the

research and why their opinion in particular would make a valuable contribution. They all agreed immediately to the interview without question, but this agreement may be related to them feeling that they had to grant the interview as it was part of the process evaluation of the intervention in which they were employed. Two of the interviews were conducted at the participants' offices. At the third participant's request her interview was conducted at a restaurant nearby her office as she felt that it offered more privacy than she had at her office. All of the interviews were audio recorded and lasted between 45 minutes and an hour.

The interviews were kept informal and conversational. At the start KD ensured that each participant had understood why the interview was being conducted (i.e. not to judge them, but to learn more about the project) and that the conversation would audio-recorded. The interviews did not follow a strict set of questions. Instead KD sought to clarify through the interview what the background of each participant was, and how they experienced being LHW supervisors. As issues arose in the interview KD sought to further clarify what the participants meant in an attempt to gain as much depth in the description of each individual's experience. Participants were encouraged to describe their experiences as fully as possible, including the good, the bad, the challenging and the rewarding aspects.

#### *Paper IV*

Individual interviews were chosen because each of the participants was a key informant with a depth and range of individual experience and knowledge about the LHW policy process in South Africa. The sampling process strove to be as representative as possible and to reach all key informants, but some may have been missed. Participants were contacted in advance of the interview via telephone and email, so as to explain the nature of the research and why their opinion in particular would make a valuable contribution. Some participants were initially hesitant about granting an interview. This may be related to the contentious nature of LHW policy making in South Africa and to the time constraints of participants as many of them held senior positions in their organisations. Once participants agreed to be interviewed, KD travelled across South Africa so that each of them could be interviewed face to face at their preferred professional setting. All of the interviews were audio recorded and lasted between 30 and 105 minutes.

Reflecting the professional status of the participants, the interviews were less informal than the FGDs (II) and the supervisor interviews (III), but the conversational style was maintained. The interviews were a balance of structure and openness. They were structured in advance around the specific key informant (e.g. policy developers were asked about their policy development experience, while policy commentators were asked about the experience of trying to engage with government to make comments). But they were also sufficiently open so as to allow participants to speak freely and share their insights on LHWs, LHW policy development and the issue of gender in implementation, in policy and in policy development. The outcome was that the interviews were very different from each other, but they all focused on the issue of LHWs, policy development and gender from the perspective of the participants experience and insights.

## **Data Analysis**

### *Paper I*

The aim of the analysis process was to compare and pool data for studies that evaluated broadly similar types of interventions. This analysis was conducted by a statistician in consultation with the review authors. Data from 74 studies were pooled for the following outcomes:

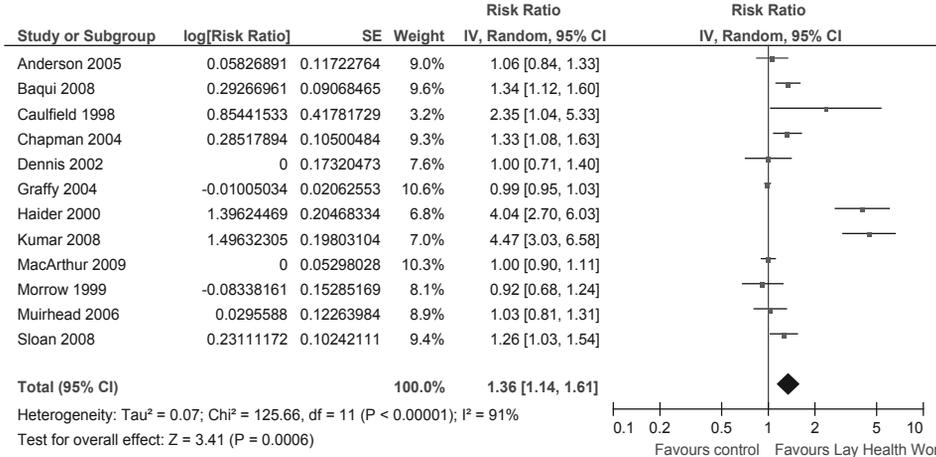
- Immunisation uptake
- Reduction in mortality and morbidity in children under five
- Success at breastfeeding promotion
- Success at support to mothers of sick children
- Reduction and prevention of child abuse
- Success at parent child interaction or health promotion
- Reduction in poor pregnancy outcomes
- Improvement in TB treatment and prophylaxis.

The remaining eight studies were too diverse to be usefully grouped.

The analysis process also included an investigation of heterogeneity between the studies; an assessment of the risk of bias in included studies using the Cochrane Collaboration Risk of Bias tool (118); and an assessment of the quality of the evidence using the GRADE approach (118, 129). For further details of the statistical tests conducted in the process of analysis see Paper I.

Figure 2 below is an example of an analysis of the pooled data. This example shows how the statistician pooled all the data from the studies of interventions that promoted the initiation of breastfeeding. The outcome of the analysis is represented both numerically and graphically.

**Forest plot of comparison: LHW interventions to promote initiation of breastfeeding compared with usual care, adjusted for clustering (15)**



**Figure 2**

*Papers II-IV*

KD had the main responsibility for the analysis, but there was a continuous discussion between all the authors in order to validate the findings. Thematic content analysis was used in all the papers (125, 130). Each verbatim transcript of the FGDs and individual interviews were regarded as a unit of analysis (131). All of the analyses began with the authors reading the verbatim transcripts in order to get a grasp of the whole. This was followed by an annotation of the texts noting all the authors’ thoughts about the material in relation to the different study aims and research questions. Annotation was followed by categorisation into themes and sub-themes or categories. The data were continuously compared in order to triangulate and validate the results (132).

In paper II the categorised quotes or sections of text were physically cut from hard copies of the transcripts, and pasted onto newsprint paper along with other quotes fitting in the same theme or category. These quotes were then read within their groups, reorganised where

necessary, and finally a narrative account of the grouped quotes was written up as a reflection of the categories and themes.

In paper III the analysis started with data emersion (reading and annotating) in the individual transcripts. Thereafter an overall framework describing the transcripts collectively was developed. This framework was then used to categorise all the transcripts, adapting the categories where necessary. Using a word processor, quotes from each individual interview was grouped with quotes from the other interviews according to the selected categories from the framework. The framework also shaped how the narrative account of the findings was written.

Paper IV also followed the thematic content analysis approach of a descriptive presentation (130) of the data at a manifest level (131). The transcripts were read and reread to obtain a sense of the whole. Each interview was regarded as a unit of analysis. Meaning units were identified in each interview. Thereafter meaning units from all interviews with similar content were combined into themes. Themes were then grouped into categories where after the themes were given a name.

### **Quality of the research process**

Research is the pursuit of knowledge and research, whether qualitative or quantitative, attempts to reach some level of probable truth in this pursuit. Kvale argues that reaching such truth depends on the quality of the craftsmanship of the research (133). Different research traditions have used varied terms and concepts to describe and define the process and techniques through which such quality is ensured (131, 133, 134). These concepts include validity, reliability, trustworthiness, dependability and confirmability (131, 133). They are used in assessing the research process as a whole including the development of the research question, the appropriateness of the research design, the methodological conduct of the research process and the reporting of the research findings (131, 133, 134). How researchers view validity is largely related to how they view the construction of what truth is. Some researchers may believe that there is one truth and that research therefore might be used in the pursuit of this objectifiable truth. Others might believe that there are multiple and relative truths. These debates go back to ancient philosophies, but they

impact on how current researchers pursue the science of their inquiry (135). I am influenced by the belief that there are multiple truths and thus in my pursuit of validity I am drawn to theorists such as Kvale who argues that validity of research knowledge is socially constructed (133). Larsson suggests that validity might be viewed as a conversation about the world or reality, raising the question of what the research adds to discussion of the topic (136). If one follows this line of argument then the dialogical aspect in the construction of validity will require a dialogue both within the programme of inquiry and a dialogue with peers about the programme of inquiry.

In the course of their external dialogue researchers need to show through debate that the knowledge they construct can be verified and is defensible (133). Research authors need to therefore be explicit in their explanations about all of their research processes and findings in order that others may assess the quality of their research. In public health these issues are particularly important because the findings of research may be used to make decisions about the delivery of healthcare at a population level.

As a part of the external dialogue on this thesis I present below examples of the measures used here to ensure the quality and rigour of the research:

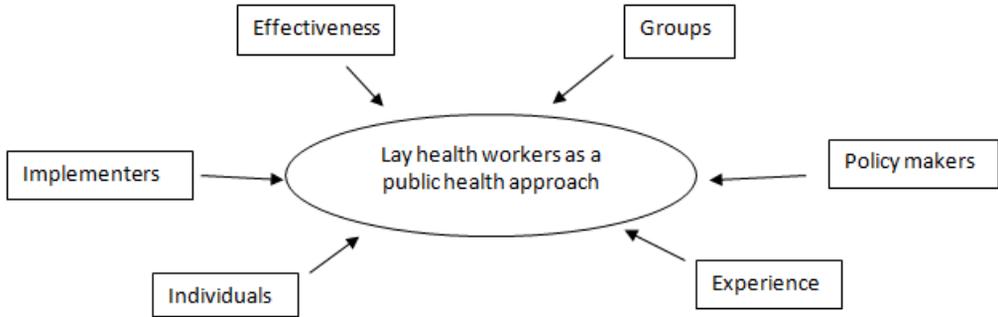
- *Using accepted research standards:* The systematic review (I) adheres strictly to the methods for Cochrane Reviews described in the Cochrane Handbook of Systematic Reviews of Interventions (118). In particular it makes explicit its search strategy allowing readers and policy makers the opportunity to evaluate the breadth and appropriateness of the search.
- *Inter-researcher reliability:* In the systematic review (I) each title, abstract and article was assessed for inclusion or exclusion by at least two reviewer authors.
- *Use of experts:* The review authors (I) included experts in their field, who took responsibility for aspects of the process such as statistical synthesis.
- *Peer review:* Papers II and III were part of two separate large studies. These papers relied on the larger team for peer review of the research process throughout. Paper IV had a small team, but knowledgeable colleagues outside of this team were consulted throughout the research process. Within the team there was continuous discussion throughout the whole research process. All of the findings (I-IV) have been discussed at lectures and seminars or presented at conferences.
- *Selection of participants:* Careful attention was paid to the selection of appropriate participants in papers II-IV. This meant ensuring that participants were selected on the basis of their experience in relation to the research question and phenomena

being investigated. Furthermore attention was also paid to ensuring that varied voices on the question of LHW interventions and policies were represented in the research process and findings.

- *Training and experience of the researchers:* Kvale (133) emphasises the person of the researcher as impacting on the quality and validity of the research. KD has many years of experience in qualitative interviewing with participants across a range of age, race, class and professional backgrounds. This contributed to the rigour of the data collection process. She was also supported in the research process by the experience of her supervisors (KCR and MC).
- *Reliability of data collection:* All interviews and FGDs (II-IV) were audio recorded, initially using a tape recorder and later using digital recorders. The recordings were transcribed and checked before being used for data analysis.
- *Rigorous qualitative data analysis:* The qualitative analyses (II-IV) were led by KD in continuous collaboration and discussion with co-authors on each paper. In reporting on the analysis, select quotes from the interviews and FGDs are offered for further validation by the reader.

Internal to this thesis the dialogue of validity was pursued through exploring the appropriateness of LHW programmes through multiple perspectives. The use of more than one method or perspective in research is an aspect of validity or the validation process, and is sometimes called triangulation (135). Some theorist, such as Yin argue that real triangulation is when the researcher verifies the same fact from multiple viewpoints within the same study (132). Yin's argument therefore follows that different sub-studies within the same programme of inquiry results in a non-convergence of multiple sources of evidence. Given my belief in multiple truths, I am more influenced by theorists who view triangulation as a means of combining multiple perspectives in understanding the same phenomena (135). I do not believe that triangulation can result in a single verifiable fact; instead I feel that triangulation assists researchers to uncover multiple truths and in the process a bigger picture of the whole phenomena is reached. Richardson goes even further in suggesting that triangulation in itself may be a limiting term as it only offers the possibility of three perspectives and thus as an alternative she offers the term crystallization as an even more multidimensional approach (137). The multidimensional approach attempted in this thesis is illustrated in figure 3 below.

**Multiple perspectives drawn on:**



**Figure 3**

In an effort to meet its aim, this thesis attempted to reach for truth by creating a dialogue between the four papers (I-IV) and also within the study of each paper. Although in its pursuit of validity this thesis could not attempt triangulation in its strictest sense (the four papers each look at their own questions rather than a single unifying question shared between them), it is influenced by the concept of triangulation as bringing together multiple perspectives. Denzin proposes that there are four types of triangulation (138): “(a) data triangulation (i.e., use of a variety of sources in a study), (b) investigator triangulation (i.e., use of several different researchers), (c) theory triangulation (i.e., use of multiple perspectives and theories to interpret the results of a study), and (d) methodological triangulation (i.e., use of multiple methods to study a research problem)” (135, p.114). Thus using Denzin’s proposed four types of triangulation as a framework, the manner in which the multiple perspectives were utilized in this thesis and within the included papers is elucidated below.

- *Methodological triangulation*: In this thesis a quantitative systematic review is combined with qualitative studies. Thus the thesis contributes both findings on the effectiveness of LHW interventions and provides findings on the kinds of settings in which LHW interventions take place (139, 140).
- *Data triangulation*: Paper I is a review of 82 different studies, synthesised to find a higher level of answer than just one study would have rendered. Papers II, III and IV draw on participants from different backgrounds and with different experiences of LHW interventions and policies. Together these perspectives provide a broader understanding of LHW programmes and policies in South Africa, than just one group of participants might have done.

- *Investigator triangulation*: Each paper has multiple authors, from different professional, academic and geographical backgrounds. The debate and discussion between authors on each paper enhanced the rigour of the process.
- *Theory triangulation*: Although not in the individual papers, an attempt has been made at the level of the thesis to look at the findings from a public health perspective and to consider certain aspects from a gender perspective.

## ETHICS

Paper I is a systematic review and as secondary research it has not required ethical approval (141). The broader study in which paper II was included received approval from the Research Ethics Committee of the Faculty of Applied Sciences of the Cape Technikon, Cape Town, South Africa and by the Karolinska Institute in Stockholm, Sweden (#03-405). The broader study in which paper III was included was approved by the Ethics Committee of the University of the Western Cape (#0607/4). The qualitative study on which paper IV is based was approved by the Ethics Committee of the South African Medical Research Council (#EC07-007). The ethical issues and dilemmas relating to each study are described below.

The lack of requirement and the fact that there is no accepted standard for assessing of ethical issues in systematic reviews (141) does not mean that systematic reviews are above ethical concern (142). Vergnes and colleagues (142) point to several potential ethical dilemmas in systematic reviews such as the original studies not being ethically sound and the use of original individual data without further informed consent from the individual. They suggest that systematic review authors need to include ethical assessment of the included studies as part of their methods and that they can then offer a brief discursive report of this in the findings (142). This was not done for the study of paper I. Although the Cochrane Handbook of Systematic reviews does not have a stated requirement for reviews to be ethically assessed, it does point to at least two areas in which reviewers are required and recommended to act ethically (118). Firstly, reviewers are required to explicitly declare any conflict of interest. All review authors adhered to this by signing a detailed declaration of interest, including for example whether or not they were authors on included studies. Secondly, the handbook raises the question of health equity as a matter of ethical concern in public health and health promotion interventions (Section 21.5) (118). The authors of the Handbook point out that overall positive intervention outcomes may not necessarily be

equitable. They argue that an overall positive outcome for the whole population may not be positive for all sub-sections of that population. For example, outcomes which favour wealthier people may not favour poorer people equally. Thus the authors suggest that the reviewers as far as possible assess and report on outcomes from the original studies in relation to their impact on disadvantaged communities and populations. In doing so they suggest that the reviewers may contribute to more equitable healthcare. While the review did not explicitly include such an assessment, it does implicitly include a number of comparisons that are of interest to low- and middle-income countries (LMICs) such as an assessment of LHW interventions in TB and HIV care. Furthermore 33% (n = 27) of the included studies were conducted in LMICs, and most others were directed at low income or vulnerable groups in high income countries.

Paper II is based on a set of FGDs with farm workers who were trained as LHWs. The interviews took place in the context of their training sessions. Although all of the participants agreed to partake in the discussions it is possible that some of them may not have felt that they had the choice of declining from participation. They were already at the venue and may not have felt comfortable with getting up and walking out, especially in a big group where they would have drawn attention to themselves. Furthermore farm workers have traditionally been some of the most marginalised members of South African society. They hold persons of authority such as nurses in high esteem. Given that the training was being offered through the health services they may not have felt that they had the authority or power to decline the request of the nurse trainer. To overcome this, the research question and process was explained to participants before the start of the FGD. During this explanation participants were assured that they could leave at any time, and that whatever was said in the discussion would remain anonymous (no names were recorded). Despite these reassurances though, the power imbalance may have influenced participants to be more positive or silent in their responses than they would have been if they had just been discussing the intervention amongst themselves without the presence of the researchers or other professionals. However when presenting the findings from this paper at a large meeting which included some of the participants, many of them vigorously agreed to the presentation of both the positive and negative aspects of their experience.

Paper III is based on three individual interviews and it presented a similar ethical dilemma as paper II in terms of the power imbalance between the researcher and the participants. A request to do the interview along with information about the nature of the interview was sent to each participant in advance. While each of them agreed to be interviewed and signed the informed consent forms before the interview, it is likely that none of them felt that they had the choice to refuse to be interviewed, given that the research was being conducted by their current employers. Furthermore their absolute anonymity in the reporting process could not be guaranteed especially since they were the only three supervisors in the intervention. A concern before the interviews therefore was that the participants would feel compelled to present a positive view of their experiences and thus that the interviews may be biased. However, despite the lack of anonymity each of the supervisors offered very frank observations of their experiences, describing both positive and negative experiences.

Ethical approval was required for the study of paper IV for the aspects of the research that dealt with human subjects (i.e. the individual interviews), but not for the analysis of the policies which are public documents. The key ethical consideration in this paper was in relation to the identity of the participants who are likely to be well known within public health circles nationally and even internationally. Thus their opinions may be easily recognisable in reporting even if this is done anonymously. Despite some participants being public officials and others being published researchers, they were being interviewed in their individual capacity, in the hope that they would not only relay the “official position” but also their own opinion. Therefore they were informed as part of the process of obtaining informed consent of the possibility that they may be recognised in the reporting. This information was communicated to them both verbally and in writing. They were given the option of withdrawing and the option of deciding how anecdotes from their interviews will be reported on. At the point of consenting, two participants asked to see the final draft before publication. Both were shown the final draft and neither requested any changes.

## FINDINGS

The findings presented here are a summary of the main findings in papers I-IV and follows the research questions outlined in the beginning of the thesis.

### **The effectiveness of LHWs interventions internationally (I)**

LHWs were shown through the systematic review (I) to be effective in some areas of primary and community health care and not in others. The meta-analysis showed evidence of moderate quality [as assessed using the GRADE approach (118, 129)] that LHWs can be effective in health promotion in the following areas: childhood immunisation, breastfeeding initiation, any breastfeeding, and exclusive breastfeeding. While LHWs were effective in improving pulmonary TB cure rates, their support had little or no effect on preventative treatment completion for TB. Although LHWs were shown to be effective in reducing child morbidity and child and infant mortality, and increasing the likelihood of seeking care for childhood illness, the quality of the evidence was low. There were also some studies such as that of LHW interventions around child abuse and parent-child interaction which were inconclusive. Studies of interventions with pregnant mothers at risk of poor perinatal outcomes were also grouped. Analysis of these studies showed that while LHWs were not able to reduce the frequency of low birth weight babies, they may impact on children's development if they are implemented in the early postnatal period. Several studies were too diverse to be included in the meta-analysis. These included studies with interventions around dental carries, substance abuse, health insurance, child safety and injury reduction, and nutrition.

Although the search was comprehensive and the review authors sought to include studies from high, middle and low income countries, the majority (n = 55) of studies which met the inclusion criteria were from high income countries. Further details of the contexts in which these studies took place are given below:

- *Immunisation (children and adults)*: Eight studies evaluated LHW interventions to promote immunisation uptake. Although these were conducted in high and middle income countries, they were tested among populations of low socioeconomic status. Seven of the studies which met the inclusion criteria were directed at children under the age of 5 and only one was directed at adults (not included in meta-analysis). The

LHWs were mostly volunteers recruited from the communities in which the intervention was tested.

- *Child morbidity and child and infant mortality, and care seeking for ill children*: Ten of the eleven studies included were conducted in low income countries. As with the studies for immunisation, they were targeted at families of low socioeconomic status. There was no uniformity in where the LHWs were selected from as they came from a diverse and unrelated range of backgrounds. For example some were nominated from their communities, while others were in government employ.
- *Breastfeeding (any, initiation, exclusive)*: Eighteen studies evaluated the promotion of breastfeeding. Ten of these were from high income countries, five from middle income countries and three were conducted in low income countries. Most of the studies were set in rural areas and most of the interventions (thirteen) were delivered to women from low income communities. The LHWs were mostly volunteers, selected as peers from the same community as the mothers to whom the intervention was delivered.
- *TB (cure and completion)*: Eight studies evaluated the delivery of care by LHWs to adults with pulmonary TB. Half of the studies were set in low and middle income countries and most were in urban settings. Seven of the studies were conducted in low income settings. The LHWs were generally peers of the people they treated. Some had recently successfully completed treatment while others were individuals drawn from the districts in which they lived.
- *Child abuse*: Eight studies were conducted in urban areas in the USA with families at risk of child abuse (e.g. mothers below the age of 20 or with substance addiction problems). Only five of the studies provided any information on the LHWs, who were said to be familiar with the areas in which they worked.
- *Parent-child interaction*: Five studies were conducted in high income settings with young, single or first time mothers from low socioeconomic backgrounds. The LHWs were drawn from the same communities.
- *Risk of poor perinatal outcomes*: In ten studies LHWs, delivered interventions to pregnant women and women in the early postpartum period. Nine of these studies were set in high income countries, and the tenth was set in Jamaica. All except one study in the USA were set in urban populations. The LHWs were mostly mothers themselves.

In summary LHWs have been shown to be effective in certain areas of health care delivery, but the extent to which this has been shown in developing country settings is limited.

## The experience of LHWs and LHW supervisors (II, III)

To elucidate the experiences of frontline workers, LHWs themselves (II) and LHW supervisors (III), a qualitative approach was chosen. The findings offer insight into the values, desires, aspirations, fears and concerns of everyday frontline LHW intervention workers.

The findings (II & III) emphasise the need for technical soundness in the delivery of healthcare by LHWs. LHWs (II) saw their competency in dealing with the health needs of their communities as important and they reflected on how much this was valued by the communities and the health services. The supervisors (III) emphasised their role in ensuring that LHWs were technically proficient. For them this meant that they had to be hands on in supervising LHWs in the field:

*Telephone call support it's not effective at all for myself because the peer supporter only tells you what she thinks you need to know but you haven't seen what she did and that's the difference. But when you're there you are able really to give the support that she needs because you've seen what she was doing and you see what she needed to do and you also see where she can improve what she could have done.*

Participants (II & III) reflected that this technical healthcare competency was enhanced and strengthened through continuous training in the intervention. For the LHWs the skills they gained were also of personal value:

*On this course I gained knowledge, I gained something that no one can take away from you.*

They also emphasised that success in the delivery of the intervention went well beyond healthcare delivery and efficiency. For example, the LHWs spoke of the qualities which enabled them to work within their communities such as interpersonal effectiveness, being available and being trustworthy. They also brought attention to their role as advocates for the communities' broader well-being:

*We all come together in the hall, and then we talk about it. And then we go together to the farm owner, and then we tell him that this is wrong or this is right.*

In the process of the intervention LHWs suggested that communities were becoming independent in managing their healthcare.

Similarly the LHW supervisors described their tasks as far broader than just ensuring that LHWs delivered the correct infant feeding messages. The supervisors had to manage the

LHWs within very challenging contexts. They emphasised that the LHWs came face to face with the communities they were dealing with and as such the community context impacted upon them. They had to support LHWs in dealing with emotionally difficult client interactions, violence in the community and HIV. Supporting the LHWs through HIV went beyond the challenges of this disease in the client provider interaction, to supervisors having to support LHWs who themselves were also HIV positive. Having to give this kind of support was challenging to the supervisors themselves:

*I sometimes also feel that I need some counselling of some sort, myself, because I sit at home sometimes and think 'Good heavens, she is ill again, what does one do?'* Overall the interviews with the supervisors showed that their role was that of containing the experience of delivery of the intervention for the LHWs, and as such they had to be prepared to deal with all issues that arose including job satisfaction. Analysis of their accounts showed that their prior experience before becoming supervisors shaped how they approached this task.

While LHWs and LHW supervisors expressed a sense of fulfilment from their work, the findings also revealed that incumbents experienced pressure from being at the frontline. LHWs revealed that this pressure was linked to an added burden or responsibility for caring, which LHWs experienced as a result of living in the same communities as the people they served. As the quote below reveals caring for the health of the community came on top of having to take care of one's own family:

*It is difficult work to be a lay health worker. And but, you want to, like I said, you want to uplift your community. You are after all there to help, hey. Look at for example, now you get some men again...you must surely... you are a full-time employee. You clock-in at 8 o'clock or 7 o'clock this morning, till tonight, 5:30, 6 o'clock, hey. You are away from your home all day. Tomorrow morning you clock in again, come home only at night. You left your home just like that. You have your household responsibilities, you have your children, you must take care of your home, you must, all your... Now so and so comes to you, now he still comes to knock on your door. You go there (to where the problem is), 'the child is chesty or the child's tummy is working, can't you quickly go there'. Look he actually has put his trust in you, hey. I am now there to help in his need or if illness comes. Automatically you leave the thing that you were busy with.*

In summary the delivery of LHW interventions can be regarded as a very human task in which the LHWs and their supervisors are at the coal face or forefront in dealing with community needs. The LHWs and the LHW supervisors in the present studies, expressed

that competence in the field went beyond technical skills related to health care delivery. Full competency thus required being able to deal with the community context in which the interventions took place. This context could be emotionally difficult. LHWs in particular also pointed to the extra responsibility for caring which female LHWs carried. Together the findings show training and support as crucial for both LHWs and LHW supervisors in dealing with the responsibility for caring in the communities in which they worked.

### **Lessons from policy development (IV)**

Initially paper IV was designed to explore the place of gender in an example of contemporary LHW policy development. The findings from the research however gave insight into both the overall process of LHW policy development and the specific place of gender within this process.

The data revealed the complexity of LHW policy development. Although LHWs are a healthcare issue, the data showed that neither healthcare concerns nor the Department of Health were always the main drivers of the policy. Although LHW policy had been implemented since 2003, the present study focused on the redevelopment of LHW policy as was contemporary at the time of data collection (2009-2010). The data showed that this policy redevelopment was driven by issues which arose out of the implementation of the earlier policies. The key issue, as pointed to by participants, was the need to resolve problems around the working conditions of LHWs which were described as appalling, chaotic, corrupt, mismanaged, unstable and exploitative. Although all of the participants agreed that most of the LHWs in South Africa were women, there was no suggestion that the policy redevelopment was driven by concerns around gender. In other words, the fact that the persons experiencing these difficult working conditions were women was not linked in the policy redevelopment considerations.

The data also revealed that there were many actors in this process of policy redevelopment, and this related to the nature of the policy and the nature of the policy problem. Because the policy problem was seen as the need to resolve LHW working conditions, it was seen as appropriate within the Department of Health that the Human Resources Directorate be responsible for redevelopment of the policy:

*this has come about mainly because of the HR working conditions of [LHWs] on the ground; now the reason why HR is involved it's because they are more to do with HR issues ...that's why it is not located here [in a health programme], it is located there under Strategic Health Programs where HR and working conditions is their core competency.*

In turn because the policy involved issues of employment, the Department of Labour was drawn in. Then, because this employment of LHWs required decision making around budgets and resource allocation, participants suggested that higher level politicians had a say in the policy development. Because NGOs would ultimately be responsible for implementing the policy and employing LHWs through government funding, civil society also had a voice in the process. The only voice which did not seem to be represented was that of LHWs themselves.

The data suggested the existence of an expectation that these various actors would be engaged and consulted in the policy development process, and that this required some level of coordination:

*Yes they've been having many workshops that [the policy writer] has been coordinating and [a public health researcher] has been part of that process.*

Not all actors were happy with this process. Some found it frustrating while others felt that some of the feedback and expectations were creating a paralysis in the development process. Furthermore analysis of the data suggested that some actors had more power in the process than others. Participants suggested that some actors, such as smaller NGOs had a very limited voice in the process.

The findings also showed that within this process of negotiation and lobbying there were three key areas of debate. The first area was around where the responsibility for caring should be placed. Some participants felt that it was appropriate that communities take some responsibility for their own caring through LHW programmes. Others were concerned that this shifted the responsibility for essential health services away from government. Another area of debate was around the model of LHW care. The debate centred on whether LHWs should be specialist (dealing with single disease areas) or generalist (dealing with a range of general healthcare problems). Participants felt that while research evidence supported specialists, experience on the ground suggested that LHWs operated as generalists. This debate remained unresolved. The third and largest debate was around whether or not LHWs should be incorporated into the civil services or whether they should

continue to be employed outside of the State by NGOs. At the time of the interviews this debate was polarised into government favouring externalised employment, and civil society favouring LHW incorporation, but even within this polarisation there were variations of opinion.

### ***The place of gender considerations within policy development***

In all of the debates and negotiations that fed into the LHW policy development process, the issue of gender was given very little focus. This was despite some participants seeing a link between the issue of working conditions (which drove policy redevelopment) and gender. One participant suggested that this was because the debates centred on exploitation and not gender:

*Look the debates are not always formulated around the notion of the gendered nature of people. It's formulated around the exploitation. It's not the gendered aspect is not always put into it. So in fact it's up to us people who are researchers to actually start to note that this is also related to the gendered notion of it.*

The findings suggested that there was no pressure on the Department of Health and policy makers within it, to consider the issue of the gendered impact of LHW on its incumbents. The two quotes below reveal the difference in pressure exerted by the Department of Labour as compared to the office of the gender desk within the Department of Health:

*Department of Labour has specified that if you employing people regardless of who's employing them, if they are employed to do a piece of work for you for X number of hours the minimum conditions of service apply... uniforms in some instances, leave days, maternity leave... You see and that's where it becomes a big problem for us. When you add up all of these things you get a bill that you then can't afford.*

*Every department by law needs to have a general gender focal point. Which is an office, and in some departments they report to the Minister and others the Director General. In our instance they report to the Director General, their role is to go through all policies and see if they are fair, gender neutral, if that's appropriate etcetera, but in truth the capacities of these officers are not strong. So you know whether they have the real capacity to go through every policy to look at them, is an issue. But we have an office.*

These quotes suggest that the gender desk was limited in its capacity to influence this policy as compared to the Department of Labour.

In summary paper IV showed that, although there was some awareness of LHWs in South Africa being in the majority women, transforming the policy to be more gender sensitive

was not considered. The redevelopment process addressed the issue of LHW working conditions but did not link this to working conditions of LHWs as women. Although there were many actors who were engaged in the policy process, LHWs themselves were not engaged. Even though the policy debates raised issues that would impact on female LHWs, such as where the responsibility for caring should lie, the debates seemed to be gender blind. The findings suggest that the absence of gender from the redevelopment process may be related to the issue of exploitation not being linked to gender, and a lack of pressure on the policy developers to consider issues of gender.

## DISCUSSION

In South Africa, the process of public health and primary health care reform is continuously evolving. Currently there is a particular emphasis on reforming policies around human resources for health. It has been argued that such policy reform can be strengthened by reflection and inclusion of evidence from research studies (143-146). The contribution of such evidence to policy making, it is argued, can be both cost saving and life saving (147). However, policy making has been pointed to as a complex human activity which requires consideration of context and experience, thus more than just findings from quantitative epidemiological studies (110, 139, 140, 148, 149). This thesis focuses on LHWs as one aspect of human resources for health. It hopes to contribute to the evolving process of health care reform internationally and in South Africa specifically. It therefore attempts to add to the body of knowledge available to policy makers by building the evidence base for LHW effectiveness internationally, reflecting on the experience of small localised LHW programmes in South Africa, and considering the experience of developing a national LHW policy for South Africa.

### **How effective have LHWs been in programmes across the world and how does this apply to South Africa?**

LHW interventions continue to be promoted internationally (26) and implemented within countries as local or national level programmes (150). In particular the renewed focus (13) on LHWs has come in the wake of the increasing burden of HIV (18), and the need to find solutions to the human resource problems facing developing countries (47, 49). Countries on the African continent are particularly plagued by such human resource shortages (49). Of the 57 countries identified by the WHO as facing critical health worker shortages, 63% (n=36) occur in Sub-Saharan Africa (48, 98). These continental burdens have not escaped South Africa, a country burdened by HIV (89) and an inequitable spread of its health workforce (53).

The findings from the systematic review (I) show promise for countries such as South Africa, but these findings need to be approached with caution. Although LHW interventions were shown to be effective, this effectiveness was only shown in a limited range of areas in relation to South Africa's health care needs (80, 89). It is estimated that South Africa is

unlikely to meet its targets in relation to improving the national under-five mortality rate, the infant mortality rate and reducing the incidence, prevalence and death rates for TB (80, 89). In this regard the findings from the systematic review (I) can be viewed positively as it shows LHWs as effective in all of these areas. Importantly though, while LHWs are being increasingly utilised in HIV care (18), there were no studies of LHWs in HIV care that were found to be eligible for inclusion in the statistical meta-analysis (I).

LHWs were also shown to be effective in all areas of breastfeeding promotion, including promoting exclusive breastfeeding (I). While breastfeeding is generally regarded as important to an infant's optimal nutrition (34), exclusive breastfeeding until six months, along with antiretroviral treatment, has been recommended for feeding HIV positive infants (113). In cases where the mother is HIV positive (but not the infant), exclusive breastfeeding until six months is still shown to be more protective for the infant than formula feeding (113). Exclusive breastfeeding until six months has also been shown to be protective against gastrointestinal and respiratory infections (151), in particular diarrhoea and pneumonia (152). Thus the positive results for the effectiveness of LHWs in breastfeeding promotion and in particular exclusive breastfeeding promotion is important to South Africa and potentially other countries burdened by high rates of vertical HIV transmission (153). Caution however needs to be exercised when considering that most (10 out of 18) of the studies on breastfeeding included in the review (I) were conducted in high income countries. This is not to say that the evidence cannot be applied to low and middle income countries, but rather that policy makers need to consider how the tested interventions can be adapted for their settings (139).

### **What can we learn from the experience of LHWs and LHW supervisors?**

When it comes to deciding on policy and intervention implementation options, policy makers need to know not only whether or not an intervention was effective, but also how the delivery of the intervention was experienced (110). Qualitative research studies of implementation such as II and III can shed light on such experiences (140).

The overwhelming finding reported in papers II and III is that while participants felt rewarded and fulfilled in their tasks as LHWs and LHW supervisors, the contexts in which

they worked and the challenges they faced required that they be adequately supported. While the review (I) showed that LHWs in wealthier countries such as the USA may be able to deliver their interventions without direct contact with their client base (such as over the telephone), in developing countries LHWs tend to offer their services by physically visiting households and living in the communities which they serve (16, 150). This was the case in both interventions explored as part of this thesis (II, III). A qualitative study, not included in this thesis, but linked to the intervention explored in paper III, showed that LHWs were required to go out every day and visit mothers at their homes (16). These visits required the LHW to be skilled at constant negotiation not only with the mother, but with her extended family so as to gain entry into the home for each visit. Both paper II and III showed that such constant interaction with their communities was experienced as demanding for LHWs and for those who supported them through supervision. In considering whether or not to implement LHW interventions, be it on a small scale or a national scale, policy makers and health care managers therefore need to carefully consider whether or not they are able to offer such support. LHW interventions have however been plagued by the problem of supervision and support for a long time, with a lack of such support being blamed for the failure of LHW interventions in the 1980s (154). At the time questions were raised about the extent to which nurses could offer such support and supervision (155), and recent studies in South Africa point to the issue remaining unresolved (18, 101). A recent review of LHW programmes internationally focuses specifically on how such support and supervision might be built into the scale up of LHW interventions to national programmes (150). The capacity of a national health system to enable such support does however require that the system in itself is strong (103, 111). The national Department of Health in South Africa is in the process of scaling up LHW interventions to be a part of its reengineered PHC system. Whether or not this health system will be able to offer LHW interventions the necessary support is questionable given that the system has historically been plagued by issues of poor leadership and stewardship (53, 156).

Despite the seeming vulnerability of LHWs, their power should not be underestimated. LHWs have previously been described as street level bureaucrats (101, 157). Lipsky (158) first introduced the concept of street-level bureaucracy to explain the role of frontline workers as policy implementers in government agencies (159). Since then the role and

experience of frontline workers as street-level bureaucrats in implementation has been explored in a range of settings, including African settings (157, 160-162). These street-level bureaucrats give life to policy in the way they implement it. It is argued that “the decisions and actions of street-level bureaucrats, actually ‘become’, or represent the policies of government agencies they work for.... because a citizen most often and directly experiences policy as the decision that the street-level bureaucrat makes about their particular case”(159, p.1). Thus even though street-level bureaucrats are at the bottom end of bureaucracies the discretion they exercise when implementing policies is regarded as being very powerful, because this will ultimately determine what is delivered to the client or the patient. The way that LHWs exercise their discretionary power has been explored in studies in Kenya and South Africa (101, 157). In a programme in Kenya it was found that LHWs were providing more care and service than what they were directed to do (157). Amongst other factors identified, the authors suggest one reason for this was that these LHWs were given prestige and respect as women in a context in which there were very limited opportunities for poor rural women (157). In contrast a study in South Africa found that when older female LHWs felt that changes in policy excluded them, they responded by withdrawing their voluntary services which they had been providing to their communities for years (101). An argument is therefore made that policy makers and higher level bureaucrats need to take into account the values and realities of street-level bureaucrats such as LHWs (160). I would argue on the basis of the findings from papers II and III, that if policy makers in South Africa and elsewhere want LHWs to exercise their discretionary power in favour of the overall health system goals, then ensuring that these LHWs are adequately supported is imperative.

### **Gender and the development of LHW policy in South Africa**

The findings from paper II and III of this thesis point together with several previous studies to the gendered nature of LHW implementation in South Africa (71, 105, 106, 109, 163). These studies have in particular pointed out that LHWs in South Africa are mostly women who are made vulnerable because of ambiguous employment contracts and arrangements, and because of their role as frontline workers in difficult contexts. The extent to which these gender concerns were taken up in contemporary LHW policy development was

explored in paper IV. The findings (IV) show that the issue of gender did not enter the content or debate around the LHW policy being developed.

South Africa is one of the countries in the world that does, on paper, seem to take the issue of gender seriously (80, 164, 165). Gender rights are protected in the Constitution (85), there is a national gender policy (165), a gender policy specifically for the Department of Health (166), and a national gender machinery responsible for oversight of gender issues throughout government policies and processes (164). However, findings from paper IV would suggest that these processes have not impacted on this specific policy development process. A previous study focusing on land reform in South Africa shows that this problem is not only limited to this particular policy process (167). The study showed that there was a disjuncture between high-level commitments to gender equity and the lack of gender equity in practice in South Africa's land reform process (167). As a consequence the land reform programme was blunted in its ability to target poor, rural women. While the author points to political, organisational and social factors as contributing to this problem, she also repeatedly points to the lack of an organised women's voice. She claims that "the low political priority accorded gender policy is itself a reflection of weak levels of organization among rural women" (167, p.115). Similarly she says that the limitations of the policy are partly due to "the absence of a strong women's movement to raise the political stakes around gender policy" (167, p.140).

The findings from paper IV along with this study on land reform raise questions as to the extent to which we as South Africans are really sensitized around the issue of gender, and what it means to take a gender perspective or even to practice gender mainstreaming within government. In the interviews (IV) it was clear that participants from within the Department of Health were genuinely interested in transforming LHW policy so as to better care for LHWs, yet this interest was never expressed in relation to gender. When the activities undertaken by the Department in relation to gender were described, this was limited to events such as Women's Month or the annual 16 Days of Activism for No Violence against Women and Children. If there are at least 38 500 LHWs in South Africa and most of these are presumed to be women (55), then why do questions of gender and gender relations not come naturally? When the issue of gender is taken up in public health

research in South Africa, the extent to which it is explored seems limited. One such example is a study of men as caregivers in HIV care (168). Rather than challenging the gender relations which result in more women doing caring work than men, this study seemed to be encouraging a shift in attitude towards men being more sensitive (64, 67, 169). Other gender related studies seem to mostly focus on issues of sexual behaviour and violence which are notable problems (53), but not the extent of what could be explored. South Africa is said to show progress towards the promotion of gender equality and the empowerment of women as part of its Millennium Development Goals (80). Yet this assessment is limited to a measure of educational enrolment and completion, and to the number of women in parliament. Thus there seems to be a persistent recognition of gender issues, but a blindness around gendered transformation.

The arguments of gender theorists, particularly proponents of the concept of a gender order or a gender social order, would suggest that the gender blindness of this approach to policy development is not simply due to ignorance and a lack of awareness, but that it is socially and politically constructed (169-172). Gender order is defined as “the way society is organized around the roles, responsibilities, activities and contributions of women and men, in other words, what is expected, allowed and encouraged in relation to what women and men do in different contexts” (171, p.1). This ordering it is suggested, is part of a system of power which privileges some groups while disadvantaging others and which works with other systems of power such as racial categories and social class (170). The arguments presented by Connell (172) suggest that it is not only at the interpersonal and family levels that gender orders are constructed, but also at the level of the State, in other words the State (whom Connell argues is predominately male) through its actions (such as policies) can reproduce or transform gender orders. The transformation or non-transformation is particularly evident around policy choices made in relation to care (169). As an example, a State wanting to transform the national gender order may through policy interventions encourage equal responsibility for childcare between parents. Such an attempt at transformation has not yet been evidenced in South Africa. Instead, it could be suggested that in the process of reform around care policies the State has acted to support but maintain the notion of women as best suited to caring (173). A study exploring the reform of social welfare policy in South Africa found that the policy discourse was dominated by

familialist notions thus reinforcing the burden of care on women rather than transforming it (173). In the LHW policy development explored in paper IV, policy actors did not appear to obviously want to burden women with caring, but the issue of gender transformation did not come onto the policy making agenda either. Buse et al (174) argue that the non-decision making that results in issues not reaching the policy making agenda (i.e. what issues will be considered for inclusion and change in the policy or not) is a power in itself, in the same way that making a decision to change is an expression of power. Taking into consideration the above arguments then, the LHW policy in its current form (IV) is not simply gender blind – it is created within a national and global system which promotes and maintains women as carers. Within this broader system no decision was taken to use the development of this LHW policy to promote gender transformation.

The findings from paper IV also point to the absence of the voice of LHWs whether men or women in policy development. Health policy reform is a process which involves many actors and interest groups (175, 176) who exercise different degrees of power in influencing change or preventing change in the health policy reform process (175-178). This power is particularly exercised in championing what issues will reach the policy agenda (179-181). Unlike in developed countries, public participation in agenda-setting in developing countries has been limited (180). One might therefore ask if LHWs, women and men, rural and urban, educated or not, were to have their voices heard in the process, what power might these voices exercise and what changes to policy choices would it bring? Including such voices is particularly important in ensuring that LHWs are not treated as a homogenous group. Although it is true that most LHWs in South Africa are women and most of them are black, previous studies and experience from the ground have shown distinct differences between these women. A study of LHWs in the Eastern Cape showed clear distinction between the needs and values of older women (altruism, community respect) and the needs and values of younger women (career opportunity, furthering skills and education) (101). Thus further policy development would have to consider not just that LHWs are mostly women, but how the various backgrounds of these women intersects and interacts with their experience of being carers and being LHWs (169, 170, 182).

Government has a responsibility to care for its citizens and to care for LHWs as female carers. Literature on a political economy of care (64, 66, 67) emphasises the collective responsibility for caring, including government's responsibility for taking care. This resonates with the public health imperative of collective responsibility for ensuring good health care (3, 4). Thus taking care of care workers may be seen as part of government's public health responsibility.

## **Methodological discussion**

A strength of this thesis is that it has looked upon the topic of LHWs from multiple perspectives. Each of the four papers in this thesis has its own limitations, but in drawing them together in one thesis they complement each other in a way that strengthens the whole.

The systematic review (I) followed a very prescribed set of criteria about what kinds of studies the review authors may include. The strength is in the rigour of the reviewing process and the transparency with which this process is reported on. Part of the rigour of the systematic review is to ensure that every study conducted across the world, no matter the language, that meets the inclusion criteria will be found, considered and reviewed. It does however need to be acknowledged that the process of starting from 9705 titles and abstracts to the selection of 82 studies for inclusion is completely human and thus open to human error. For example, reviewing a couple of thousand extracts can be extremely tiring and one can miss something and make mistakes. None the less, the possibility of such mistakes was reduced by a large review team who agreed on the same set of criteria and who independently cross checked each other's selections. The outcome of this process is that rather than being able to assess the effectiveness, and therefore also areas of ineffectiveness, of LHW interventions from only one or two studies, the review authors are able to make this assessment on the basis of several studies, (82 in the case of the present review), conducted in a wide range of settings, with a wide range of patients, for a wide range of conditions, throughout the world. The limitation of the paper is that it only includes RCTs. Some who regard RCTs as the gold standard of epidemiological research would regard this as strength though, arguing that it provides a synthesis of the best available evidence (147). The counter argument is that a range of studies, such as cross

sectional studies or observational studies, which may have been reliably conducted are not included because they are not RCTs (183). A further argument may be made that systematic reviews such as these provide a very limited and decontextualised answer to the question of effectiveness (139, 140).

As a counterbalance to the systematic review, the findings from papers II and III attempt to provide a thick description (110) of the experience of implementing LHW interventions in South Africa. The strength is that it attempts to give voice to the experience of LHWs and LHW supervisors through their own accounts and as relayed in discussion not only with the researchers but with each other. These accounts are made visible through translated, verbatim quotes included in the text of the articles. Such voices provide an important insight into the day to day experience of interventions. As the findings from paper IV shows the voice of people on the ground has been underrepresented, if represented at all, in the LHW policy development process. The limitation of both paper II and III is that they only explore the experience of single interventions. Furthermore, although these papers have been reported on side by side in the thesis, the participants come from two completely unrelated interventions and so there are limits to which the findings from each paper can be used to complement each other. It may have been more useful if the thick description could have been based on accounts from LHWs and LHW supervisors who had worked on the same intervention. However this was not possible for practical reasons. None the less, the fact that similar issues (such as the need for support and the intervention being emotionally taxing) were reported by these two different participant groups, strengthens the external validity (184) of each paper and suggests that the findings may be close to reaching “the truth”(133).

Paper II is based on FGDs. Traditionally FGDs do not involve more than about eight participants (185). This allows enough participants to create group interaction without having so many participants that the voice of certain participants would be drowned out. Larger groups are also thought to be harder to control. The FGDs in paper II were however very large, with a range of 12 to 21 participants. Because of the limited access we had to the LHWs in the intervention, the researchers had no choice but to work with groups of this size. It is possible and probably likely that some voices were lost as a consequence of having

such large groups. But it is also possible and likely that in such a large group of people with whom they were familiar, that participants felt less awkward with the strangeness of the research process. KD and the research assistant, while being of the same race as the participants, were very different to them in many other ways – as middle class educated urbanites who spoke a very different Afrikaans to participants and came as guests of the intervention leaders. Given this difference between the interviewers and participants, the FGDs may have allowed for the participants to feel more safe given that they were in the majority. KD subsequently tried interviewing a different group of LHWs using individual interviews (not included in this thesis), but the distance between the researcher and the researched proved very large. Consequently, those individual interviews lasted no longer than 20 minutes on average and yielded very little data of any use. In the future it may be better to consider working with a small group of LHWs over a longer period of time. This may help to establish trust and subsequently enable more depth in data collection.

Papers III and IV both utilised individual interviews. As with paper II, KDs identity interacted with the research process. In the case of paper III, KD was slightly more professionally senior than the three participants. One of them was however much older than KD and had many more years of professional work experience. Thus in the research interaction the participant probably regarded herself as senior to KD. Through her demeanour in the interviews, KD tried to convey trustworthiness. By being sincere, she hoped that it would show that she could be trusted in holding the participants' confidences and in her ability to represent the stories they were telling her. In paper IV this power balance swung to the other side as KD was in a junior position to all of the participants. All of them were senior professionals, several held PhDs, some were professors, some medical doctors and they all had years of experience in their professions. The challenge in these interviews was to not be intimidated by the seniority of the participants and to still conduct an interview in which the participants felt that KD was competent enough to trust with the stories they had to tell. Furthermore, the fact that KD works in the same professional circles as all of the participants was both a door opener for some interviews, and delayed her access to conducting others. Some of the participants may have trusted KD because they already knew her or if not then she was introduced to them through her professional networks, others may have delayed granting her an interview for exactly the same reason. Trust is an

important issue in all research. In qualitative research where so much relies on the person of the researcher since it is the researcher who is the research tool in data collection, this becomes highlighted even more. Throughout the process KD tried to be as trustworthy as possible in her interactions, analysis and reporting, accepting also her own limitations.

Although there have been several studies up till now which have looked at gendered issues related to LHWs, there have as far as we know not been any which have looked at how this is addressed in the policy development process. The strength of paper IV is that it does not only look at the content of the policy being developed, but also at the process of development (176). Through the use of individual key informant interviews it attempts to understand how this content was conceptualised during the process of policy development. It does so by taking into account the perspectives of those people who were directly engaged with the process and those people who were close enough to the process to be critically reflective.

### **Generalisability**

In any research study, the question of generalisability is important (184). For public health in developing country settings this is particularly important as policy makers may not have the luxury of having had studies conducted in their settings related to their questions of interest (120, 122, 147). Such generalisability is strengthened in both qualitative and quantitative studies by reliability, representativeness and credibility (184). In qualitative research such generalisability is enhanced when the research process and data extracts are made explicit so that the reader can consider the extent to which the reported findings are applicable to their settings. Furthermore it is not only the actual findings, but the concepts explored (concept or theoretical generalisability) that may be relevant beyond the study (184).

The author of this thesis attempted to be as explicit as possible in the reporting of the methods and in the reporting of the findings so as to enhance generalisability. Findings from papers (I-IV) included in this thesis are confirmed by other studies, they add to the knowledge base on studies of LHWs (13) and they add to studies of gendered policy making (167). The findings presented in this thesis may be useful to public health practitioners and policy makers both in South Africa and in contexts similar to South Africa.

## CONCLUSIONS AND IMPLICATIONS

This thesis supports a cautionary attitude towards the implementation of LHW programmes as public health interventions. It has shown that although LHWs can be effective, that the evidence for their effectiveness in developing countries is limited. Furthermore this thesis has also shown that LHW intervention experience points to the need for strong support and supervision from the health system. Despite the majority of LHWs in South Africa being women and the availability of research which points to gendered concerns around LHW interventions, the issue of gender was not included in LHW policy development in this country. This may possibly be related to a broader issue of not knowing how to address gender in practice, rather than simply the problem of this policy development process.

Findings from this thesis would suggest that governments hoping to implement new or continued LHWs programmes and policies, need to do so with consideration not only for the health care of its citizens, but also with consideration for the protection of the LHWs themselves. As has been shown elsewhere (71, 102), LHWs in this thesis were in the majority women. While government attempted to address the exploitation of these women as LHWs, they did not consider this from a gendered perspective. This thesis suggests therefore that more work needs to be done to convince policy makers to consider not just how LHWs are exploited, but also to consider how they as women specifically are even more open to exploitation, and to consider how through policy interventions the lives of these women and the people they serve could be improved. The gender blindness observed in paper IV is not reserved for LHW programmes and policies alone, but part of a larger gender order which favours gender blindness and with hidden assumptions about the place of women as carers (186).

One of the discoveries made through conducting this thesis is that there has been a considerable amount of research on the issue of LHWs in South Africa. It is therefore recommended that before any further future research be conducted that this body of locally generated knowledge be collated and reviewed. This, along with continued international studies will provide a useful resource from which continued policy making for LHWs can be revised.

## **Implications for practice**

- Implementation of LHW interventions should be approached with caution.
- LHW interventions need strong support and supervision within strong health systems.
- The protection of LHWs should be considered with as much weight as the desire to improve the health of citizens through LHW programmes.
- The link between LHW interventions and gendered exploitation has been made in research. This still needs to be made in policy and practice.

## **Implication for future research**

- Future research should increase the knowledge base on the effectiveness of LHW interventions in developing country settings.
- Future research could explore how to deliver better support and supervision to LHWs.
- The existing body of locally generated research knowledge on the issue of LHWs in South Africa needs to be collated and reviewed.
- The breadth of public health research on gender needs to be expanded so as to better inform policy and implementation decisions.
- Future research could explore how to effectively include the voices of ordinary women, such as LHWs, in policy making for health and other areas.
- To increase the depth of our understanding of LHW experience in future it may be useful to follow individual LHWs over a period of time during which a stronger rapport can be built than is possible in an individual interview.
- Future studies could explore family and community responses to these and other issues. There is to date no known study which considers how the families and communities of recipients of LHW interventions receive these interventions. We know anecdotally that LHWs visiting a particular home regularly may raise suspicion about illness in the home and that this may lead to stigma in the community for the family and the LHW.
- Questions have also been raised in the public arena about LHWs as providing second class care.
- The response of LHW programme implementers (NGO staff and health services staff) is also important. The extent of research amongst such persons and what gaps there may be in this body of knowledge needs to be explored with a view of strengthening this knowledge base.
- Future research may explore more of the mechanisms involved in the interpersonal interactions between LHWs and clients.

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Figure 1 was designed by DK Design Creative Consultants, 2012. Figure 3 is KDs own design.

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## Förteckning över NHV-rapporter

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- 1983:2 Methods and Experience in Planning for Family Health – Report from a seminar. Harald Heijbel & Lennart Köhler (eds).
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### 1984

- 1984:1 Långvarigt sjuka barn – sjukvårdens effekter på barn och familj. Andersson, Harwe, Hellberg & Syrén. (FoU-rapport/shstf:14). Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.
- 1984:2 Intersectoral Action for Health – Report from an International Workshop. Lennart Köhler & John Martin (eds).
- 1984:3 Barns hälsotillstånd i Norden. Gunborg Jakobsson & Lennart Köhler. Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.

### 1985

- 1985:1 Hälsa för äldre i Norden år 2000. Mårten Lagergren (red).
- 1985:2 Socialt stöd åt handikappade barn i Norden. Mats Eriksson & Lennart Köhler. Distribueras av Allmänna Barnhuset, Box 26006, SE-100 41 Stockholm.
- 1985:3 Promotion of Mental Health. Per-Olof Brogren.
- 1985:4 Training Health Workers for Primary Health Care. John Martin (ed).
- 1985:5 Inequalities in Health and Health Care. Lennart Köhler & John Martin (eds).

### 1986

- 1986:1 Prevention i primärvården. Rapport från konferens. Harald Siem & Hans Wedel (red). Distribueras av Studentlitteratur, Box 141, SE-221 01 Lund.
- 1986:2 Management of Primary Health Care. John Martin (ed).

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- 1986:3 Health Implications of Family Breakdown. Lennart Köhler, Bengt Lindström, Keith Barnard & Houda Itani.
- 1986:4 Epidemiologi i tandvården. Dorthe Holst & Jostein Rise (red). Distribueras av Tandläkarförlaget, Box 5843, SE-102 48 Stockholm.
- 1986:5 Training Course in Social Pediatrics. Part I. Lennart Köhler & Nick Spencer (eds).

### 1987

- 1987:1 Children's Health and Well-being in the Nordic Countries. Lennart Köhler & Gunborg Jakobsson. Ingår i serien Clinics in Developmental Medicine, No 98 och distribueras av Blackwell Scientific Publications Ltd, Oxford. ISBN (UK) 0 632 01797X.
- 1987:2 Traffic and Children's Health. Lennart Köhler & Hugh Jackson (eds).
- 1987:3 Methods and Experience in Planning for Health. Essential Drugs. Frants Staugård (ed).
- 1987:4 Traditional midwives. Sandra Anderson & Frants Staugård.
- 1987:5 Nordiska hälsovårdshögskolan. En historik inför invigningen av lokalerna på Nya Varvet i Göteborg den 29 augusti 1987. Lennart Köhler (red).
- 1987:6 Equity and Intersectoral Action for Health. Keith Barnard, Anna Ritsatakis & Per-Gunnar Svensson.
- 1987:7 In the Right Direction. Health Promotion Learning Programmes. Keith Barnard (ed).

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- 1988:1 Infant Mortality – the Swedish Experience. Lennart Köhler.
- 1988:2 Familjen i välfärdsstaten. En undersökning av levnadsförhållanden och deras fördelning bland barnfamiljer i Finland och övriga nordiska länder. Gunborg Jakobsson. Avhandling.
- 1988:3 Aids i Norden. Birgit Westphal Christensen, Allan Krasnik, Jakob Bjørner & Bo Eriksson.
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- 1988:5 Training Course in Social Pediatrics. Part II. Perinatal and neonatal period. Bengt Lindström & Nick Spencer (eds).

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1989:4 Traditional Medicine in Botswana. Traditional Medicinal Plants. Inga Hedberg & Frants Staugård.

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1989:6 Omstridda mödrar. En studie av mödrar som förtecknats som förståndshandikappade. Evy Kollberg. Avhandling.

1989:7 Traditional Medicine in a transitional society. Botswana moving towards the year 2000. Frants Staugård.

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1990:4 Coffee and Coronary Heart Disease, Special Emphasis on the Coffee – Blood Lipids Relationship. Dag S. Thelle & Gerrit van der Stegen (eds).

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- 1991:5 Growth and Social Conditions. Height and weight of Stockholm schoolchildren in a public health context. Lars Cernerud. Avhandling.
- 1991:6 Aids in a caring society – practice and policy. Birgit Westphal Victor. Avhandling
- 1991:7 Resultat, kvalitet, valfrihet. Nordisk hälsopolitik på 90-talet. Mats Brommels (red). Distribueras av nomesko, Sejrhøgade 11, DK-2100 København.

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- 1992:1 Forskning om psykiatrisk vårdorganisation – ett nordiskt komparativt perspektiv. Mats Brommels, Lars-Olof Ljungberg & Claes-Göran Westin (red). sou 1992:4. Distribueras av Fritzes, Box 16356, SE-103 27 Stockholm (Allmänna förlaget).
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- 1993:1 Kronisk syke og funksjonshemmede barn. Mot en bedre fremtid? Arvid Heiberg (red). Distribueras av Tano Forlag, Stortorget 10, NO-0155 Oslo.
- 1993:2 3 Nordiske Konference om Sundhedsfremme i Aalborg 13 – 16 september 1992. Carl-Gunnar Eriksson (red).

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- 1993:3 Reumatikernas situation i Norden. Kartläggning och rapport från en konferens på Nordiska hälsovårdshögskolan 9 – 10 november 1992. Bjarne Jansson & Dag S. Thelle (red).
- 1993:4 Peace, Health and Development. A Nobel seminar held in Göteborg, Sweden, December 5, 1991. Jointly organized by the Nordic School of Public Health and the University of Göteborg with financial support from SAREC. Lennart Köhler & Lars-Åke Hansson (eds).
- 1993:5 Hälsopolitiska jämlikhetsmål. Diskussionsunderlag utarbetat av WHOs regionkontor för Europa i Köpenhamn. Göran Dahlgren & Margret Whitehead. Distribueras gratis.

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- 1994:1 Innovation in Primary Health Care of Elderly People in Denmark. – Two Action Research Projects. Lis Wagner. Avhandling.
- 1994:2 Psychological stress and coping in hospitalized chronically ill elderly. Mary Kalfoss. Avhandling.
- 1994:3 The Essence of Existence. On the Quality of Life of Children in the Nordic countries. Theory and Practice. Bengt Lindström. Avhandling.

### 1995

- 1995:1 Psykiatrisk sykepleie i et folkehelseperspektiv. En studie av hvordan en holistisk-eksistensiell psykiatrisk sykepleiemodell bidrar til folkehelsearbeid. Jan Kåre Hummelvoll. Avhandling.
- 1995:2 Child Health in a Swedish City – Mortality and birth weight as indicators of health and social inequality. Håkan Elmén. Avhandling.
- 1995:3 Forebyggende arbeid for eldre – om screening, funn, kostnader og opplevd verdi. Grethe Johansen. Avhandling.
- 1995:4 Clinical Nursing Supervision in Health Care. Elisabeth Severinsson. Avhandling.
- 1995:5 Prioriteringsarbeid inom hälso- och sjukvården i Sverige och i andra länder. Stefan Holmström & Johan Calltorp. Sprit 1995. Distribueras av Spris förlag, Box 70487, SE-107 26 Stockholm.

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- 1996:1 Socialt stöd, livskontroll och hälsa. Raiili Peltonen. Socialpolitiska institutionen, Åbo Akademi, Åbo, 1996.

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- 1996:2 Recurrent Pains – A Public Health Concern in School – Age Children. An Investigation of Headache, Stomach Pain and Back Pain. Guðrún Kristjánsdóttir. Avhandling.
- 1996:3 AIDS and the Grassroots. Frants Staugård, David Pitt & Claudia Cabrera (red).
- 1996:4 Postgraduate public health training in the Nordic countries. Proceedings of seminar held at The Nordic School of Public Health, Göteborg, January 11 – 12, 1996.

### 1997

- 1997:1 Victims of Crime in a Public Health Perspective – some typologies and tentative explanatory models (Brottsoffer i ett folkhälsoperspektiv – några typologier och förklaringsmodeller). Barbro Renck. Avhandling. (Utges både på engelska och svenska.)
- 1997:2 Kön och ohälsa. Rapport från seminarium på Nordiska hälsovårdshögskolan den 30 januari 1997. Gunilla Krantz (red).
- 1997:3 Edgar Borgenhammar – 65 år. Bengt Rosengren & Hans Wedel (red).

### 1998

- 1998:1 Protection and Promotion of Children's Health – experiences from the East and the West. Yimin Wang & Lennart Köhler (eds).
- 1998:2 EU and Public Health. Future effects on policy, teaching and research. Lennart Köhler & Keith Barnard (eds)
- 1998:3 Gender and Tuberculosis. Vinod K. Diwan, Anna Thorson, Anna Winkvist (eds)  
Report from the workshop at the Nordic School of Public Health, May 24-26, 1998.

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- 1999:1 Tipping the Balance Towards Primary Healthcare Network. Proceedings of the 10th Anniversary Conference, 13-16 November 1997. Editor: Chris Buttanshaw.
- 1999:2 Health and Human Rights. Report from the European Conference held in Strasbourg 15-16 mars 1999. Editor: Dr. med. Stefan Winter.
- 1999:3 Learning about health: The pupils' and the school health nurses' assessment of the health dialogue. Ina Borup. DrPH-avhandling.

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- 1999:4 The value of screening as an approach to cervical cancer control. A study based on the Icelandic and Nordic experience through 1995. Kristjan Sigurdsson. DrPH-avhandling.

### 2000

- 2000:1 Konsekvenser av urininkontinens sett i et folkehelsevitenskapelig perspektiv. En studie om livskvalitet hos kvinner og helsepersonells holdninger. Anne G Vinsnes. DrPH-avhandling.
- 2000:2 A new public health in an old country. An EU-China conference in Wuhan, China, October 25-29, 1998. Proceedings from the conference. Lennart Köhler (ed)
- 2000:3 Med gemenskap som grund - psykisk hälsa och ohälsa hos äldre människor och psykiatrisjuksköterskans hälsofrämjande arbete. Birgitta Hedelin. DrPH-avhandling.
- 2000:4 ASPHER Peer Review 1999. Review Team: Jacques Bury, ASPHER, Franco Cavallo, Torino and Charles Normand, London.
- 2000:5 Det kan bli bättre. Rapport från en konferens om barns hälsa och välfärd i Norden. 11-12 november 1999. Lennart Köhler. (red)
- 2000:6 Det är bra men kan bli bättre. En studie av barns hälsa och välfärd i de fem nordiska länderna, från 1984 till 1996. Lennart Köhler, (red)
- 2000:7 Den svenska hälso- och sjukvårdens styrning och ledning – en delikat balansakt. Lilian Axelsson. DrPH-avhandling.
- 2000:8 Health and well-being of children in the five Nordic countries in 1984 and 1996. Leeni Berntsson. DrPH-avhandling.
- 2000:9 Health Impact Assessment: from theory to practice. Report on the Leo Kaprio Workshop, Göteborg, 28 - 30 October 1999.

### 2001

- 2001:1 The Changing Public-Private Mix in Nordic Healthcare - An Analysis John Øvretveit.
- 2001:2 Hälsokonsekvensbedömningar – från teori till praktik. Rapport från ett internationellt arbetsmöte på Nordiska hälsovårdshögskolan den 28-31 oktober 1999. Björn Olsson, (red)
- 2001:3 Children with asthma and their families. Coping, adjustment and quality of life. Kjell Reichenberg. DrPH-avhandling.

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- 2001:4 Studier av bruket av dextropropoxifen ur ett folkhälsoperspektiv. Påverkan av ett regelverk. Ulf Jonasson. DrPH-avhandling.
- 2001:5 Protection – Prevention – Promotion. The development and future of Child Health Services. Proceedings from a conference. Lennart Köhler, Gunnar Norvenius, Jan Johansson, Göran Wennergren (eds).
- 2001:6 Ett pionjärbete för ensamvargar  
Enkät- och intervjuundersökning av nordiska folkhälsodoktorer  
examinerade vid Nordiska hälsovårdshögskolan under åren 1987 – 2000.  
Lillemor Hallberg (red).

### 2002

- 2002:1 Attitudes to prioritisation in health services. The views of citizens, patients, health care politicians, personnel, and administrators. Per Rosén. DrPH-avhandling.
- 2002:2 Getting to cooperation: Conflict and conflict management in a Norwegian hospital. Morten Skjørshammer. DrPH-avhandling.
- 2002:3 Annual Research Report 2001. Lillemor Hallberg (ed).
- 2002:4 Health sector reforms: What about Hospitals? Pär Eriksson, Ingvar Karlberg, Vinod Diwan (ed).

### 2003

- 2003:1 Kvalitetsmåling i Sundhedsvæsenet.  
Rapport fra Nordisk Ministerråds Arbejdsgruppe.
- 2003:3 NHV 50 år (Festboken)
- 2003:4 Pain, Coping and Well-Being in Children with Chronic Arthritis.  
Christina Sällfors. DrPH-avhandling.
- 2003:5 A Grounded Theory of Dental Treatments and Oral Health Related Quality of Life. Ulrika Trulsson. DrPH-avhandling.

### 2004

- 2004:1 Brimhealth: Baltic rim partnership for public health 1993-2003.  
Susanna Bihari-Axelsson, Ina Borup, Eva Wimmerstedt (eds)
- 2004:2 Experienced quality of the intimate relationship in first-time parents –  
qualitative and quantitative studies. Tone Ahlborg. DrPH-avhandling.

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Why, and What Did we Learn?  
Erik Blas. DrPH-avhandling
- 2005:3 Socio-economic Status and Health in Women - Population-based studies  
with emphasis on lifestyle and cardiovascular disease  
Claudia Cabrera. DrPH-avhandling

### 2006

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Synnöve Ödegård. DrPH-avhandling
- 2006:2 Interprofessional Collaboration in Residential Childcare  
Elisabeth Willumsen. DrPH-avhandling
- 2006:3 Innkost-CTG: En vurdering av testens prediktive verdier, reliabilitet og  
effekt. Betydning for jordmødre i deres daglige arbeide  
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### 2007

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Kaja Põlluste. DrPH-avhandling
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Bengt Åhgren. DrPH-avhandling
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Sirikka Elo. DrPH-avhandling
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Gunilla Kulla. DrPH-avhandling

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- 2010:3 R Uvärdering av verksamheten vid Enheten för Asyl- och flyktingfrågor, Västra Götalandsregionen
- 2010:4 R Utvärdering av försöksverksamhet med samverkansgrupper och coacher i Vänersborg och Mellerud
- 2010:5 R Utvärdering av projekt GEVALIS – Unga vuxna
- 2010:6 R Utvärdering av Program Sexuell hälsa, Västra Götalandsregionen
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Anne Clancy. DrPH-avhandling
- 2010:8 Living with head and neck cancer: a health promotion perspective – A Qualitative Study  
Margereth Björklund. DrPH-avhandling
- 2010:9 R Barnhälsoindex för stadsdelarna i nordöstra Göteborg, Ett förslag till uppföljning av barns hälsa och välbefinnande, Lennart Köhler. NHV i samarbete med Västra Götalandsregionen, Angereds närsjukhus
- 2010:10 R Utvärdering med lärande ansats av pandemiplanering inklusive vaccinationsprogram i Västra Götalandsregionen

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Thomas Munk Larsen, Merete Nordentoft, Mika Gissler, Jeanette Westman, Kristian Wahlbeck
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Lena V Kallings, på uppdrag av Nordisk nettverk for fysisk aktivitet, mat og sunnhet

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En kunnskapsoversikt  
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Rafael Lindqvist, Steen Bengtsson, Lars Fredén, Frode Larsen, David Rosenberg, Torleif Ruud, Kristian Wahlbeck
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### 2012

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Karen Daniels. Dr.PH- avhandling