UNIVERSITY OF THE WESTERN CAPE

Faculty of Community and Health Sciences

RESEARCH MINI THESIS

ASSESSMENT OF THE UPTAKE OF REFERRALS BY COMMUNITY HEALTH WORKERS TO PUBLIC HEALTH FACILITIES IN UMLAZI, KWAZULU-NATAL.

A minithesis submitted in partial fulfilment of the requirements for the degree of Masters in Public Health in the Faculty of Community and Health Sciences in the University of the Western Cape.

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ABSTRACT

Background: Globally, neonatal mortality (i.e. deaths occurring during the first month of life) accounts for 44% of the 11 million infants that die every year (Lawn, Cousens & Zupan, 2005). Early detection of illness and referral of mothers and infants during the peri-natal period to higher levels of care can lead to substantial reductions in maternal and child mortality in developing countries. Establishing effective referral systems from the community to health facilities can be achieved through greater utilization of community health workers and improved health seeking behaviour.

Study design: The Good Start Saving Newborn Lives study being conducted in Umlazi, KwaZulu-Natal, is a community randomized trial to assess the effect of an integrated home visit package delivered to mothers during pregnancy and post delivery on uptake of PMTCT interventions and appropriate newborn care practices. The home visit package is delivered by community health workers in fifteen intervention clusters. Control clusters receive routine health facility antenatal and postpartum care.

For any identified danger signs during a home visit, community health workers write a referral and if necessary refer infants to a local clinic or hospital. The aim of this study was to assess the effectiveness of this referral system by describing community health worker referral completion rates as well as health-care seeking practices and perceptions of mothers.

A cross- sectional survey was undertaken using a structured questionnaire with all mothers who had been referred to a clinic or hospital by a community health worker since the start of the Good Start Saving Newborn Lives Trial.

Data collection: Informed consent was obtained from willing participants. Interviews were conducted by a trained research assistant in the mothers' home or at the study offices. Road to Health Cards were reviewed to confirm referral completion. Data was collected by means of a cell phone (mobile researcher software) and the database was later transferred to Epi-info and STATA IC 11 for analysis. Descriptive analysis was conducted so as to establish associations between explanatory factors and referral completion and to describe referral processes experienced by caregivers. Significant associations between categorical variables were assessed using chi square tests and continuous variables using analysis of variance.

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Results:

A total of 2423 women were enrolled in the SNL study and 148 had received a referral for a sick infant by a CHW by June 2010. The majority (95%) of infants were referred only once during the time of enrolment, the highest number of which occurred within the first 4 weeks of life (62%) with 22% of these being between birth and 2 weeks of age. Almost all mothers (95%) completed the referral by taking their child to a health facility. Difficulty in breathing and rash accounted for the highest number of referrals (26% and 19% respectively). None of the six mothers who did not complete referral recognised any danger signs in their infants. In only 16% of cases did a health worker give written feedback on the outcome of the referral to the referring CHW.

Conclusion:

This study found high compliance with referrals for sick infants by community health workers in Umlazi. This supports the current primary health care re-engineering process being undertaken by the South African National Department of Health (SANDOH) which will involve the establishment of family health worker teams including community health workers. A key function of these workers will be to conduct antenatal and postnatal visits to women in their homes and to identify and refer ill children. Failure of mothers to identify danger signs in the infant was associated with non-completion of referral. This highlights the need for thorough counseling of mothers during the antenatal and early postnatal period on neonatal danger signs which can be reinforced by community health workers. Most of the referrals in this study were neonates which strengthens the need for home visit packages delivered by community health workers during the antenatal and post-natal period as currently planned by the South African National Department of Health.

Recommendations:

This study supports the current plans of the Department of Health for greater involvement of CHWs in Primary Health Care. Attention should be given to improving communication between health facilities and CHWs to ensure continuity of care and greater realization of a team approach to PHC.

DECLARATION

I declare that:

Assessment of the uptake of referrals by community health workers to public health

facilities in Umlazi, KwaZulu-Natal is my own work, that it has not been submitted for

any degree or examination in any other university, and that all the sources I have used

or quoted have been indicated and acknowledged by complete references.

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Full name: DUDUZILE FAITH NSIBANDE Date: May 2011

Signed.....

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LIST OF ABBREVIATIONS

AIDS - Acquired Immunodeficiency Syndrome

ANC - Antenatal care

ARV - Antiretroviral

ART - Antiretroviral treatment

AZT - Azidothymidine (Zidovudine)

CHW - Community Health Worker

DOH – Department of Health

DTP – Diphtheria, Tetanus and Polio

HIV - Human Immunodeficiency Virus

HH/C IMCI - Household and Community Component of IMCI

IMCI - Integrated Management of Childhood Illnesses

IYCF - Infant and Young Child Feeding

IMR - Infant Mortality Rate

KZN - KwaZulu - Natal

MMR – Maternal Mortality Rate

MNCWH – Maternal, Neonatal, Child and Women's Health

MRC - Medical Research Council

MTCT - Mother-to-child transmission of HIV

NDOH – National Department of Health

NMR – Neonatal Mortality rate

NVP – Nevirapine

PHC - Primary Health Care

PMTCT- Prevention of mother-to-child transmission of HIV

PMMH - Prince Mshiyeni Memorial Hospital

RTHC - Road to Health Card

WHO - World Health Organisation

UNICEF – United Nations Children Fund

SANDOH – South African National Department of Health

SADHS - South African Demographic and Health Survey

SNL- Saving Newborn Lives



Definition of terms

Referral:

A referral can be defined as a process in which a health worker at one level of the health system, having insufficient resources (drugs, equipment, skills) to manage a clinical condition, seeks the assistance of a better or differently resourced facility at the same or higher level to assist in, or take over the management of, the client's case.

Health seeking behaviour:

These are personal actions to promote optimal wellness, recovery and rehabilitation.

Community health workers:

Community health workers (CHWs) are trained paraprofessionals who serve as health and human service resource persons in the communities where they live and work. As trusted members of the communities they serve, CHWs primarily assist isolated and vulnerable families and groups by acting as an extension of the Primary Health Care service, reaching out to people at household level.

Referral completion

In this study referral completion is defined as mothers/caregivers taking children to health care facilities following a referral by a Good Start community health worker.

Integrated Management of Childhood Illnesses

This is a system used by health care workers using clinical signs to identify illnesses in infants and children, and there after giving treatment or referring children to other levels of health care.

Neonatal death/mortality:

Death of infants during the first 28 completed days of life per 1,000 live births in a given year or period. Neonatal deaths may be subdivided into early neonatal deaths, occurring during the first seven days of life, and late neonatal deaths, occurring after the seventh day but before 28 completed days of life. This is considered a good indicator of both maternal and newborn health and care.

Counseling

This is a process of exchanging opinions and ideas between the health care worker and the client, with an aim of assisting the client to take a decision.

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Exclusive breast-feeding:

Feeding practice in which an infant receives only breast milk and no other liquids or solids (including water), but may receive drops or syrups consisting of vitamins, mineral supplements, or medicines.

Post-natal period:

The period beginning one hour after delivery of the placenta and continuing until six weeks (42 days) after the birth of an infant.

CHAPTER 1

1.1 Introduction

A significant fall in mortality among children has been observed among children under 5 years of age in the past thirty years in developing countries worldwide; however there has been a slow decrease in neonatal mortality rates. Globally, neonatal mortality (i.e. deaths occurring during the first month of life) accounts for 44% of the 11 million infants that die every year (Lawn, Cousens & Zupan, 2005; Gorgia & Sachdev, 2010). Literature suggests that almost all these deaths occur in middle and low income countries and more than 50% of these occur at home (Lawn, Cousens & Zupan, 2005). Three quarters of neonatal deaths occur during the first week of life and among these, two thirds occur within the first 24 hours after birth. Despite the introduction of several high-impact health and nutrition interventions in South Africa, nearly 9 children die every hour from causes that could be prevented by simple cost-effective interventions (Lawn, Cousens & Zupan, 2005; UNICEF 2009). WHO (2008) estimates that 75000 children die in South Africa every year, 22 000 of which are newborns (Kallander, Tomson, Nsungwa-Sabiiti, Senyonjo, Pariyo & Peterson, 2006; SANDOH, 2010d). The infant mortality rate varies in different population groups with 47/1000 live births in the black population compared to 11 in the White and 18 in the Coloured populations (SANDOH, 1998).

South Africa is one of nine countries where under-five mortality rates have increased over the past ten years. HIV/AIDS has been identified as one of the leading contributors to this increase, estimated to account for 40% of under-five mortality (UNICEF, 2001). The South African Burden of Disease Review in 2005 found neonatal diseases, pneumonia, diarrhoea and malnutrition as the main causes of mortality in children less than 5 years often secondary to HIV infection (SANDOH, 2010b; Lawn, Cousens, Zupan et al., 2005).

South Africa has the highest number of people living with HIV of any African country; with KwaZulu – Natal province being worst affected. It is estimated that 5.2 million South Africans were infected with HIV in 2008. The highest prevalence (32.7%) was among young females aged 25- 39years. In KZN the HIV prevalence among pregnant women attending public facilities was 39.5% in 2009 (SANDOH, 2010a).

South Africa is one of the ten countries that are not on track to achieve the Millennium Development Goals (MDGs) to reduce infant, under-5 and maternal mortality rates by 2015. The SANDOH has acknowledged that in order to increase the likelihood of meeting the health MDGs, the health system needs to be strengthened through re-engineering of the current PHC approach. In order to do this, the DoH has drawn on experiences in Brazil. Brazil's Family Health Programme is probably the most impressive example worldwide of a rapidly scaled up, cost effective, comprehensive primary health care system. This programme is based on a simple model - multidisciplinary teams, comprising a doctor, nurse, nurse auxiliary, and four to six community health workers who work in their local health units located in geographically defined areas. Each community health worker is responsible for a number of families in a defined area, and conducts home visits to every household at least once a month. Although child and maternal health forms the bulk of their work, they are multifunctional and integrated within the PHC system (Harris and & Haines, 2010; Magalhães, de Castro & Senna, 2006).

Lessons learnt from the success of Brazil's Unified Health Programme/Family Health Programme, have led to the revision of the SANDOH PHC service package in 2010. The PHC approach will change from a passive, curative-oriented and based on individual

health care to a proactive population-based approach utilising community health workers. The District Health System, which is the vehicle that drives its implementation, will be strengthened ensuring local accountability, community participation, developmental and inter-sectoral involvement (SANDOH 2010c, SANDOH, 2010d).

A critical component of primary level management of ill children is the Integrated Management of Childhood Illness (IMCI) strategy. It was implemented in South Africa in 2002. It is a WHO/UNICEF broad strategy, adopted by more than 80 countries, for reducing child mortality and improving child health and development in developing countries. It recognises that most sick children present with signs and symptoms related to more than one disease entity. It uses an integrated approach to managing sick children, and is designed to address the major causes of child mortality at community, primary health care, and district hospital levels by improved case-management, improved health systems support and improved family and community practices. It uses tools to classify sick children into mild, moderate, and severe groups. Children with a severe classification receive initial treatment and urgent referral to hospital (WHO, 1997; UNICEF ESARO, 1999; Schellenberg, Bryce, de Savigny et al., 2004). Community programmes delivering Integrated Management of Childhood Illness are a means of creating effective links between clinics and community-based maternal and child health services and referral of severely ill children to hospital is key in the IMCI approach (Peterson, Nswanga-Sabiiti, Were, 2004).

In KwaZulu-Natal, the community component of the Integrated Management of Childhood Illnesses programme is not yet well established and the post-natal care component of maternal and child health programmes is also weak. There is poor postnatal

follow up of mothers and newborns, with no standardised community visits. Given the scale of the HIV epidemic in KZN and its impact on neonatal health status, the role of community health care workers in the early identification and referral of sick babies to health facilities becomes critical.

There is growing literature on health seeking behaviours and on factors influencing health services utilization in developing countries, but very few are focused on the effectiveness of CHW referrals (Gorgia & Sachdev, 2010; Bhutta, Memon, Soofi, Salat, Cousens & Martines, 2008). A study on effectiveness of patient referrals in Pakistan found that in higher-level facilities there was lack of documentation and information on referred patients and there was no feedback to the referring health worker (Siddiqi, Kielmann, Khan et al., 2001).

Community-based health programmes focusing on maternal and child health are increasing in developing countries as weak health systems are unable to bear the entire responsibility for health care. To complement facility based care, home-based strategies to promote optimal neonatal care practices have been proposed. This involves home visits for the promotion of optimal care, home-based management of neonatal infections and other danger signs, and promotion of preventive interventions.

Community based programmes play an important role of identifying health problems that require further management and referring to health workers with expertise at a higher level. Little is known about the effectiveness and outcome of referrals from community based health workers to formal health services. This study aims to contribute knowledge in this area from a large community based intervention in KwaZulu-Natal.

1.2 Rationale

Health care providers often experience challenges when trying to facilitate referral of clients to higher levels of health care. Non-functional referral strategies and constrained health systems are major obstacles to effective primary health care delivery. The community component of IMCI using community health workers was developed to improve the linkages for referral between community and health services. However, low completion of referral is a major problem resulting from difficulties for health workers, patients, households, and communities (Macintyre & Hotchkiss, 1999; Schellenberg, Bryce, de Savigny, 2004). Several studies have reported low referral completion rates between 24 and 58% for infants and children to first—level hospitals (Kalter, Salgado, Moulton, Nieto, Contreras & Egas, 2003b; Darmstardt et al., 2009). Although this problem has been investigated in other regions, there have been few studies on constraints to referral and health seeking behaviour in sub-Saharan Africa (Kallander, Tomson, Nsungwa-Sabiiti, et al., 2006). Very little is known about factors associated with the uptake of referrals of infants by CHWs. Non-compliance with referral recommendations may lead to an increase in child mortality especially in a high HIV prevalence setting.

The purpose of this mini- thesis is to describe the outcome of referrals by community health workers within the Good Start Saving Newborn Lives intervention study. It seeks to describe health seeking behaviour of care-takers/mothers and to identify constraints to successful and timely referrals. The results of the study could be used to inform the current development of the PHC re engineering strategy of the SANDOH which will utilise community health workers as a critical link between communities and health care facilities.

CHAPTER 2 Literature Review

In 2007, 9.2 million children died before age five globally. Africa and Asia together accounted for 92 per cent of these deaths (UNICEF, 2009). Half of the world's under-five deaths occurred in Africa, which remains the most difficult place in the world for a child to survive until age five (Lawn et al., 2006). Globally, severe infections are estimated to account for 36 per cent of all newborn deaths (UNICEF, 2009). Sub-Saharan Africa predominantly bears the highest burden of childhood deaths. Infant mortality rates (IMR) in Africa range from 50/1000 to 191/1000 and under-five mortality rates (U5MR) range from 100/1000 to 320/1000 (UNICEF, 2001). Increasing access to and use of health services is the prime goal of many low income countries in order to attain the health Millennium Development Goals (MDGs).

2.1 Maternal, newborn and child health services in South Africa

2.1.1 Major Maternal and Child Health Problems:

According to the Saving Mothers Report (2002-2004) the top five causes of maternal mortality in the 2005-2007 triennium were non-pregnancy-related infections (43.7%), mainly due to AIDS, hypertension (15.7%), obstetric haemorrhage (12.4%), pregnancy-related sepsis (9%) and pre-existing maternal disease (6%). The mortality rate of HIV-positive women was nearly ten times the rate of HIV-negative women, but preventable direct obstetric causes made up a significant proportion of deaths in both groups. The National Committee on Confidential Enquiries into Maternal Deaths (NCCEMD) assessors attributed 23.1% of maternal deaths in the 2005-2007 report to AIDS (Blaauw and Penn-Kekana, 2010; SANDOH, 2004).

Data from the Saving Babies (2003-2005) and Saving Children (2005) Reports show that the death of a mother is associated with a four-fold increased risk of death in her young children. Across the country just over half of all childhood deaths occur outside the health system. According to McKerrow and Mulaudzi (2010) the major causes of childhood death are neonatal problems, intestinal infections or diarrhoeal disease, acute respiratory infections, unnatural deaths and TB. Malnutrition and HIV and AIDS underlie many of the deaths. According to the death notifications during 2007, deaths in the neonatal period comprised 21.9% of childhood deaths with 54% occurring between one and twelve months of age and 24.1% occurring between one and five years of age (McKerrow and Mulaudzi, 2010; Stephen and Patrick, 2006).

It is estimated that 75000 children under five years die every year in South Africa because of preventable and/or treatable causes, 22 000 of these children die during the first month of life. Socio-economic determinants of health such as poverty, illiteracy and gender inequities have played a significant role in disparities in child and maternal health outcomes. Under-five mortality has been reported to be consistently higher in rural areas than urban areas, irrespective of the population group. Similarly, rates have been found to be twice as high among mothers of grade 1-5 education level, compared to those of grade 12 and above. Infant and under five mortality rates for Africans are more than two-fold that of coloured infants and four-fold than that of white infants (SANDOH, 2010d).

Child under nutrition and HIV/AIDS are major contributors to under five mortality in South Africa According to the Saving Children Report (2005) 60% of children who die in South Africa are malnourished and 50% have clinical evidence of AIDS.

2.1.2 Service coverage:

With the advent of the first democratic Government in 1994, South Africa introduced and implemented primary health care (PHC) policies to ensure equitable, accessible and affordable health care for all, especially for the majority of populations who were marginalized during the apartheid era. The focus was laid on preventive and promotive services, at the centre of which was the provision of Maternal and Child Health services (MCH). These policies included the revitalisation and building of PHC facilities and introduction of the Free Health Care policy for pregnant women and children below the age of six to eliminate the economic barriers which prevented many from accessing basic services (Clarke, Dick and Lewin, 2009; SANDOH, 2010c).

The success of these efforts were shown by improved PHC utilization rates; for example, the number of under-5 children visiting PHC facilities increased to an average of 4,1 times a year between 1990 and 2003. As a result, there was a slight decline in under-five mortality- between 1990 and 2003 from 60 to 58 per 1000 live births (SADHS, 2003). Maternal mortality however, has remained around 140-150/100,000 live births over the last 15 years. A third of pregnant women book for their first ANC visit after the fifth month of gestation; this leads to delays in the identification and management of diseases and women cannot fully benefit from the ANC services offered along the continuum of care, including PMTCT interventions (SANDOH, 2010d).

South Africa has achieved a high coverage of most facility-based high impact maternal and child health interventions: 92% of pregnant women attend antenatal care at least once and 73% attend four times, 68% of pregnant women are tested for HIV during pregnancy,

91% of mothers received medical care by a skilled attendant at delivery, 97% and 83% of infants are immunised against DPT3 and Measles respectively. However, according to the Saving Mothers, Saving Babies and Saving Children Reports, only 52% of children are fully immunized and the quality of maternal and child health care has been reported to be inadequate (SANDOH, 2010 d).

Despite this high coverage, South Africa is currently not on track to reach MDG goals four and five. South Africa needs to reduce under-five mortality to less than 20 per 1000 live births and maternal mortality to 38 per 100 000 live births by 2015 so as to achieve the MDG targets (SANDOH, 2010d).

2.2 Community-based maternal and child health programmes.

The PHC Approach is a philosophy and a conceptual model that forms the basis of the 1978 Declaration of Alma-Ata. It promotes the delivery of essential good quality health care that is comprehensive and not fragmented, based on practical, scientifically sound and socially acceptable methods and technology, made universally accessible and equitable at a cost that is affordable, with community participation. It includes community development and promotes multi-sectoral approaches to address the social determinants of health. Community health workers are one cornerstone of the PHC approach and have been used extensively in some low income countries to provide promotive, preventive and in some cases curative services to communities (Friedman, 2005).

In South Africa, despite the amount of resources spent, the PHC approach has not been able to improve outcome indicators over the past 16 years (SANDOH, 2010d). There has been less attention given to the implementation of the PHC approach over the past 15

years. After 1994 the South African government was reluctant to support community health worker programmes, instead favouring to use nurses and doctors. The impact of HIV/AIDS and TB which contributed to poor health outcomes and the ongoing migration of health professionals which made it unlikely for SA to achieve the MDG goals for infant, under-five and maternal health by 2015, has led to recent increased support for CHW programmes (Clarke, Dick and Lewin, 2009).

There is convincing evidence that many of the health and nutrition needs of women and children in high-burden countries could be met by CHWs with minimal additional training. The World Health Organization has promoted wider use of CHWs to provide selected maternal and child health (MCH) interventions and to promote key family care practices. CHWs play a crucial role in the support and delivery of health and nutrition services in sub-Saharan Africa. They have shown to be critical in addressing the human resource crisis affecting the health sector in the developing world. In countries such as Gambia, Tanzania, Zambia, Madagascar and Ghana, the use of CHWs has proven to be not only cost-effective, but also to enhance the performance of community health programmes. Different models have been used including part-time unpaid volunteers in Kenya, Lesotho and Uganda, part-time paid workers in Kenya, South Africa and Uganda and full time paid workers in Kenya and Uganda (http://www.kyanya-aicdd.org).

There is international consensus that using CHWs to deliver integrated, proven, cost-effective interventions such as mother-baby packages delivered within households will save newborn lives (Lawn, Cousens & Zupan, 2005; Font, Quinto, Masanja et al., 2002).

A multi country evaluation of the IMCI strategy has shown that it is rare for mothers to recognize and report neonatal problems; commonly feeding problems are usually observed by community health workers (Ali, Emch, Tofail & Baqui, 2001; WHO, 2008).

A systematic review of 5 randomised- controlled trials in south Asia comparing intervention packages such as home visits during ANC and during the neonatal period found that home visits during the neonatal period are associated with reduced neonatal death and stillbirths in poorly resourced settings, especially when coupled with community mobilization activities (Gorgia & Sachdev, 2010). Studies in Bangladesh and Tanzania showed that community health workers were able to identify and classify neonates with severe illness needing referral to the next level of care with high sensitivity and specificity and refer them to the next level of care (Darmstadt, Baqui, Choi, Bari et al., 2009; Kallander, Tomson, Nsungwa-Sabiiti, et al., 2006.) With training and supportive supervision, CHWs have been able to deliver a package of less complex maternal and child health and nutrition interventions such as vitamin A supplementation, antibiotics for community-based management of pneumonia, ORT for management of diarrhoea, de-worming and insecticide treated bed nets (Winch, Bagayoko, Diawara et al, 2003; Kalter, Schillinger, Hossain et al., 2003b).

In a randomised-controlled trial in northern Pakistan, CHWs were able to visit families within a week of the birth, with 56% of families being visited within the first 48 hours. The intervention which included counselling sessions to mothers during home visits resulted in a significant reduction in the average stillbirth rate from 65.9 to 43.1 per 1000 births (p 0.001), while the neonatal mortality rate decreased from 57.3 to 41.3 per 1000 live births. Sixty-two percent of episodes of newborn illness that were recognized and

treated by CHWs were managed successfully at home, while 72% of sick newborns who were referred for treatment sought care in public sector facilities (Bhutta, Memon, Soofi, Salat, Cousens & Martines, 2008).

A systematic review conducted by Lewin, Munabi-Babigumira, Glenton et.al. (2010), on lay health workers for maternal and child health and infectious diseases, showed that the use of lay health workers, compared to usual healthcare services, may lead to an increase in the number of women who breastfeed their children and whose children have their immunization schedule up-to-date. The review further found that lay health worker programmes may increase the number of parents who seek help for their sick children and decrease the number of children under five years of age who suffer from fever, diarrhoea and pneumonia as well as infant deaths. The review suggests that through task shifting, lay health workers could be used to deliver a range of maternal and child health services usually delivered by professionals (Lewin, Munabi-Babigumira, Glenton, et.al, 2010).

A non-randomized intervention study in rural KZN, utilising lay breastfeeding counsellors with no tertiary education who were trained on breast feeding and received mentoring and supervision, achieved reduced rates of serious breast health problems and higher rates of exclusive breastfeeding following intensive counselling during home visits (Bland, Becquet, Rollins, Coutsoudis, Coovadia and Newell, 2009).

Clark, Dick & Lewin (2009) warn that although CHWs have an important role to play in meeting the health and social needs, health policy makers need to conduct research before implementing a standardised national generalist CHW programme. Broader priority issues such as the cost- effectiveness, training, political expectations and funding models of these programmes need to be evaluated and debated.

2.1.3 CHW Policy in South Africa

The Government of South Africa introduced the national community health worker policy within the PHC system in 2004 to decentralise PHC services. Other initiatives which employ CHWs and provide stipends to improve household income were established in the same year, namely:

- i) the Accelerated and Shared Growth Initiative of South Africa (ASGI-SA) a poverty reduction strategy aimed at addressing the socioeconomic determinants and the root causes of poverty and
- ii) the Expanded Public Works programs (EPWP), under the Department of Public Works –aimed at providing job opportunities for the poor while fostering community development by communities themselves.

Although CHWs have been a feature of PHC in South Africa, they have largely been employed through NGOs and have not been incorporated within the formal health system (Friedman, 2005). This however is due to change with several policy shifts relating to the use of CHWs in the PHC system. In 2010 the SANDOH developed the Framework for Accelerating Community-based Maternal, Neonatal, Child and Women's Health and Nutrition (MNCWH&N) Interventions which sets out the roles and functions of community based MNCH workers (SANDOH, 2010d).

It is envisaged that CHWs will be central to the proposed new PHC package forming part of PHC Outreach teams. They will spending at least 80-90% of their time in the community and develop maps and health profiles for their catchment areas. A regulatory framework for CHWs will be developed and clear career-paths. CHW roles will be comprehensive and they will be integrated within health facility teams so that they do not

operate as a parallel system (Appendix 4 – Diagram of the proposed PHC outreach teams) (SANDOH, 2010c; SANDOH, 2010d).

The Community MNCWH&N framework builds on the existing community Integrated Management of Childhood Illness (C-IMCI) to maximise service coverage, and quality and it uses a life cycle approach from pregnancy, through delivery to early childhood and within the health system continuum from communities and households. The framework has six main service delivery modes, namely;

- i) regular home visits,
- ii) establishment of community-based support groups,
- joint outreach preventive and curative services by professional nurses andCHWs
- iv) twice-yearly child health days and
- v) monthly visits to Early childhood and Development centres;
- vi) an effective community mobilisation strategy is required to support all these service delivery modes (SANDOH, 2010d).

2.3 Referral systems

Health care workers at all levels of health care delivery are often faced with practical constraints when dealing with clients that require referral to higher levels of care. There may be lack of clarity about health worker roles and responsibilities, poorly defined protocols, transport problems and poor communication between the initiating and the receiving facilities. Ideally, referrals should be facilitated in situations where referral is difficult and written feedback on the findings and treatment given to the initiating facility (Siddiqi, Kielmann, Khan et al., 2001).

The implementation of a functional and well-managed referral system is necessary in changing the disease patterns presenting at hospitals and primary health care facilities. A good referral system is a support system that makes health services more effective, efficient and equitable to its users. Siddiqi, Kielmann, Khan et al., (2001) conducted a household survey in Pakistan on the effectiveness of referral. They found that more than half of patients did not consult local health facilities and expressed dissatisfaction with the quality of service offered at local PHC centres as the reason. They found major deficiencies in the referral system of the public sector. These included lack of managerial competence and non-availability of emergency obstetric services, intentional by-passing of local PHC by consumers leading to under-utilization of PHC centres.

Criteria have been developed by USAID for an effective referral system which includes:

- a) an adequately resourced referral centre;
- b) communication and feedback systems;
- c) designated transport;
- d) specific protocols for identification of complications;
- e) personnel trained in their use,
- f) teamwork between referral levels;
- g) a unified records system and
- h) mechanisms to ensure that patients do not bypass a level of the referral system (Cervantes, Salgado, Choi & Kalter, 2003; Siddiqi, Kielmann, Khan et al., 2001).

The key to reducing infant mortality lies in improving linkages between communities and the health care system. Referral difficulties may occur with any components of a referral system and usually influence the success of referral (Murray, Davies, Phiri & Ahmed, 2001). Literature suggests that referral systems are usually dysfunctional and weak in many district health systems in rural Africa, yet substantial improvements in maternal and child morbidity and mortality are impossible to achieve without an effective referral system. Early identification of illness and referral to the next level of care might substantially reduce complications of childbirth as well as neonatal deaths (WHO, 2005; Pokhrel & Sauerborn, 2004). Monitoring and evaluation of referrals is possible through accurate documentation of all referrals ('in' and 'out') in registers at all levels (Cervantes, Salgado, Choi & Kalter, 2003; SANDOH, 2003).

2.4 Coverage and compliance with referral

A number of studies in low income countries have utilised community health workers to implement key maternal and child health interventions. Where referral is difficult, community health workers have been used to facilitate referral to health care facilities through assisting with transport, cost and accompaniment. Winch, Leban, Casazza, Walker & Pearcy (2002) reviewed experiences of NGOs working in community –based child programmes and drafted the implementation framework for household and community IMCI. They emphasize the role that facilitated referral can play in reducing neonatal deaths. This can be done through promoting the benefits of referral compliance, monitoring referral and compliance and addressing barriers to compliance. CHWs and health care workers often fear criticism if they misclassify and unnecessarily refer a client to a health facility. As a result, when in doubt, they may decide not to recommend referral (Kelly, Osamba, Garg, Hamel et al., 2001).

Experience from IMCI programs in some African countries suggests that a referral rate of less than 20% indicates a well functioning health system that is able to resolve problems at different levels (Cervantes, Salgado, Choi & Kalter,2003; WHO, 2005). Higher referral rates, up to 27% have been reported in areas with a better economy; while in sub-Saharan Africa lower referral rates, between 5 and 8% have been reported (WHO, 2008). The latter could either imply that very severe cases are not identified either because health workers lack the skill to identify severely ill cases or infants are not brought to health facilities when referred (Font, Quinto, Masanja et al., 2002).

Darmstadt, El Arifeen, Choi, et al., (2010) conducted a cluster- randomised controlled trial of a community - based maternal and newborn intervention in Bangladesh. Although there were critical challenges in reaching newborns during household surveillance, they managed to achieve 70% coverage for post-natal home visits. However, referral compliance was 54% for those who had received a referral recommendation. This study found that families with neonates less than 7days old were 30% less likely to comply with referral. This was despite assistance given by project staff to eliminate barriers to referral completion (transportation to hospital, cost and information on danger signs). Family perception of the seriousness of the illness and male gender were associated with higher referral completion rates. Another survey in Pakistan found that less than 50% of seriously ill clients consulted the nearest public health facility; the rest either by-passed the clinic and consulted the tertiary hospital and others consulted private clinics. The latter finding may not be generalised to other countries because in Pakistan, private medical care is omnipresent in urban and rural areas and enjoys a significantly higher reputation and utilization than public hospitals (Darmstadt, El Arifeen, Choi et al., 2010; Siddiqi, Kielmann, Khan et al., 2001).

Referral completion rates can also vary depending on the source of referral. Data from two studies conducted in Uganda (home-management of malaria and IMCI paediatric referral to hospital) showed community-based referral having a higher completion rate (87%) compared to primary health care facilities to hospital referral (28%) (Kallander, Tomson, Nsungwa-Sabiiti, 2006; Peterson, Nswanga-Sabiiti, Were, 2004). Similarly, high referral completion rates from community based referral were found in Mali. Giving home treatment before a referral was found to have a negative effect on timely referral completion both in community based and facility based referral (Winch, Bagayoko, Diawara et al., 2003).

Although referral completion rates have generally been found to be low, most studies were small pilot studies conducted in districts and most represent a cross–sectional picture and did not adequately capture many changes taking place in the transitional society. Most of the studies on this topic were conducted among mothers and are based on individual recall, thus prone to subjectivity and recall- bias (Ali et al., 2001; Winch, Bagayoko, Diawara et al., 2003).

2.5 Factors that influence referral completion/compliance

Families often share beliefs and behaviours related to illness and health and therefore become important in shaping each other's decisions on health seeking (Sepehri, Moshiri, Simpson & Sarma, 2008). Caretakers move from no action, home treatment, over the counter medicine, traditional care, public health and prayer. Therefore policy makers need to understand the drivers of health-seeking behaviour in a population so as to develop rational policies that provide efficient, effective, accessible, acceptable, cost-effective and

affordable services (Shaik & Hatcher, 2004; Winch, Bagayoko, Diawara et al., 2003). The decision to utilize a health care system, public or private, formal or informal, may depend on a number of factors. These include socio-demographic, cultural, economic and political systems, the status of women, disease patterns, gender, environmental conditions and the health care system itself (Sepehri, Moshiri, Simpson & Sarma, 2008; Shaik & Hatcher, 2004).

2.5.1 Cultural and socio-demographic factors

Women's autonomy- Gender inequalities prevail in most families and have dramatically affected the health status of women and children in Africa. In some studies in Africa, such as Uganda and Tanzania, it has been documented that some mothers relied on decisions from their husbands or parents before consulting maternal and child health services. The family figures may decide that mothers consult traditional healers, homeopaths and use home treatments instead of local health care services. Women are often expected to comply with men's decisions about consulting health practitioners since they rely on men for providing for the cost of consultations even during emergencies (Shaik and Hatcher, 2004; Urassa, Massawe, Lindmark & Nystrom, 1997).

Cultural practices – Certain cultural practices in African communities such as confinement during the post-partum period, though meant to be beneficial to the mother-baby pair may negatively undermine the health of women and children when they need to seek medical care. It is acceptable in most African families to first consult traditional healers before consulting western practitioners. In an ethnographic study on health seeking practices for children with dengue fever, Cambodia, Khun and Manderson (2007) found that villagers routinely used home remedies including herbs, 'cupping and coining

(scratching and bleeding and rubbing) parts of the body, use of diviners and traditional healers to alleviate symptoms. Unavailability of health care staff at night or in emergencies was reported, as well as inconvenient waiting times. It is also common practice in African culture to first consult traditional healers and diviners before consulting western medicine.

Demographic factors- According to the Saving Children Report (2006:48), there are three "deadly" delays that threaten the lives of children in South Africa. These are; delays in recognizing problems and deciding to seek care, delays in transportation to facility and delays in receiving appropriate care." Rural populations face higher than average costs to reach services. In Mexico and Ecuador, delays in consulting health care facilities have been reported among infants classified as urgent referrals. Delays of more than 24 hours are mostly influenced by the severity of illness as perceived by caretakers (Kalter, Salgado, Moulton et al., 2003b). Home remedies and self care and consulting traditional healers are commonly used in rural South African communities. Advice of the elders especially women has been reported to affect health seeking and feeding practices among infants.

Institutional factors such as local knowledge systems affect decision making and the understanding of symptoms of illness. Mothers' assessment of severity of illness coupled with an assumption that fever is normal, that the disease may be self limiting and use of home remedies contribute to low referral completion. There is also a belief that local health workers can only treat mild cases and that only medical doctors can treat severe childhood illnesses (Peterson, Nswanga-Sabiiti, Were, 2004).

Individual factors such as age, marital status and education have a significant influence on health seeking behaviour. In Vietnam, married individuals were more likely to seek care than unmarried and education was found to increase the likelihood of using health services as much as 72% and 50% for those with post-secondary and secondary education respectively, compared to those with no education. Mothers with schooling had a better socio-economic standing and therefore were more likely to perceive illness and seek care (Sepehri, Moshiri, Simpson & Sarma, 2008; Cervantes, Salgado, Choi & Kallander, 2003).

Gender and age – Gender of the household head plays a significant role in the health care decision- making process. There may be conceptually different household dynamics underlying girls' and boys' illness perception which ultimately determines health seeking behaviour. Literature from a household survey using the Nepal Living Standards Survey, clearly shows that child gender bias exists in allocation of health care and food between infant boys and girls. Pokhrel & Sauerborn (2004) found that although gender counts in illness perception, this was not necessarily the case in subsequent decision making related to health seeking. A community randomised controlled trial among neonates in rural Bangladesh found that referral of neonates 0-6days old were 30% less likely to be completed compared to older children and male sex was also positively associated with referral compliance (Kallander, Tomson, Nsungwa-Sabiiti, et al., 2006). Further studies are required to explore if this gender bias exists in health seeking especially in some cultures within the South African context, where strong son–preferences exist. There is evidence that mortality rates decrease when programmes are "grafted on the social environment in which mothers are literate and trained to observe their children's health"

(Darmstadt, El Arifeen, Choi et al., 2010; Mrisho, Obrist, Schellenberg et al., 2009:1479).

2.5.2 Socio-economic factors:

"Accessibility and affordability to a health care facility is considered a fundamental societal right, particularly for children" (Noorali, Luby & Rahbar, 1999: 194). Transport and money are important predictors of referral completion. Distance and cost have been identified as the main reasons cited for delay in referral in a study of parents' experiences on paediatric referral in Uganda. Parents reported that poverty hindered referral completion more than transport problems. Lack of money was the main reason for non completion of referral- the median cost of completing referral was about nine US dollars, the cost of treatment and consultation being the main cost. A survey conducted in Nepal on care-seeking behaviour for childhood illnesses found that family income, the number of symptoms and perceived severity are major deterrents to seek prompt care (Peterson, Nswanga-Sabiiti, Were, 2004; Sreeramareddy, Shankar, Sreekumaran, Subba, Joshi & Ramachandram, 2006).

Individuals' likelihood of seeking treatment varies and is greatly influenced by the income across quintiles and the availability of health insurance. According to Khun & Manderson (2007: 9) "women consider health care as a commodity, with a price attached to the service". Khun & Manderson (2007) further illustrate how household poverty and other contextual factors shape the care seeking pathway. Wealthier households use facilities more frequently than poor households and the introduction of user fees influences health seeking behaviour (Khun & Manderson, 2007; Lomoro, Ehiri, Qian & Tang, 2002). A study on decisions to use government facilities in a rural district of

Pakistan revealed that the treatment cost had a significant effect on the use of government facilities; the less the cost, the greater the use of government facilities (Noorali, Luby & Rahbar, 1999). A longitudinal community based study of mothers' care seeking behaviour during infant rearing that was conducted in South Western Ethiopia found that improved socio-economic status of families and at least elementary schooling of mothers would change mothers' behaviour in seeking treatment for infants. A lower utilization rate was also found to be influenced by accessibility of health care facilities (Tessema, Asefa and Ayele, 2002).

In developing countries, the cost of consultation has been a major barrier in health seeking. Although South Africa offers free PHC services, the expenditure relating to the cost of transport especially during the night can be cumbersome thus limiting the choice of health provider and may influence decisions on health seeking- behaviour (Tlebere, Jackson, Loveday et al., 2007).

2.5.3 Perceived quality of care within facilities

Health workers' negative attitudes have frequently been a reason cited for lower utilization of health services. This erodes the level of trust and confidence the community have in health service providers (Mrisho, Obrist, Schellenberg et al., 2009). Perceptions of the quality of care, perceptions about services, and of the capacity of staff to handle illnesses influence health seeking behaviour. A common reason for not seeking care for fatally ill neonates is the perception by parents that health staff would respond negatively to their social circumstances (Khun & Manderson, 2007). Long waiting times, flexible hours of operating and drug availability are major determinants of health seeking behaviour.

"Long waiting times remain a source of much anger and bitterness among users of the public health care sector, as well as among health care providers working in the public health care sector. It generates so much anger and bitterness that it is the commonest and most persistent complaint of patients using the public health sector. The quest for reducing waiting times therefore cannot be ignored" (SOPH, 2010: 2). Health worker attitudes and patient satisfaction with care play a major role. Peterson, Nswanga-Sabiiti, Were (2004) found that care-takers associated referral centres with long waiting times (even for referred children), harsh health workers, inadequate drugs and language problems.

Anecdotal evidence from South Africa suggests that some clinics may limit the number of clients they attend to per day by issuing numbers at the security gate. This practice results in clients with severe illness being turned away by security personnel without being assessed by health care personnel.

Reyers, Perez-Cuevas, Salmoron, Tome, Guiscafre & Guiteiere (1997) assert that environmental variables such as mothers receiving differing, confusing and contradictory advice on how to manage the illness all have a considerable influence on the course of sickness episodes and on care seeking behaviour.

Studies conducted in developing countries suggest that although community education on maternal and neonatal danger signs is important, provision of core resources and supplies for emergency obstetric interventions, as well as protocols for management and referral are necessary in improving maternal and child survival (Urassa, Massawe, Lindmark & Nystrom, 1997; Murray, Davies, Phiri & Ahmed, 2001).

Physical accessibility-Accessibility to health care is one of the deterrents to effective utilization of primary health care services. An effective referral system ensures a close relationship between all levels of the health system and helps to ensure people receive the best possible care closest to home. There is a tendency to shop around for the health care service that is perceived to offer the best quality of care. Because medical doctors are not always available everyday in PHC facilities, patients often by-pass the immediate level of care in an attempt to be seen by a medical practitioner and this leads to overcrowding (Shaik & Hatcher, 2004).

Physical access to health care, including distance, transport costs and the conditions of the roads are important predictors of health seeking behaviour (Noorali, Luby & Rahbar, 1999). In Tanzania 75% of mothers, who completed hospital referral in the rural Kilombero District, came from within a 10 km distance. Other larger studies conducted in Lusaka, Zambia on referral practices found similarly that cost and transport to facilities were the main barriers to successful referral. The distance, road network and water route between referral and receiving structures has also been shown to influence compliance to referral (Atkinson et al., 1999; Källander et al., 2006).

In conclusion, community health workers are a vital link between communities and the formal health care system. Effective referral is a key factor in the success of community based health programmes yet little is known about how effective community referrals are in South Africa. This study seeks to describe the outcomes of referrals by community health workers within a child health intervention study in a peri- urban setting in South Africa.

2.6 Aim

To quantify referral completion rates of infants referred by community health workers to public health facilities in Umlazi, KwaZulu-Natal.

2.7 The specific objectives were:-

- To describe health-care seeking practices and perceptions of mothers whose infants were referred to health care facilities by CHWs.
- 2. To describe referral processes, reasons for referral and outcomes of referrals.
- To describe mothers' perceptions of the quality of care received at health facilities and by CHWs.
- 4. To describe factors influencing non completion of referral and delayed referral completion within a peri-urban township.

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CHAPTER 3 METHODOLOGY

3.1 Introduction

This chapter describes the methodology of the study. It sets out the purpose, objectives, definition of terms, study design, study population, sampling procedures and data collection tools. Data processing and analysis, issues of validity and reliability, ethical considerations and limitations of the study are also addressed.

3.2 Study design – Good Start Saving Newborn Lives

The Good Start Saving Newborn Lives study (SNL) is a cluster- randomised intervention trial that was implemented between 2008 and 2011. It consists of 30 randomized clusters (15 in each arm) within Umlazi township, a peri-urban sub-district of Ethekwini district, located about 30 minutes from Durban city. The study area was divided into clusters based on information from the 2001 census and a baseline survey was undertaken in all clusters to determine baseline rates of key newborn caring practices and mortality. Based on this information it was determined that no stratification or matching of clusters would be necessary.

In the intervention clusters trained CHWs identified and recruited pregnant women.

CHWs were employed by the Medical Research Council, the lead institution carrying out the research. All aspects of the training, implementation and supervision of the community workers had been planned to approximate the community MNCWH worker framework recently developed by the South African government. The main purpose of the Good Start Saving Newborn Lives study was to evaluate the effectiveness and cost of an

integrated home visit package in increasing uptake of PMTCT interventions and appropriate newborn care practices.

CHWs visited mother- baby pairs twice during pregnancy and 6 times during the early postnatal period to deliver a package of interventions relating to maternal and child health. Women were assisted with birth preparedness and early newborn caring practices. Post-natal home visits by CHWs took about 45 minutes each and were conducted at the following intervals:

- a) within the first 24-48 hours,
- b) within day 3 or 4,
- c) within day 10-14,
- d) between week 7 and 8 and
- e) two extra visits were done for low birth weight infants.

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They addressed the following during post natal visits: Assessment of the newborn (feeding, breathing, colour, thermal care, bleeding, neonatal eye-care, and completed a checklist of danger signs); assessment of the mother (bleeding, signs of infection, breast condition e.g. mastitis; early recognition of illness); assessment and support for appropriate feeding (exclusive breastfeeding); hygienic cord care; thermal care including Kangaroo care for pre-term babies, ARV prophylaxis for infants of HIV positive women; information and support for women with post-partum "blues".

The role of the CHWs with regard to referral was to have the skills to identify danger signs in newborns during home visits. CHWs would facilitate a referral where necessary by completing a referral form which could be taken to the facility (Appendix 3). They

also encouraged women to consult health care facilities for routine postnatal care (Good Start SNL Protocol, 2007).

CHWs were recruited within their clusters and trained initially for 4 weeks and received refresher courses quarterly. The main study outcome is collected during a structured interview with mothers at 12 weeks postpartum in the PMMH study office. Some data such as basic demographics was captured from this main study interview and not asked again during the interview for the referral sub study.

3.3 Study design – referral sub study

This sub-study was a descriptive cross-sectional study that used quantitative methods. Cross-sectional studies measure the prevalence, exposure and effect at the same time and it is possible to quantify associations between certain variables although causality cannot be determined. Cross sectional surveys are less costly than cohorts since data collection occurs at one time period (Stone & Campbell, 1984). Quantitative research was considered appropriate for this study because it is an objective process which relies upon measurement to analyse different variables relating to practices, perceptions and knowledge of mothers.

3.4 Study site

Umlazi township, the area where this study was conducted, has a population of approximately one million which is served by a district hospital and 10 primary health care facilities. The housing settlements consist of a mixture of formal and informal housing. The infant mortality rate is around 60/1000 live births, and the neonatal mortality rate around 25/1000 live births (Ijumba & Barron, 2005). The antenatal HIV

prevalence for Ethekwini district was 41.4% in 2009 (SANDOH, 2009). All primary health facilities offer a comprehensive primary health service and over 98% of all births in Umlazi occur in one major hospital, Prince Mshiyeni Memorial Hospital. PMTCT was introduced in all primary health facilities in 2003. In July 2009, all KwaZulu-Natal provincial clinics started to give dual therapy (AZT and NVP) to all HIV positive pregnant women and their infants. By June 2010 all Umlazi clinics started to implement the New Clinical Guidelines for PMTCT which recommended that all pregnant women with a CD4 count of 350/mm and below be started on ARTs early and that HIV positive women can safely breastfeed provided their children or themselves are taking ARV's during the breastfeeding period (SANDOH, 2010b).

3.4 Study Population and sample

The study population was all mothers residing in any of the fifteen intervention clusters of the Saving Newborn Lives study whose sick infants had been referred by community health workers to health care facilities. The student and a research assistant used CHW referral books to identify all women who had received infant referrals from community health workers between July 2008 and 10 June 2010.

The inclusion criteria were all mothers or caregivers:

- who were enrolled in the Saving Newborn Lives study
- who resided in one of 15 intervention clusters during study enrolment
- —whose sick infants were referred by CHWs to health care facilities

The exclusion criteria were:

 All mothers who no longer resided in Umlazi during the time of the sub study. All mothers who denied receiving infant referrals despite being listed in CHW referral books.

A total of 2423 women had been enrolled in the Good Start Saving Newborn Lives study by June 2010 and it was estimated that approximately 400 had received referrals by CHWs. This study planned to approach all mothers who's infants had been referred for several reasons: Firstly, this study formed part of the ongoing process evaluation of the CHW intervention and the study team needed accurate data on the outcome of all referrals made by CHWs; secondly, sampling a subset of referrals would have led to bias due to seasonal variations; thus including all mothers would ensure that mothers referred at different time periods are included; thirdly, referral rates from CHWs have not been well researched in South Africa therefore estimates for the sample size calculation would be based on data from other countries which could have very different rates compared to South Africa. It was feared that using a sub sample of referrals might have resulted in inadequate power to detect significant associations given that the total number of referrals was expected to be small. The list of referrals compiled from CHW records was used as the basis for sampling all mothers who were referred.

3.5 Data collection method

A pre-coded structured questionnaire was developed with the assistance of the supervisor (Appendix 1). Some of the questions were adapted from an Infant Verbal Autopsy Tool used in a previous study in this area (Tlebere, Jackson, Loveday et al., 2007). It consisted mainly of closed-ended questions and multiple-response questions with a few open ended questions. Major sections contained demographic information, health-seeking

behaviour, review of infant referrals, perceptions of quality of care and a review of the infant Road to health Chart.

The questionnaire was translated into Zulu and loaded onto a cell phone using the mobile researcher software. This cell phone data collection system is a well established electronic data collection method in South Africa which has been used for several large surveys. It is a web-based system that allows electronic surveys or questionnaires to be designed in a word processing programme and then sent via GPRS to standard entry level mobile phones for use in interviews. The system was developed by a private digital solutions company, Clyral. No network coverage is required during survey completion. Completed surveys are then automatically uploaded to the host computer; this requires network coverage, if there is no signal, surveys are securely stored until a signal is found and then automatically transmitted (Tomlinson, Solomon, Singh et al., 2009). Pre-testing of the instrument was done on mothers in the control arm of the study as they were not part of the target population for this study. Road-to-Health cards were also reviewed to validate referral completion and to collect other variables of importance. Some data was not collected during this additional data collection visit since it had already have been collected from mothers at the 12 week study endpoint interview (such as mothers' demographic characteristics). This data was retrieved from the main study database and merged with the sub study data.

Data collection for the sub-study was conducted between 13 Jan and 25 June 2010. There was no sampling since all referrals on the list were contacted sequentially starting with the first referral that took place. Mothers were contacted either telephonically or by a home visit and were requested consent to participate. The data collector had to first confirm that

the mother had received a referral for her child by a CHW before continuing with the interview. Following an explanation about the study, willing participants chose to be interviewed either at home or at the PMMH study clinic. The later aimed at minimizing contextual bias as some clients may respond differently when they feel privacy is compromised. Mothers who denied receiving a CHW referral, despite appearing on the CHW referral list, were not interviewed. Interviews were also not conducted where infants' mothers had died or with mothers who had relocated from Umlazi. Mothers who could not be contacted after 4 telephonic attempts and/or two home visits were classified as lost to follow-up. To increase the sample size, all mothers who had reported visiting health facilities for child consultations during the 12 week main study interview were contacted to check if these were referrals by CHWs.

3.6 Data management and analysis

Open – ended questions were coded and then entered into excel. Prior to analysis the sub study dataset was merged with the main study 12 week dataset in order to obtain basic demographic information on the sub study sample. Since data was entered onto a cell phone existing logic, range and consistency checks were built-in, which minimised post-data collection quality control. Data was available on a daily basis in an excel spreadsheet and ongoing quality control was undertaken as the data was received to check for completeness and inconsistencies (Bowling. 1997).

Data was converted from the mobile researcher database to excel and imported to STATA version 11 and epi info for analysis. Data were explored initially using basic frequencies for categorical data and means for continuous data. Univariate analysis was undertaken using chi square tests for categorical data and one way analysis of variance for continuous

data. A significant level of 0.05 was used. Important findings are reported even if not statistically significant but if they are of public health importance (Gehlbach, 1993).

3.7 Validity and reliability

Validity is an indication of the extent to which an instrument measures what we think it is supposed to be measuring (Sarantakos, 1998). In this regard, study instruments for respondents were developed in English and were then translated into Zulu which is the local language spoken. The instruments were translated back to English in order to ensure the validity and accurateness of meaning. Key terms used in the questionnaire were well defined. The data collector who conducted the face-to face interviews was experienced and well trained in data collection and interviewing skills. Using the mobile researcher cell phone system with its built in branching and skip logic as well as enforced validation provided comprehensive validity and reliability checks. Automated upload of completed surveys from the cell phone to the server significantly reduced the potential loss of data and immediate real-time access to data improved data quality (Tomlinson, Solomon, Singh et al., 2009). Following pre-testing of the tool, some changes were done to improve content validity and reliability. No one working in the Good Start Saving Newborn Lives study was involved in data collection to minimize social acceptability bias.

Reliability refers to dependability or a way a tool such as questionnaire will produce similar results in different circumstances if nothing changes (Sarantakos, 1998). The same questionnaire was used for all participants and the same data collector conducted all of the interviews.

3.8 Limitations

There were several limitations due to the nature of the cross-sectional research design.

Firstly one cannot determine causal associations or the temporal sequence of events.

Secondly selection bias might have been introduced due to the numbers of clients who were lost to follow up due to relocation or denying receiving referrals despite being on the lists. Recall bias might have occurred as events under study occurred between 2 weeks and 18 months prior to the interview. To address this, data from participants interviewed more than six months following referral was analysed separately to assess the potential for recall bias before pooling all data. Since severe illness or hospitalisation of an infant is a fairly major family event we did not anticipate that recall bias will pose a meaningful problem.

There was a possibility of social acceptability bias being introduced on responses relating to the quality of care by CHWs due to the fact that the researcher and data collector were known to the CHWs by being employees of the Medical Research Council although neither worked on the SNL study. The CHWs did not use algorithms to classify infant illness and the study did not analyse the severity of disease therefore some referrals might have been for mild illnesses and this may have resulted in non- compliance. Clinic registers were not checked to validate CHW assessments or to determine the accurateness of CHW assessments. Mothers that denied receiving a referral were excluded; however their denial could have been due to the fact that they did not comply with referral recommendations.

A weakness of this study is that besides the mother's 12 week demographic data, no data was collected from mothers that did not complete referral regarding their experiences

following not going to health facilities as advised, such as the outcome of alternative health seeking actions like use of traditional healers, faith healers as well as the health outcome for infants.

3. 9 Ethical considerations

Ethical approval of the protocol was obtained from the University of the Western Cape

Ethics Committee. Written permission was also obtained from the KZN Provincial

Department of Health. Participation was voluntary for all mothers who were referred to
health facilities by CHWs. Participant information sheets explaining details about the
study, benefits and risks, the voluntary nature of the study and assuring them of
confidentiality were provided in Zulu and read to all participants (Appendix 2).

Participants were assured of anonymity and confidentiality; a unique participant number
was used instead of names and all survey data were encrypted, thus maintaining the
confidentiality of responses. Written informed consent was administered before the
interviews started. Mothers interviewed at the PMMH study clinic were reimbursed for
travelling costs. Although there was no anticipated harm from this study; there was
provision that participants found to be requiring emotional support arising as a result of
study processes would be referred to the Department of Health counsellors in health
facilities.

3.10 Contribution of the student

The student did not work in the Good Start-Saving Newborn Lives study but periodically assisted during training of CHWs on IYCF. For the mini-thesis, the student was involved in all aspects of the research i.e. the development of the research proposal, questionnaire

development, field worker training, data collection supervision, data cleaning and creation of variables, data analysis and write up with the guidance and support of the supervisor.

3.11 Generalizability

This refers to whether findings from the sample can be inferred to the population, depending on the inclusion and exclusion criteria, response rate and representativeness of the sample (SOPH, 2008). The study included all women who had received a CHW referral for their infants therefore no selective sampling was undertaken, the study also had a high response rate with 73% of the total referrals on record interviewed and 78% of the reported referrals interviewed. The study setting is a high HIV prevalence peri-urban township which is typical of many peri-urban informal areas in South Africa. Results need to be generalised with caution to settings with similar HIV prevalence, peri-urban location and infant mortality.

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CHAPTER 4 RESULTS

4.1 Study profile

The study was conducted between 13 January and 25 June 2010. According to study referral records, 148 infants were referred by CHWs between January 2008 and 10 June 2010. This represents a referral rate of 6%. Infants were referred by CHWs from all 15 clusters. The median number of referrals per cluster was 7 (Range 2-16). Of these 148, 10 mothers could not be contacted. Interviews were conducted with 110 mothers who consented to participate; either in their homes or at the PMMH project office. 10 mothers who denied having ever received infant referrals despite appearing in the referral records were not interviewed, 16 mothers had relocated, 1 refused participation and 1 had died. For the purpose of the study, we decided to exclude the 10 mothers who denied having been referred despite appearing in the CHW referral books. If they were included, the number of non-completed referrals would have increased from 6 (5%) to 16 (13%). Data collected at 12 weeks was missing on 7 mothers for the basic demographic variables.

4.1.1 Characteristics of mothers

Mothers who completed referrals and those who did not complete referrals were similar for all demographic characteristics except for child support grant receipt and parity (Table 1a). The mean age of mothers was 24 and 23 years for completed and non-completed referrals respectively. The mean educational level was Grade 10 for both mothers. The majority of mothers interviewed were single (80% amongst completed referrals and 83% amongst non complete referrals). There was a higher percentage of mothers with at least one other child among mothers that did not complete referral (67%) compared to those that completed referral (53%).

More than 80% of mothers interviewed had electricity and all mothers received water from a piped source. There was a higher receipt of the child support grant amongst mothers who completed referral (36%) compared to those who did not (17%) and this reached borderline significance (p =0.07). However the number of women in the non referral completion group is very small and there is substantial missing data for this question. Over 80% of mothers were unemployed, most of whom received a state grant and had a mean monthly income of around R2000.

From the hospital records of all referred mothers, 63% were HIV positive, 25% negative and 12% had missing status. The majority of mothers who did not complete referral were HIV positive (67%). Seventy-seven percent of mothers delivered at Prince Mshiyeni Memorial Hospital. Among non-completed referrals, all, except one mother delivered at Prince Mshiyeni Memorial Hospital.

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Referral completed n=104		Referral not completed n=6	
24.7	(5.9)	23.5	(3.6)
Grade 10.5	(1.7)	Grade 10.6	(2.5)
83	(79.8)	5	(83.3)
3		1	(16.7)
10		0	, ,
	, ,		
· ·			(100)
101	(100)		(100)
55	(52.8)	4	(66.7)
			(33.3)
	, ,		(====)
	, ,		(100)
101	(100)		(100)
8	(7.6)	0	
	, ,	1	(16.7)
			(23.7)
			(83.3)
			(03.3)
			(100)
101	(100)	0	(100)
37	(35.5)	1	(16.7)
			(33.3)
			(50)
			(100)
104	(100)	0	(100)
80	(78.2)	5	(83.3)
			(65.5)
DIVI V EIND			(16.7)
	(0.0)		(10.7)
			(100)
104	(100)	0	(100)
93	(89.4)	6	(100)
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	(/	-	()
1	(0.9)	0	
8	(7.6)	0	
88	(84.6)	6	(100)
7	, ,		` /
104	(100)	6	(100)
			` /
52	(50)	3	(50)
			(50)
			(50)
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	(62.5)	4	(66.6)
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65 27	(62.5) (25.9)		, ,
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* p=0.07
Table 1a. Characteristics of mothers

Most households were headed by females (59%), of which the infant's mothers constituted 14% (Figure 1).

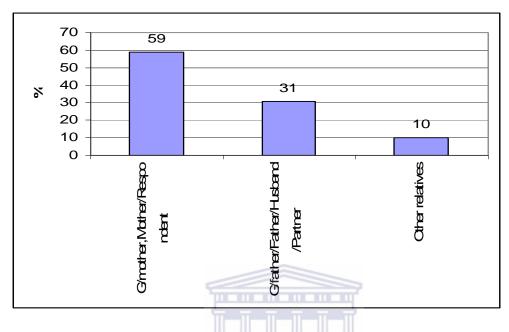


Fig1: Head of household

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4.1.2 Characteristics of infants CAPE

All interviews were conducted with the infant's mothers, except one. The majority of infants were older than 16 weeks (71%) at the time of the interview. The mean age of children at the time of the first referral was 2 weeks (range 1-4 weeks). Less than half were still being breastfed with the lowest proportion amongst infants older than 16 weeks (37%) (Table1b).

More than half of mothers (56%) stated that their infants had been ill once or twice since birth. The 3 most common causes of illness were difficulty in breathing (24%), diarrhoea (17%) and fever (8%). Six respondents reported that their infants had died. The major cause of death was difficulty in breathing (83%) and the mean age of the infants at the time of death was 4.2 months (range 2.1 - 7.3). All of these infants had completed

referrals; 5 of these died in hospital and one died at home. The deaths occurred within one day of visiting the health facility for 5 respondents (83%) and within 4 weeks for the remaining death. Two infants were referred on to a public hospital within hours of arriving at the first facility and one was admitted. All of the deaths occurred after the last CHW visit at 8 weeks. It is not known whether the death was related to the initial referral by the CHWs.

Characteristics of the infants	Referral completed n=104		Referral not completed n=6	
Gender n (%)		_		
Male	52	(50)	2	(33.3)
Female	52	(50)	4	(66.7)
Total	104	(100)	6	(100)
Age at interview n (%)				
Below 6weeks	8	(7.7)	1	(16.7)
6weeks- 9weeks	9	(8.9)	1	(16.7)
10weeks-13weeks	6	(5.8)	1	(16.7)
14weeks-16weeks	5	(4.8)	1	(16.7)
Above 16weeks	76	(73)	2	(33.3)
Total	104	(100)	6	(100)
Age at first referral n (%)				
Birth - 2weeks	22	(21,2)	2	(33.3)
3 -4 weeks	41	(39.4)	3	(50)
5- 8weeks	32	(30.8)	0	
9-12weeks	7	ESTERN (6.7)	1	(16.7)
Do not know	2	(1.9)	0	
Total	104	(100)	6	(100)
Alive at time of interview n (%)				
Alive	98	(94.2)	6	(100)
Died	6	(5.8)	0	
Total	104	(100)	6	(100)
Breastfed in the 24 hours before				
the interview n (%)				
Yes	38	(36.5)	4	(66.7)
No	60	(57.7)	2	(33.3)
Missing	6	(5.8)	0	
Total	100	(100)	6	(100)

Table 1 b. Characteristics of infants

4.2 Uptake of referral

4.2.1 Referral rates and location

Out of 2423 mothers that were enrolled in the main SNL study by 10 June 2010, 148 infants had been referred (6 %). The majority (95%) of infants were referred only once during the time of enrolment, the highest number of which occurred within the first 4 weeks of life (62%) with 22% of these being between birth and 2 weeks of age. The facility referral completion rate was 95%. Only 6 mothers did not complete referral as advised by CHWs (5%). The majority of CHW referrals were to PHC facilities (92%), 8 mothers were referred to a public hospital (7%) and one went to a general practitioner.

4.2.2 Infants' age at last referral

For the majority of infants (40%) the most recent CHW referral was between the ages of 3-4 weeks, 26% were between 5-8 weeks and, 22% were between birth and 2 weeks. The lowest referral rate (11%) was observed among infants between 9 - 12 weeks (Figure 2).

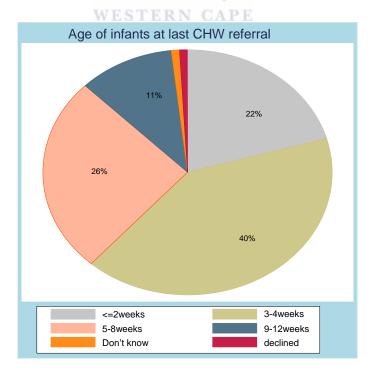


Figure 2: Age of infants at last referral

4.2.3 Referral reasons

Difficulty in breathing and rash accounted for the highest number of referrals (26% and 19% respectively), redness/ discharge around the cord accounted for 17% of referrals while convulsions, ear problems and weak abnormal cry were least experienced (1% each) (table 2).

CHW reason for referral	Number of children referred	Number who completed referrals
Fever	1	1
Difficulty breathing	29	29
Difficulty sucking	3	2 (67%)
Redness/discharge around the	19	17 (89%)
cord		
Jaundice	13	13
Weak and abnormal cry	1	1
Diarrhoea	5	5
Vomiting	2	2
Accident	2	2
Eye discharge	10	10
Rash	U2NIVERSITY of	18 (87%)
Constipation	WESTERN CA	3
Ear problem	1	1
Eye discharge	10	10

Table 2: Referral reasons and completion

4.3 Mothers' Experiences and Perceptions

The following data relates to respondents' experiences and subsequent actions the last time their infants were referred by CHWs:

4.3.1 Illness identification

In the majority of the cases it was the infant's mother (75%) who identified that the infant was ill; in 13% of cases it was the child's grandmother or grandfather and only 9% of illnesses were identified for the first time by CHWs during home visits. There was a significant difference between mothers who did complete the referral and those that did not with regard to recognition of danger signs. None of the six mothers who did not complete referral recognised any danger signs in their infants. Amongst mothers who did complete the referral, about half (48%) were able to recognize danger signs that indicated that the child should be taken to the clinic or hospital (p = 0.01). The most common danger signs recognised were fever (25%) and difficulty breathing (28%).

4.3.2 Home treatment

Home treatment was used by 24% of mothers, the most common being over the counter medicines (58%), followed by eye instillation of breast milk for eye problems (23%).

None of the mothers reported using herbs as home treatment. The mean duration of using home treatment was 4 days (Range 1-7).

4.3.3 Factors that influence delays in referral completion

Referral completion was immediate for a quarter of mothers (25%), for those who didn't go immediately but within 12 hours (13%) the mean number of hours was 5. The majority of mothers took more than 12 hours to complete the referral (63%) and the mean number of days was 2. The most common reasons for a delay in completing referral (i.e. not going immediately) were not realising the seriousness and the clinic being closed (table 3).

Reasons for a delay in completing referral	Freq.	Percent
Facility too far	1	1.28
Did not realize seriousness	29	37.18
Lack of funds	6	7.69
Transportation not easy	3	3.85
Clinic closed/ too late to be attended	22	28.21
Mother ill	1	1.28
Weather	1	1.28
Fear of nurses attitudes	2	2.56
Using other treatment	3	3.85
Traditional reasons	1	1.28
Other responsibilities	8	10.26
Don't know	1	1.28
Total	78	100

Table 3: Reasons for delay in referral completion

4.3.3.1 Transport

Most mothers (55%) walked to the facility that they were referred to whilst 38% took a taxi. Eighty-three percent of respondents reported not experiencing any difficulty with transport to a facility. The journey to facilities took less than thirty minutes for about two-thirds of mothers (76%); and none of the respondents travelled for more than one hour before reaching the facility. The median cost of transport to facilities was R10.00 (range R5-R250). Ten mothers stated they had difficulty getting money, however, none of the respondents stated they could not get the money.

4.3.3.2 Health facility quality of care

The longest waiting time at the facility was more than 2 hours for 22% of respondents; however, 31% reported waiting less than 30 minutes before being attended. All respondents were attended by a nurse or midwife except 12 who reported seeing a doctor

first. Eighteen (17%) respondents did not give a CHW referral slip to the providers. The most common reason being that is was forgotten at home.

4.3.3.3 Health worker response to referral slips

The majority of mothers who brought referral slips were attended to quickly (78%).

Despite bringing the referral slips, some mothers were told to follow the queue (10%) and others were told nothing was wrong with the baby (7%). It was also rare for health workers to give written feedback on the outcome of the referral to the referring CHW (16%).

4.3.3.4 Perceptions of quality of service for facilities and CHWs

The majority of mothers felt that the quality of service at health care facilities was good (71%), although a greater proportion rated the quality of CHW counselling as good (98%). Most respondents (72%) reported that CHWs had visited them more than 5 times between the third trimester and 8 weeks postpartum.

4.4 Outcome of referral

The main diagnoses given by health workers were difficult breathing (13%), redness or discharge around the cord (13%), rash (13%), jaundice (11%) and eye discharge (9%). Only one infant was admitted to hospital following referral and this is one of the six infants who died. Among those who completed referral, 17 mothers felt there was no change in their infants' condition and 2 infants became worse but the majority felt their infant's condition had improved. Among these referrals, ten (9%) and three infants were further referred to second and third health care facilities respectively. This was either due to health care workers recommendations (48%) or due to the mothers' own decision

(52%). Most infants were referred to a hospital as the second place of referral (57%), two were referred to another PHC clinic and a third went to a general practitioner. The most common reason reported for a second referral was to receive better care.

4.5 Mothers' reasons for non completion of referral

Mothers that did not complete referral stated that they did not realize the seriousness of the condition (33, 3%), felt no treatment was necessary (33, 3%) and chose other treatments (33, 3%).

4.6 Review of RTHC

Only one infant did not have a RTHC because it had been lost. Out of 109 cards reviewed, only 54 (50%) had the mothers' HIV status indicated. Out of those whose HIV status was marked, forty-eight (89%) were HIV positive and therefore their infants were HIV exposed. PCR testing was indicated on 4 out of 48 RTHC of exposed infants of which one was HIV positive. Cotrimoxazole was recorded as issued to 52% of HIV exposed infants and the feeding method was indicated on 95% of RTHC. Infants had an average of 8 visits to health care facilities (Range 1-35).

4.6.1 Immunization status at age of interview:

100 RTHC of the age group 6 weeks and above were reviewed, 97% of infants had received 6 weeks immunization, 92% were up to date with 10 weeks immunization and 88% were up to date with 14weeks immunization. Immunization status for infants below 6 weeks and any immunization given after 14weeks was not assessed. Only immunizations given at 6, 10 and 14 weeks were checked from Road to Health Cards.

CHAPTER 5

5.1 Discussion

The following summarises the primary findings of this study:

- Referral of infants to primary health facilities by community health workers during the first 12 weeks of life showed a very high completion rate (95%).
- Most referrals were for neonates (62% between birth and 4 weeks of age) a critical period for timely referral to prevent neonatal deaths.
- Most mothers did not go immediately to the health facility as advised by the CHW- the majority (63%) waited over 12 hours although the clinic being closed was one reason for the delays.
- Recording on infant RTHC by health workers was found to be poor. Critical
 information such as the mothers' HIV status is important to ensure continuity
 of care from facility to community levels.
- Mothers' lack of recognition of danger signs is a barrier to referral completion as none of the mothers who did not complete referral recognised any danger signs in their infants.
- Communication on the outcome of referrals from nurses back to CHWs was poor.

High referral completion

Our findings of high referral completion support previous studies in Uganda, and rural Pakistan. A referral completion rate of 87% was reported in western Uganda on community referral in home management of malaria and in rural Pakistan a referral completion rate of 72% for sick newborns was reported in a pilot study that investigated the feasibility of delivering a package of community-based interventions for improving

peri-natal care using lady health workers (LHWs) and traditional birth attendants (Kallander, Tomson, Nsungwa-Sabiiti et al., 2006; Bhutta, Memon, Soofi, Salat, Cousens & Martines, 2008).

A number of factors could potentially have led to the high referral completion rate in our study. Firstly, CHWs were carefully selected and resided within the communities and this may have created improved trust, respect and effective communication. CHWs were also provided with airtime which enabled them to arrange transport, accompany mothers ("facilitated referral") and contact study supervisors for advice. Secondly, the use of referral letters; the majority of mothers with referral letters reported that they were attended to quickly (78%) after arriving at the clinic. Kallander, Tomson, Nsungwa-Sabiiti, et al., (2006) in a case series study on referral in home management of malaria in Western Uganda indicated that use of referral slips and "counter referral" slips could contribute to improved referral compliance. Thirdly, Umlazi is reasonably well resourced and facilities are easily accessible, most within a walking distance. Similarly a study in Tanzania also found that proximity to health facilities contributed to improved referral completion; 75% of mothers who completed hospital referral in the rural Kilombero District, came from within a 10 km distance (Atkinson, 1999). Finally, training and field supervision of CHWs was intensive, with weekly contact sessions for reporting, problemsolving and mentoring. This level of supervision is unlikely to be feasible in a scaled-up national CHW programme.

The finding of high referral completion within an urban township context is an encouraging finding with regard to the current NDOH plans to formalise CHW involvement in the health sector as it shows that it is possible to extend the health system

to communities for early detection of childhood illnesses. This result is an indication that mothers do respect CHW judgement and listen to their advice.

Results contrary to our study findings were reported for hospital paediatric referrals in Uganda which found a referral completion of 28% (Peterson, Nswanga-Sabiiti, Were, 2004) and in maternal health-care seeking behaviour for acute respiratory infection in children in Ecuador which had a referral completion of 42% (Luque, Whiteford & Tobin, 2008). Critical barriers to referral compliance include the ability to reach newborns at delivery and in the immediate postnatal period when the vast majority of neonatal mortality occurs (Darmstadt, El Arifeen, Choi, et al; 2010). In these two studies, lack of money, distance and transport problems were attributed to low referral completion rates. In contrast we found that transport was not a barrier to referral completion in a context where the majority of mothers could walk to a health facility.

The neonatal period a critical time for referrals

In our study most referrals were for neonates, which is a critical time when identification of illness can save lives. Most referrals were for respiratory problems which is a major cause of neonatal death in developing countries.

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These findings support the move towards greater community based care for mothers and newborn infants as CHWs can play a major role in implementing interventions that increase maternal and newborn survival. There is evidence that fewer neonatal deaths occur when mother and baby are visited within 48 hours of birth. The greatest risk is during the first day after birth, when it is estimated that between 25 and 45 percent of neonatal deaths occur (UNICEF, 2009). Routine post-natal visits especially during the

high-risk post-partum period are critical to provide life saving interventions, particularly for mothers who are HIV-positive (maternal and infant ARV prophylaxis or treatment) and for babies born prematurely (cord care and warmth). During post-natal visits complications can be promptly detected and referred to more expert services if required. Delay of even a few hours before appropriate care can be delivered can be fatal for complications such as neonatal sepsis, post-partum haemorrhage, and hypothermia. Previous evaluations by Darmstadt, Bhutta, Cousins, Adam, Walker & de Bernis (2005) have shown that early identification of newborn illnesses done at community level followed by immediate referral has a potential to significantly reduce neonatal mortality.

Data from Bangladesh show that a home visit on the first or second day after birth can reduce neonatal deaths by two thirds, but later visits are less effective at reducing mortality (Darmstadt, El Arifeen, Choi et al., 2010; Lawn, 2009). Even in the absence of complications, these visits can offer an opportunity to provide essential information and guidance on maternal and newborn health – such as initiating exclusive breastfeeding, psychological support for 'post-natal blues', hygienic practices, and identification of danger signs of illness and locally available resources for referral (UNICEF, 2009; Lawn 2006).

Families' responses to referral

We found that most mothers didn't go immediately to the health facility as advised- the majority waited over 12 hours. Delays in care seeking and inadequate referral are important predictors of child health. In South Africa infant deaths are audited as part of the Child Health Identification Programme. In one of the audit hospitals, King Edward Hospital in Durban, twenty five percent of child deaths were due to modifiable factors

such as, family delaying in seeking care and failure to realize the severity of illness (Stephen & Patrick, 2006).

It is important for sick neonates to be urgently taken to health facilities to prevent complications and death. On-going health education and literacy programmes to communities on the value of consulting urgently and not waiting for illness to resolve are still required (Luque, Whiteford, & Tobin, 2008). In our study mothers cited not recognising the seriousness of illness and closed clinics as reasons for delays in consulting. Delays of more than 2 up to7days were reported in western Nepal, Cambodia and western Uganda on health care seeking, with lack of money commonly mentioned as a cause for delays (Sreeramareddy, Shankar, Sreekumaran, Subba, Joshi & Ramachandram, 2006; Khun & Manderson, 2007; Kallander, Tomson, Nsungwa-Sabiiti, et al., 2006). Access to PHC is considered a fundamental societal right. Restrictive hours and irregular hours of operation are common barriers to access to child care services. High patient volumes have led to facilities limiting the number of patients seen per day and/ or allocating different days for different services (Luque, Whiteford & Tobin, 2008).

Failure to recognise danger signs - a barrier to referral

In our study all mothers who did not complete referral reported that they failed to identify danger signs. It is possible that there may have been differences in the perception of severity between mothers and CHWs, therefore the mothers may not have perceived the symptom to constitute a danger sign. A study in western Nepal on predictors of mothers' care-seeking behaviour found that maternal perceived severity of illness was an important factor influencing care-seeking behaviour. Seventy percent of mothers who sought care during childhood illness reported that they had perceived the child's illness as serious.

Mothers did not seek medical care for their children when the child had one symptom, because they believe many of these resolve on their own (Sreeramareddy et al., 2006). A longitudinal community-based study on mothers' health care seeking during infant rearing in South West Ethiopia found that 33% of ill infants did not get medical care because mothers adopted a wait-and see attitude; this was attributable to mothers' perceptions of the severity of conditions (Tessema, Asefa and Ayele, 2002).

A survey of Child health care in South Africa (Child Healthcare problem Identification Programme) found that 59% of child deaths were due to modifiable factors of which not recognising severity of illness constituted 16% (Lawn, 2006). Equipping communities and families with appropriate healthcare messages on danger signs and care seeking can prevent a number of childhood deaths.

CHW - health system interaction and communication

This study found that less than a quarter of health workers gave feedback to the CHW on the outcome of the referral. Poor feedback to CHWs following referrals is cause for concern given that the SANDOH is proposing to develop family health teams of CHWs linked to health facilities- communication between them is very important and will need to improve and be more formalised. Core standards for clinics and community health centres in the proposed re-engineered PHC services stresses the importance of appropriate recording of referrals within and outside the clinic and stresses that referrals should be assessed and discussed as part of continuing education for the health team to improve outcomes of referrals (SANDOH, 2010c).

Siddiqi, Kielmann, Khan et al., (2001) in a study on the effectiveness of patient referral in Pakistan found that only 15% were referred on a prescribed referral form; the majority was referred either verbally or with informal notes and there was no feedback to initiating facilities.

Health facility quality of care

This study found that only half of the RTHCs reviewed had the mothers HIV status recorded. The RTHC serves as a tool for continuity of care and communication between different providers so it is critical that information like HIV status, PCR results and infant feeding practices are recorded on the card. To respect the patient's right to privacy, the SANDOH introduced a coding system to indicate the HIV status, and however, this is often misunderstood by health care workers and leads to missed opportunities and lack of continuity of care.

Strengths and limitations

A strength of our study was a strict definition of referral (only CHW referral), we excluded those women in the main study who reported that they themselves had identified danger signs in their infants and consulted health care facilities. Furthermore we attempted to interview all women who had received a referral from a CHW and had a very high participation rate. This study therefore provides a comprehensive assessment of referral completion in an urban township setting.

Most women in the study took their children to the clinic when referred by a CHW resulting in very few women who did not complete a referral, and thus the ability to make comparative analyses was restricted. This study was undertaken within a randomised community trial of CHW home visits to pregnant and postnatal women. The CHWs could

therefore have been better trained and supervised than CHWs working in routine, non research settings. Furthermore given the coverage of PHC clinics in Umlazi which are within walking distance of the majority of the residents of the township, these results should be generalised with caution to similar urban settings that are relatively well resourced in terms of health care facilities.

Most of the referrals were managed at PHC level, suggesting less severe illnesses. It is possible that details of experiences during a CHW referral may have merged in respondents' minds with other episodes of health service use around the time of referral which could have resulted in more recall bias than anticipated.

The results of this study are based on cross-sectional data and relate to only one CHW referral event, thus could not capture changes taking place in a changing health system and society. Further research is needed especially on health care worker experiences of CHW referral so as to inform policy makers on referral strategies for the proposed PHC outreach teams.

The process of referral could have benefited from additional qualitative research to more fully describe mothers' experiences of the referral process which a quantitative study could not capture.

We estimated the number of referrals in the study to be around 400 infants but found a lower figure of 148. This sample size estimation was based on literature from other African countries. The lower than anticipated referral rate found in this study could be due to several reasons; firstly CHW visits and therefore referrals only occurred during the first

8 weeks after birth secondly, newborn illness is an emergency so it is possible that some neonates were taken to health facilities before CHWs conducted a home visit and these were not included in the CHW referrals.

5.2 Conclusion

In conclusion, the use of CHWs to deliver community based maternal and child health care is consistent with the current process of PHC re-engineering in South Africa which will formalise the role of CHWs in the PHC system. These findings suggest that well-trained and supervised CHWs are able to conduct surveillance and referral for newborn illnesses to health facilities.

Our data provide evidence that mothers' decisions on health seeking behaviours for their infants can be positively influenced by a simple intervention using a community-based care and outreach strategy within the existing health-care system. Unseen barriers such as the care-givers' perception of illnesses severity, clinic organization and access were also found to play an important role in health- care seeking decisions.

The results of this study highlight the important role played by CHWs in the early detection of newborn illness. Understanding the individual and operational barriers to referral completion by policy makers, health planners and providers has implications for informing the PHC packages currently planned for comprehensive maternal and child health services.

The very high completion rate in our study is encouraging; as it suggests that within an urban township setting CHWs can play a significant role, within community outreach teams, to improving newborn health and reducing child mortality.

5.3 Recommendations

- Referral systems need to be clear from community to the clinic to community
 health centres to district hospital and to specialised services to ensure a continuum
 of care. It is important to establish community facility linkages by using referral
 cards and registers so as to continually monitor referral barriers (SANDOH,
 2010c).
- Facility staff should be in-serviced on their roles in referral to improve communication and referral feedback between health workers and CHWs throughout pregnancy, birth, post-partum and neonatal care. They should be trained on the use of data collection tools such as the maternity health records, RTH booklets and clinic held registers to improve continuity of care. Health care facilities should be provided with necessary resources to manage emergencies (Lawn, 2006).
- Roles of CHWs need to be integrated and their training consolidated and
 broadened to equip them with appropriate skills to address the burden of disease.
 Community IMCI needs to be taught to all CHWs as this will ensure early
 recognition of danger signs by CHWs and mothers thus minimize delay in going
 to clinics or hospitals.

- Monthly reporting and monitoring on referral outcomes should be implemented
 utilising a multi disciplinary team approach. Training and mentoring of CHWs
 and health care providers and auditing of referrals will help them to understand the
 complexities of health care seeking.
- There needs to be active collaboration between referral levels and across sectors, improved communication arrangements and standardised protocols for referral.
 The success of a community-based referral system highly depends on the tracking system for referral compliance, counter-referrals and feedback on referrals.
- Mothers and their families need to be counselled antenatally and at every
 opportunity postnatally on newborn danger signs so that they can take prompt
 action when they face a situation of an ill child.

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APPENDIX 1: Questionnaire

	Section 1. Identification
1.1	
Participant ID	
Please capture the participant's	sunique identifier:
Expects a valid GS1 identifier	(required)
1.2 PID check	
Please re-enter the participant's	s unique identifier:
Expects a numeric response (
	- 4
Constraints	
Response must be Equals 'Pa	articipant ID (1.1)'
1.3	
Interview Date	
Please enter in the date of the i	
Expects a date response (req	
1.4 Interviewer Code	UNIVERSITY of the
Please enter in the interviewer	
i lease enter in the interviewer	code ESTERN CATE
Expects a numeric response (required)
1.5	
Informed Consent Accepted	
Was consent given to continue	with the survey?
Expects a single option respon	nse (required)
Yes [1]	
No [2]	
Branches	
If response Equals 'No [2]' t	then skin to Reason for Refusal (10.1)

Section 2 Infants Health Status

<u>S</u>ubmit

	Section 2. Infants Health Status
- 4	d's Name Vhat is your child's name?
	ects a single line text response (required)
2.2 Chil	d's Gender
V	Vhat gender is your child?
Ехр	ects a single option response (required)
	Male [1]
2.3	Female [2]
-	d's DOB
₩V	Vhat is your child's date of birth?
Ехр	ects a date response (required)
	nenenenen –
2.4	
Chil	d's Condition
V	Vhat is the baby's condition?
Ехр	ects a single option response (required)
	Alive [1] WESTERN CARE
	Dead [2]
Bra	nches
If re	esponse Equals 'Alive [1]' then skip to Relationship to Child (2.12)
2.5 Cau	se of Death
- 5	Vhat was the cause of death?
	ects multiple selected options (required)
	Convulsions [1]
	Fever [2]
	Difficulty in breathing [3]
	Difficulty in sucking/eating [4]
	Redness / discharge around cord [5]
	Jaundice/ yellow eyes [6]
	Baby weak and soft [7]
	Weak and abnormal cry [8]
	Diarrhea [9]

	Vomiting [10]	
	Accident [11]	
	Other [12]	
	Don't know [88]	
	Declined to answer [99]	
Skip	requisites when <i>Cause of Death (2.</i>	5) Excludes 'Other [12]'
2.6 Cau :	se of Death Other	
-5	lease specify:	
Ехр	ects a single line text respor	se (required)
	of Death	
	Vhat date did your baby die?	
Exp	ects a date response (requi	red)
2.8		
_	th Location	mananananan
D	id the baby die at home or in ho	spital?
Ехр	ects a single option response	e (required)
	Home [1]	
	Hospital [2]	UNIVERSITY of the
2.9 Died	after Days or Weeks	WESTERN CAPE
	-	facility/discharge from the hospital did your baby die?
	ects a single option response	
	Days [1]	
	Weeks [2]	
Skip	_	Weeks (2.9) Equals 'Weeks [2]'
2.10 How	Long Days	
	lease specify how many days:	
	ects a numeric response (re	quired)
	requisites when <i>Died after Days or</i>	Weeks (2.9) Equals 'Days [1]'
How	Long Weeks	
P	lease specify how many weeks:	
	ects a numeric response (re	quired)

2.12

Relationship to Child

W	hat is your relationship to the baby?
Ехре	ects a single option response (required)
	Mother [1]
	Father [2]
	Grandmother [3]
	Grandfather [4]
	Aunt/Uncle [5]
	Sibling [6]
	Other Relative [7]
	Non-Relative Caretaker [8]
	Don't know [88]
	Declined to answer [99]
	requisites
	when Relationship to Child (2.12) Not Equal 'Other Relative [7]'
2.13 Rela	tionship to Child Other
	lease specfy:
	ects a single line text response (required)
	UNIVERSITY of the
2.14	WESTERN CAPE
	d of Family
	Tho is the head of the family? ects a single option response (required)
Expe	ects a single option response (required)
	My Husband [1]
	My Father [2]
	My Father in law [3]
	My mother [4]
	My mother in law [5]
	The respondent [7]
	Other [6]
	Don't know [88]
	Declined to answer [99]
	requisites when <i>Head of Family (2.14)</i> Not Equal 'Other [6]'

- N	f Family Other
	se specfy: s a single line text response (required)
Expect	s a single line text response (required)
2.16	
N	Start Office at 12 Weeks you take the baby to Good Start III office at Prince Mshiyeni when she/he was 12 weeks old?
-	s a single option response (required)
□ Ye	s [1]
□ _{No}	D [2]
Ba	by less than 12 weeks old [3]
	Submit
	Section 3. Dietary 24-hour Recall
3.1 Feeding	g Instruction
	now going to ask you questions about what you fed your baby from the time you woke up yesterday
	g till you woke up this morning.
3.2 Breastf	feed Baby
	n the time you woke up yesterday morning till you woke up this morning did you breastfeed your
baby? Expect	s a single option response (required)RN CAPE
	s [1]
	0[2]
3.3	Given Items
100	n the time you woke up yesterday morning till you woke up this morning: Did you give any of the
	ng items to the child? s multiple selected options (required)
	ater [1]
	ater with sugar or glucose [2]
	uit Juice [3]
	a without milk [4]
	a with milk [5]
	luted cow's milk [6]
	ot diluted cow's milk [7]
	her powdered milk [8]

	Goats milk [9]	
	Infant formula [10]	
	Fruit/Vegetables [11]	
	Meat [12]	
	Fish [13]	
	Eggs [14]	
	Daily products (egg yoghut,cheese) [15]	
	Cereals, porridge and bread [16]	
	Prescribed medication [17]	
	Herbs/ Traditional medicine [18]	
	Over the counter medicine (eg gripe water) [19]	
	Other [20]	
	<u>S</u> ubmit	
4.1	Section 4. Community Health Worker Referral	
III S	ince Birth How may times has your child been ill since birth?	
Expects a numeric response (required) LERN CAPE		
Bra	inches	
If re	esponse Equals '0' then skip to Times Visited by Counsellor (8.1)	
Las	t Time Child got III	
	What was wrong with your child the last time they got ill? ects multiple selected options (required)	
	Convulsions [1]	
	Fever [2]	
	Difficulty in breathing [3]	
	Difficulty in sucking/eating [4]	
	Redness / discharge around cord [5]	
	Jaundice/ yellow soles [6]	
	Baby weak and soft [7]	
	Weak and abnormal cry [8]	
	weak and abhormal cry [8]	

	Vomiting [10]	
	Other [12]	
	Don't know [88]	
	Declined to answer [99]	
I duri	erred by Health Worker Have you ever been referred by the Good Start III community health worker to consult help for your child ng a period of illness? ects a single option response (required)	
	Yes [1]	
	No [2]	
	Don't Know [88]	
	Declined to answer [99]	
	nches esponse Not Equal 'Yes [1]' then skip to <i>Times Visited by Counsellor (8.1)</i>	
Amount of Times to be Referred How many times were you referred by the Good Start III CHW for your childs illness? (Referral means receiving a letter to take to the clinic/hospital?) Expects a numeric response (required) 4.5 Referral Age You are going to be asked about the age of your child at each referral. Please start with the most distant (oldest) referral and work your way to the most recent (newest). Repeat this section for value of Amount of Times to be Referred (4.4)		
	Section 5. Age at Referrals	
dista	of Child when Referred Can you remember the age of your child when each of these referrals happened? (Start with the most ant referral (oldest)) ects a single option response (required) Less than 2 weeks old [1]	
	2-4 weeks old [2]	
	4-8 weeks old [3]	
	8-12 weeks old [4]	
	Don't Know [88]	
	Declined to answer [99]	

Section 6. Community Health Worker Referral Continuation

<u>S</u>ubmit

6.1

Location of Referral

V	Where did the community health worker refer you to the last time she gave you a referral letter?
Ехр	ects a single option response (required)
	Home [1]
	Public Hospital [2]
	Primary Health Care Clinic [3]
	Outreach Site [4]
	NGO Clinic [5]
	Private Hospital [6]
	Private Clinic [7]
	General Practitioner [8]
	Community Health Worker [9]
	Traditional Healer [10]
	Spiritual/Religious Leader [11]
	Pharmacy/ drug shop [12] UNIVERSITY of the
	WESTERN CAPE Other [13]
	Don't know [88]
	Declined to answer [99]
	requisites when <i>Location of Referral (6.1)</i> Not Equal 'Other [13]'
6.2 Loc	ation of Referral Other
■P	Please specify:
Ехр	ects a single line text response (required)
0.0	
6.3 Age	at Most Recent Referral
ŀ	How old was your child at the most recent referral?
Ехр	ects a single option response (required)
	Less than 2 weeks old [1]
	2-4 weeks old [2]
	4-8 weeks old [3]
	8.12 weeks old [4]

	Don't know [88]	
	Declined to answer [99]	
V	t Recent Time Child got III What was wrong with your child to ects multiple selected option	the last time you received a CHW referral?
	Convulsions [1]	
	Fever [2]	
	Difficulty in breathing [3]	
	Difficulty in sucking/eating [4]	
	Redness / discharge around con	rd [5]
	Jaundice/ yellow soles [6]	
	Baby weak and soft [7]	
	Weak and abnormal cry [8]	
	Diarrhea [9]	
	Vomiting [10]	
	Accident [11]	
	Other [12]	UNIVERSITY of the
	Don't know [88]	WESTERN CAPE
	Declined to answer [99]	
Skip 6.5 Mos	requisites when Most Recent Time t Recent Time Child got III Oth lease specify:	Child got III (6.4) Excludes 'Other [12]'
Exp	ects a single line text respor	nse (required)
V	son Responsible for Identifying Who was responsible for identifying ects a single option response	ing that your child was ill the during this episode?
	Child's Mother/caretaker [1]	
	Child's Father/Mother's Partne	r [2]
	Grandfather/Grandmother [3]	
	Brother/Sister [4]	
	Other Family Members [5]	

	Friends/Neighbors [6]
	Fieldworker/CHW [7]
	No one [8]
	Other [9]
	Don't know [88]
	Declined to answer [99]
6.7 Time	e After Beginning of Symptoms
100	fter how much time from the beginning of symptoms did you recognise that he/she was having a
	lem or illness?
•	ects a single option response (required)
	Immediately [1]
	Hours [2]
	Days [3]
	Months [4]
	Died Immediately [5]
	Don't know [88]
	Declined to answer [99]
	requisites UNIVERSITY of the when Time After Beginning of Symptoms (6.7) Not Equal 'Hours [2]'
6.8	when Time Arter Beginning of Symptoms (6.7) Not Equal Hours [2]
	e After Beginning of Symptoms Hours
	lease specify how many hours:
	ects a numeric response (required)
	Solis a Hameric response (reguirea)
Pre	requisites
Skip	when Time After Beginning of Symptoms (6.7) Not Equal 'Days [3]'
6.9	
	e After Beginning of Symptoms Days
	lease specify how many days:
Exp	ects a numeric response (required)
Pre	requisites
	when <i>Time After Beginning of Symptoms (6.7)</i> Not Equal 'Months [4]'
	e After Beginning of Symptoms Months
■P	lease specify how many months:
	ects a numeric response (required)

6.11 **Home Treatment** What treatment did you give at home? Expects multiple selected options (required) Oral rehydration solution [1] Over the counter medicine [2] Herbs [3] Nothing [4] Other [5] Don't know [88] Declined to answer [99] If response Equals 'Nothing [4]' then skip to Danger Signs (6.14) If response Equals 'Other [5]' then skip to Danger Signs (6.14) If response Equals 'Don't know [88]' then skip to Danger Signs (6.14) If response Equals 'Declined to answer [99]' then skip to Danger Signs (6.14) **Prerequisites** Skip when Home Treatment (6.11) Excludes 'Other [5]' 6.12 **Home Treatment Other** Please specify: Expects a single line text response (required) 6.13 **Duration of Home Treatment** WESTERN CAPE How many days did you give this home treatment? Expects a numeric response (required) 6.14 **Danger Signs** Were you aware of any danger signs that indicated the child should go to the clinic or hospital? Expects a single option response (required) Yes [1] No [2] Don't know [88] Declined to answer [99] **Prerequisites** Skip when Danger Signs (6.14) Not Equal 'Yes [1]' 6.15 Type of Danger Signs Please specify what these signs were?

Expects multiple selected options (required)

Convulsions [1]

Fever/ Hot body [2]

	Difficulty Breathing [3]
	Difficulty Sucking [4]
	Redness / discharge around cord [5]
	Jaundice: Yellow palms, soles, or eyes [6]
	Baby is weak and soft [7]
	Weak abnormal cry [8]
Skip Skip Skip Skip Skip Skip Skip Skip	tion 7 Skip lecause there were no referrals to the health care facility, the section on health care facility referrals will kipped. If you feel this is incorrect, select the option to go back and correct the response. lects a single option response (required) Go back and correct response. [1] Continue. [2] nches esponse Equals 'Go back and correct response. [1]' then skip to Location of Referral
	Section 7. Health Care Facility Referrals
7.1	
100	e Your Baby to Clinic as Advised On the last occasstion that you received a referral letter from the Good Start III community health worker
	you take your child to the health care facility as advised by the CHW?
Exp	ects a single option response (required)
	Yes [1]
	No [2]
	Don't know [88]
	Decline to answer [99]
	nches esponse Not Equal 'Yes [1]' then skip to Child Not Taken for Treatment (7.8)
7.2	
- 5	e After Letter was Given
	Iow long after you were given the letter by the Good Start CHW did you or your family take the baby for timent?
	ects a single option response (required)

	Immediately [1]
	Hours [2]
	Days [3]
	Months [4]
	Don't know [88]
	Declined to answer [99]
If re	esponse Equals 'Immediately [1]' then skip to Other Health Facilities Nearby (7.11) esponse Equals 'Don't know [88]' then skip to Other Health Facilities Nearby (7.11) esponse Equals 'Declined to answer [99]' then skip to Other Health Facilities Nearby (11)
Pre Skip 7.3 Tim	erequisites of when Time After Letter was Given (7.2) Not Equal 'Hours [2]' the After Letter was Given Hours Please specify how many hours after receiving the letter you took the baby to the clinic: the best a numeric response (required)
Skip 7.4 Tim	erequisites by when Time After Letter was Given (7.2) Not Equal 'Days [3]' le After Letter was Given Days Please specify how many days after receiving the letter you took the baby to the clinic:
	pects a numeric response (required)
	WESTERN CAPE
Skip 7.5	erequisites p when <i>Time After Letter was Given (7.2)</i> Not Equal 'Months [4]'
	e After Letter was Given Months Please specify how many months after receiving the letter you took the baby to the clinic:
	pects a numeric response (required)
7.6 Chil	ld Not Taken for Treatment Earlier
1	Why was the baby not taken for treatment sooner?
Ехр	ects multiple selected options (required)
	Not customary [1]
	Facility/provider too far [2]
	Did not realize seriousness [3]
	Cost too much [4]
	Lack of funds [5]
	No one to look after Household [6]
	Transportation not easy [7]

	Safety concerns [8]	
	Other [9]	
	Don't know [88]	
	Declined to answer [99]	
	anches	much [4]' then skip to <i>Other Health Facilities Nearb</i>
(7.	11)	
(7.	11)	ow [88]' then skip to Other Health Facilities Nearby
	esponse Includes 'Declined arby (7.11)	to answer [99]' then skip to Other Health Facilities
	e <mark>requisites</mark> p when <i>Child Not Taken for</i>	Treatment Earlier (7.6) Excludes 'Other [9]'
Chil	ld Not Taken for Treatment Earl	ier Other
	Please specify: pects a single line text respons	se (required)
	erequisites	
Skip 7.8	p when <i>Take Your Baby to</i> 0	Clinic as Advised (7.1) Equals 'Yes [1]'
14	Id Not Taken for Treatment	
	What prevented you from taking t pects multiple selected options	he child to the health facility as advised by the CHW? (required)
	No treatment necessary [1]	<u></u>
	·	UNIVERSITY of the
	Not customary [2]	WESTERN CAPE
_	Cost too much [3]	
	Lack of funds [4]	
	Health facility too far [5]	
	Transportation not easy [6]	
	No one to accompany her [7]	
	Quality care not available [8]	
	Mistreatment by health staff [9]	
	Family did not allow [10]	
	Home care is better [11]	
	Did not know how to go there [1	2]
	No time to go [13]	
	Did not know where to go [14]	
	Died on the way to treatment [1	5]

	Did not realize seriousness [16]	
	Chose other treatment [17]	
	Other [18]	
	Don't know [88]	
	Declined to answer [99]	
Skip	erequisites p when <i>Take Your Baby to C</i>	Clinic as Advised (7.1) Equals 'Yes [1]'
7.9 Peo	pple Involved in Not Taking Child	for Treatment.
		ecision that the baby should not go to a facility or provider to receive
	atment? Dects multiple selected options	(required)
	Child's mother/caregiver [1]	
	Child's father [2]	
	Mother's partner [3]	
	Grandfather [4]	
	Grandmother [5]	
	Brother/sister [6]	
	Other family members [7]	UNIVERSITY OF
	Friends/neighbours [8]	UNIVERSITY of the WESTERN CAPE
	Field worker/CHW [9]	
	No one [10]	
	Other [11]	
	Don't know [88]	
	Declined to answer [99]	
		Not Taking Child for Treatment. (7.9) Excludes 'Other
_	p when <i>Take Your Baby to C</i>	Clinic as Advised (7.1) Equals 'Yes [1]'
Peo	pple Involved in Not Taking Child	for Treatment Other
	Please specify: pects a single line text response	e (required)
	erequisites p when <i>Take Your Baby to C</i>	Clinic as Advised (7.1) Equals 'Yes [1]'
7.11	-	
100		could have used that are closer to your home for this referral?

84

Expects a single option response (**required**)

	Yes [1]
	No [2]
	Don't know [88]
	Declined to answer [99]
ŀ	ons of Transport How did you take the baby to the facility/provider?
Exp	ects a single option response (required)
	Car [1]
	Bus [2]
	Train [3]
	Ambulance [4]
	Taxi [5]
	On foot [6]
	Other [7]
	Don't know [88]
	Declined to answer [99]
	esponse Equals 'On foot [6]' then skip to <i>Time Taken to Get to Clinic (7.14)</i>
7.13 Diffi	WESTERN CAPE
ŀ	How difficult was it to find/get the transport?
Exp	ects a single option response (required)
_	Very difficult [1]
	Somewhat difficult [2]
	Not a problem [3]
	Don't know [88]
	Declined to answer [99]
7.14 Tim	e Taken to Get to Clinic
	How much time did it take to go there?
Ехр	ects a single option response (required)
_	Between 5-10 minutes [1]
	Less than 30 minutes [2]
	Less than 1 hour [3]
	Approximately 1 hour [4]

	Between 1-2 hours [5]	
	More than 2 hours [6]	
	Don't know [88]	
	Declined to answer [99]	
7.15	15	
100	ost to Get to Facility	
	Did you have to spend any money to get pects a single option response (rec	-
	pects a single option response (rec	quii eu)
_	Yes [1]	
	No [2]	
	ranches response Not Equal 'Yes [1]' the	n skip to <i>Waiting Time (7.19)</i>
7.16		
Cos		
	How much money did it cost you to visi pects a decimal response (require	
EXP	pects a decimal response (require	u)
7.17 Able	17 ble to Gather Money	m-m-m-m
	How were you able to gather this mone	v? (prompt)
	pects a single option response (rec	111 111 111 111
	Very easily [1]	<u> </u>
		IVERSITY of the
	Easily [2]	STERN CAPE
	With Difficulty [3]	DIEKN GALE
	With a lot of difficulty [4]	
	Could not get the money [5]	
	Other [6]	
	Don't know [88]	
	Declined to answer [99]	
	erequisites	
5kip	tip when <i>Able to Gather Money(</i> 18	7.77) Not Equal 'Other [6]'
Able	ole to Gather Money Other	
	Please specify:	
Ехр	pects a single line text response (r	equired)

7.19

Waiting Time

waiting Time
How long after the baby first arrived at the facility/care provider was he/she examined? (In other words,
how long did you have to wait?)
Expects a single option response (required)
Immediately [1]
Less than 30 minutes [2]
Less than 1 hour [3]
Approximately 1 hour [4]
Between 1-2 hours [5]
More than 2 hours [6]
Don't know [88]
Declined to answer [99]
7.20 Type of Provider
What type of provider first treated the baby?
Expects a single option response (required)
Qualified Doctor [1]
Nurse/Midwife [2]
Health Assistant [3] UNIVERSITY of the
Community Health Worker [4] WESTERN CAPE
Traditional Healer/ Practitioner [5]
Spiritual/Religious Leader [6]
Other [7]
Don't know [88]
Declined to answer [99]
Prerequisites Skip when <i>Type of Provider (7.20)</i> Not Equal 'Other [7]'
7.21
Type of Provider Other
Please specify:
Expects a single line text response (required)
7.22 Give in Referral Slip
The state of the s
Did you give the referral slip from the Good Start III CHW to the health care worker at the health care centre?
Expects a single option response (required)
T T T T T T T T T T T T T
Yes [1]

	No [2]
	Don't know [88]
	Declined to answer [99]
	unches esponse Not Equal 'No [2]' then skip to <i>Response to Referral Slip (7.24)</i>
7.23	3
14	Giving in Slip Reason What was the reason for not giving the referral slip to the heath care worker?
	pects a single option response (required)
	Forgot it at Home [1]
	Was not given a slip [2]
	Was not told to bring the slip [3]
	Other [4]
	unches esponse Not Equal 'Other [4]' then skip to <i>Baby Illness (7.26)</i>
If re	esponse Equals 'Other [4]' then skip to Baby Illness (7.26)
7.24 Res	ponse to Referral Slip
	How did the health care worker respond after reading the referral slip?
Exp	ects a single option response (required)
	Attended to baby quickly [1]
	Told to follow the queue [2] UNIVERSITY of the
	Told nothing was wrong with baby [3]
	Other [4]
	Don't know [88]
	Decline to answer [99]
7.25 Ref	5 erral Slip Feedback
100	Did the health care worker write on the referral slip or did she give you any information to report back to
CH	W? vects a single option response (required)
	Yes [1]
	No [2]
П	Don't know [88]
	Declined to answer [99]
7.26 Bab	S by Illness
- 5	What were you told was wrong with the baby during this referral?
Ехр	pects multiple selected options (required)

	Convulsions [1]	
	Fever [2]	
	Difficulty in breathing [3]	
	Difficulty in sucking/eating [4]	
	Redness / discharge around cord [5]	
	Jaundice/ yellow soles [6]	
	Baby weak and soft [7]	
	Weak and abnormal cry [8]	
	Diarrhea [9]	
	Vomiting [10]	
	Other [12]	
	Don't know [88]	
	Declined to answer [99]	
Skip	requisites when <i>Baby I liness (7.26)</i> Excludes 'Other [12]'	
Bab	7.27 Baby Illness Other	
Expects a single line text response (required) ITY of the		
	WESTERN CAPE	
7.28 Child Admitted to Facility		
	Vas the baby admitted to the facility?	
Exp	ects a single option response (required)	
	Yes [1]	
	No [2] Don't know [88]	
	Declined to answer [99]	
	nches	
It re	esponse Equals 'Yes [1]' then skip to Condition Improve/Worsen (7.33)	
7.29 Home Care		
	Did the provider ask you to do certain things/ something at home for the babys treatment? ects a single option response (required)	
	Yes [1]	
	No [2]	

	Don't know [88]
	Declined to answer [99]
	nches esponse Not Equal 'Yes [1]' then skip to Condition Improve/Worsen (7.33)
7.30 Hom	ne Care Type
100 Mg	What did the provider ask you to do at home?
Exp	ects a single line text response (required)
7.31 Able	e to Perform Home Care
100	Were you able to do all the things the provider asked you to do?
	ects a single option response (required)
	Yes, everything [1]
	Partially yes, partially no [2]
	No [3]
	Don't know [88]
	Declined to answer [99]
	nches esponse Equals 'Yes, everything [1]' then skip to Condition Improve/Worsen (7.33)
If re	esponse Equals 'Don't know [88]' then skip to Condition Improve/Worsen (7.33)
If re	esponse Equals 'Declined to answer [99]' then skip to Condition Improve/Worsen
7.32	UNIVERSITY of the
	Able to Perform Home Care WESTERN CAPE
	Vhy could you not do them?
Ехр	ects a single line text response (required)
7.33	dition Improve/Worsen
1.	bid the baby's condition improve after treatment or did it stay the same or worsen?
	ects a single option response (required)
	Improved [1]
	No change [2]
	Worsened [3]
	Died [4]
	Don't know [88]
	Declined to answer [99]
7.34	
1.	e Quality of Care Iow would you rate the quality of care the baby received at this first facility/provider?
	ects a single option response (required)

	Good [1]	
	Fair [2]	
	Poor [3]	
	Don't know [88]	
	Declined to answer [99]	
If re	esponse Equals 'Declined t	w [88]' then skip to <i>Referred to Another Facilty (7.36)</i> to answer [99]' then skip to <i>Referred to Another Facilty</i>
7.35 Qua	lity of Care Reason	
- 1	-	d, fair or poor about the care the baby received?
Ехр	ects a single line text respon	nse (required)
7.36	erred to Another Facilty	
15		e baby to another facility/provider for care?
	ects a single option respons	
	Yes [1]	
	No [2]	
	Don't know [88]	
	Declined to answer [99]	UNIVERSITY of the
	nches esponse Equals 'Yes [1]' th	WESTERN CAPE nen skip to <i>Referred to Which Location (7.38)</i>
7.37		
15	ther Facility Own Decision	ke the baby to another facility/provider for care?
	ects a single option respons	
	Yes [1]	
	No [2]	
	Don't know [88]	
	Declined to answer [99]	
	nches esponse Not Equal 'Yes [1]]' then skip to <i>Child Has RTHC (7.49)</i>
V	erred to Which Location	where did you take the baby next)?
	Home [1]	
	Public Hospital [2]	
	Primary Health Care Clinic [3]	

	Outreach Site [4]		
	NGO Clinic [5]		
	Private Hospital [6]		
	Private Clinic [7]		
	General Practitioner [8]		
	Community Health Worker [9]		
	Traditional Healer [10]		
	Spiritual/Religious Leader [11]		
	Pharmacy/ drug shop [12]		
	Other [13]		
	Don't know [88]		
7.00	Declined to answer [99]		
7.39 Rea s	son for Referral		
V	What was the reason given for the referral (or why did you decide to take the baby to another		
facili	ity/provider)?		
Ехр	ects a single option response (required)		
	Lacked necessary equipment/ service child needed [1]		
	To get better care [2] WESTERN CAPE		
	Because baby was still sick [3]		
	No doctor/nurse was available [4]		
	Other [5]		
	Don't know [88]		
	Declined to Answer [99]		
Skip	requisites when <i>Reason for Referral (7.39)</i> Not Equal 'Other [5]'		
7.40	son for Referral Other		
	lease specify:		
	ects a single line text response (required)		
Exp	ects a single line text response (required)		
7.41			
	e Taken to Send Baby to Facility		
100	How long after the baby was seen at the first facility/provider was it sent/taken to the second		
	ity/provider place?		
	ects a single option response (required)		

	Immediately [1]
	Hours [2]
	Days [3]
	Months [4]
	Did not go [5]
	Don't know [88]
If re	Declined to answer [99] Inches Esponse Equals 'Did not go [5]' then skip to Child Has RTHC (7.49) Esponse Equals 'Don't know [88]' then skip to Child Has RTHC (7.49) Esponse Equals 'Declined to answer [99]' then skip to Child Has RTHC (7.49)
Skip 7.42 Tim	e Taken to Send Baby to Facility Hours
	Please specify how many hours: ects a numeric response (required)
	requisites o when <i>Time Taken to Send Baby to Facility (7.41)</i> Not Equal 'Days [3]'
	e Taken to Send Baby to Facility Days
	ects a numeric response (required) ERSITY of the
Skip 7.44	
	e Taken to Send Baby to Facility Months Please specify how many months:
	ects a numeric response (required)
ŀ	e Quality of Care at Second Facility How would you rate the quality of care the baby received at this second facility/provider? ects a single option response (required)
	Good [1]
	Fair [2]
	Poor [3]
	Don't know [88]
	Declined to answer [99]
If re	nches esponse Equals 'Don't know [88]' then skip to Child's Age (7.48) esponse Equals 'Declined to answer [99]' then skip to Child's Age (7.48)

7.46 Qua	lity of Care at Second Facility Reason
100	an you be specific what was good, fair or poor about the care the baby received?
	ects a single line text response (required)
7.47	
	erral for Third Facility
Α	fter this second facility/provider, was the baby referred to a third place (or did you decide on your own to
	the baby somewhere else for care)?
Ехр	ects a single option response (required)
	Yes, baby was referred [1]
	Yes, I made the decision [2]
	No [3]
	Don't know [88]
	Declined to answer [99]
7.48 Chil	d's Age
100	s the child more than 16 weeks (4 months) old?
	ects a single option response (required)
	Yes [1]
7.49	No [2]
- 5	d Has RTHC UNIVERSITY of the
Exp	loes the child have a RTHC? ects a single option response (required)
	Yes [1]
	No [2]
	nches
	esponse Equals 'Yes [1]' then skip to <i>Up to Date with Immunization (7.52)</i>
7.50 Chil	d Doesn't Have RTHC
V	What is the reason?
Ехр	ects a single option response (required)
	Card got lost [1]
	Other [2]
	Don't know [88]
	Declined to answer [99]
	requisites when <i>Child Doesn't Have RTHC (7.50)</i> Not Equal 'Other [2]'

1000	ld Doesn't Have RTHC Other				
	Please specify: pects a single line text respo	onse (required)			
	south a single into toxt 105pc	niss (Loganica)			
7.52					
100	to Date with Immunization is the child up to date with the fi	irst immunization at 6, 10 and 14 weeks? (Ask for the RTHC or if card lost			
	the mother)	no (no voine d)			
EXP	ects multiple selected optio	ns (requirea)			
_	DTP 1 [1]				
	Hib 1 [2]				
	Hep B 1 [3]				
Ш	Polio 1 [4]				
	DTP 2 [5]				
	Hib 2 [6]				
	Hep B 2 [7]				
	Polio 2 [8]				
	DTP 3 [9]	<u></u>			
	Hib 3 [10]	UNIVERSITY of the			
	Hep B 3 [11]	WESTERN CAPE			
	Polio 3 [12]				
	None [13]				
	Child less than 6 weeks of age.	.[14]			
		Spatian & CHIM Support			
8.1		Section 8. CHW Support			
Tim	es Visited by Counsellor				
How many times have you been visited and counselled by Good Start III community health worker at home?					
Expects a single option response (required)					
	Once or twice [1]				
	Three to four times [2]				
	Four to five times [3]				
	More than 5 times [4]				

	Don't know [88]
	Declined to answer [99]
8.2 Rate	e CHW Support
F	How do you rate the CHWs support you receive during home visits?
	ects a single option response (required)
	Good [1]
	Fair [2]
	Poor [3]
	Don't know [88]
	Declined to answer [99]
If re	esponse Equals 'Don't know [88]' then skip to <i>Counselling Not the Same (8.5)</i> esponse Equals 'Declined to answer [99]' then skip to <i>Counselling Not the Same (5)</i>
8.3 Rate	e CHW Support Reason
- 5	Can you be specific what was good, fair or poor about the care the baby received?
	ects a single line text response (required)
8.4 Co u	inselling Same as Heath Care Worker
Ī	Oo you feel the counselling given by CHW during home visits is the same as what other health care
wor	kers gave you at the health care facility?
Ехр	ects a single option response (required)
	Yes [1]
	No [2]
	Don't know [88]
	Declined to answer [99]
	Inches esponse Not Equal 'No [2]' then skip to IIness Cured by Traditional Healers (8.6)
8.5	
- A	Inselling Not the Same
■ P	Please explain:
Ехр	ects a single line text response (required)
8.6	on Cured by Traditional Harlara
100	ss Cured by Traditional Healers
	Vould you agree or disagree that most infant illness during the first month of life can be cured by
	itional healers.
Exp	ects a single option response (required)
	Agree [1]

	Don't know [88]	
	Declined to answer [99]	
V takii	roval from Family Head	the mother should always get approval from the family head before (required)
V	nts Not Taken Out of Home Vould you agree or disagree that hing including a visits to the clin ects a single option response Agree [1] Disagree [2] Don't know [88] Declined to answer [99]	•
	Section	9. Road to Health Card Review
V	her's HIV Status Vas the mother's HIV status indi ects a single option response Yes [1]	cated on RTHC card/code/stamp? e (required)
lf r∈	No [2] nches esponse Equals 'No [2]' the	en skip to <i>Cotrimoxazole Issued (9.3)</i>
P	her's HIV Status Yes lease specify: ects a single option response	e (required)
	HIV Positive [1]	
Bra	HIV Negative [2]	
		ive [2] then skin to Feeding Method (9.4)

9.3 Cotrimoxazole Issued
Indication of Cotrimoxazole issued to infant
Expects a single option response (required)
Expects a single option response (required)
Yes [1]
No [2]
Branches If response Equals 'No [2]' then skip to Feeding Method (9.4)
Thresponse Equals No [2] then skip to Feeding Wethod (9.4)
9.4
Feeding Method
Indication of infant feeding method?
Expects a single option response (required)
Yes [1]
No [2]
Branches
If response Equals 'No [2]' then skip to PCR Test (9.7)
9.5 Feeding Method Yes
Please select the feeding method used:
Expects a single option response (required)
Exclusive breastfeeding [1]
UNIVERSITY of the
Exclusive formula feeding [2] WESTERN CAPE
Mixed feeding [3]
Other [99]
Prerequisites
Skip when <i>Feeding Method Yes (9.5)</i> Not Equal 'Other [99]' 9.6
Feeding Method Yes Other
Please specify:
Expects a single line text response (required)
9.7
PCR Test
Indication of PCR test done?
Expects a single option response (required)
Yes [1]
No [2]

9.8 PCR Test Result
Indication of PCR result.
Expects a single option response (required)
Yes [1]
No [2]
Prerequisites
Skip when PCR Test Result (9.8) Not Equal 'Yes [1]'
9.9
PCR Test Result Yes
What were the results of the PCR test? Expects a single option response (required)
Positive [1]
Negative [2]
9.10 Number of consultations
How many times has the child been to the clinic since birth for any reasons?
Expects a numeric response (required)
penenenen "
<u>S</u> ubmit
Section 10. End
Prerequisites Skip when Informed Consent Accepted (1.5) Equals 'Yes [1]'
10.1 WESTERN CAPE
Reason for Refusal Why has the participant refused to continue with the survey?
Expects a single option response (required)
П
Does not have time [1]
Does not trust interviewer [2]
Family member disagrees with mother participation [3]
No reason given [4]
Other [5]
Prerequisites Skip when Reason for Refusal (10.1) Not Equal 'Other [5]'
Skip when <i>Informed Consent Accepted (1.5)</i> Equals 'Yes [1]'
10.2 Reason for Refusal Other
Please specify:
Expects a single line text response (required)

10.3

Comments

Please add any other comments you may have:

Expects	а	single	line	text	response	(optional)

Prerequisites

Skip when Good Start Office at 12 Weeks (2.16) Equals 'No [2]'

10.4

End

Please select 'Next' to complete the survey.

Prerequisites

Skip when Good Start Office at 12 Weeks (2.16) Not Equal 'No [2]'

10.5

End - 12 Week DC

Please select 'Next' to complete the survey. Once you have completed the survey please conduct the 12 week DC with the participant.



Appendix 2- Consent form



University of the Western Cape



School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa Tel: 021- 959 2809, Fax: 021- 959 2872

INFORMED CONSENT

TITLE OF RESEARCH

A descriptive cross-sectional study of referrals by community health workers within the Good Start Saving Newborn Lives study.

As was mentioned in the *participant information sheet* your participation in this research is entirely voluntary i.e. you do not have to participate unless you want to. Refusal to participate or withdrawal from the study will not result in penalty nor any loss of benefits to which you are otherwise entitled.

If you choose to participate you may stop at any time. You may also choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss please feel free to say so.

The information collected in this interview will be kept strictly confidential. If you choose to participate in this research study, your signed consent is required before I proceed with the interview.

I have read/ been told about this study and	my questions have been satisfactorily
answered by	(name of interviewer).

I understand that I have a right to refuse to participate or to end the interview at any time; and to choose not to answer particular questions that are asked in the study.

I am aware that I may withdraw my consent at any time without this affecting my access to health care at the hospital or clinic.

I admit that I have been informed about the possible advantages and possible disadvantages which may result from being part of this study.

I admit that I understand and accept that this study involves research and the "Information for Participants" page has been handed to me in connection with this study.

I acknowledge that I understand the contents of this form and as the PARENT/CAREGIVER freely consent to this interview as described to me:

I agree to participate in this study, and to be visited at home or to visit the Good Start Office to be interviewed

Printed name of mother (PAR	TICIPANT):	_
Signad	Date:	
	Parent/CAREGIVER	
•		
Printed name of researcher co	nducting informed consent:	
Signed:	Date:	
Researcher	أاحالها احالها أأ	
For illiterate subjects:		
	UNIVERSITY of the	
	WESTERN CAPE Date:	
Mark with a 'X'		

Appendix 3: Referral slip for CHWs in the Intervention arm



GOOD START III

CLINIC / HOSPITAL REFERRAL LETTER- INTERVENTION

Dear Sister/Doctor
During a recent home visit to the following client's home we found a health problem
that appears to require follow-up by a certified health provider.
1. Name of the client
2. Age of client
3. Referred to (Name of clinic)
4. Description of the problem
Referred by (Name of the CHW/ Supervisor)
Address
Cell phone numberDate of Referral
If cancelled, give specific reason:

Appendix 4: The Primary Health Care Outreach Team as proposed by the SANDOH

