

South African Primary Health Care
in the era of HIV /AIDS treatment and care:
Understanding the organisation and delivery of nursing care

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Declaration

I, **Andy Guise**, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.



Andy Guise

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Abstract

South African Primary Health Care in the era of HIV/AIDS treatment and care: understanding the organisation and delivery of nursing care

The integration of Antiretroviral Treatment (ART) for HIV in to South African primary health care (PHC) and task shifting are increasing nurses' role in ART and HIV care. There is evidence this role is motivating nurses to adopt more patient-centred care. This study explored this potential emergence of more patient centred care in PHC in the Free State province, South Africa.

A multi-site, mixed-method observational approach was used, building on ethnographic principles. A purposive sample of four clinics, two providing ART and two not, were the focus for observation and interviews through four phases of data collection. Emerging findings were explored in an additional six clinics in later phases of data collection. 34 professional nurses, 6 members of clinic staff and 21 patients were interviewed. A thematic analysis that aimed to develop theory grounded in the study contexts through integrating existing theory with inductively identified themes was used.

The study found care is patient centred and integrated to a limited extent, while ART and HIV care are more likely to be patient centred than other aspects of PHC. These care routines are then shown to emerge from nurses' agency mediating different levels of structure: the rules of clinic interaction and then the clinic context. Further analysis of nurses' agency explores how it is shaped by a complex identity and a health system context of constant change.

The study provides in-depth understanding of a little explored health services issue, and is the basis for recommendations to support patient centred and integrated care. The analysis supports the reconceptualisation of patient centred care to consider issues of convenience, as a response to the specific context of nurse-led PHC in South Africa. The study also introduces a structure-agency theoretical framework that can be applied to the context of nurse-led PHC.

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Abbreviations and acronyms

ART	Anti-Retroviral Treatment
CHW	Community Health Worker
EDL	Essential Drug List guidelines
FP	Family Planning
HAART	Highly Active Anti-Retroviral Treatment
HIV	Human Immunodeficiency Virus
HSR	Health Services Research
IMCI	Integrated Management of Childhood Infections
LMICs	Low and Middle Income Countries
LSHTM	London School of Hygiene and Tropical Medicine
NGO	Non Governmental Organisation
NIMART	Nurse Initiation and Management of Anti-Retroviral Treatment
OI	Opportunistic Infection
PALSA	Practical Approach to Lung Health South Africa
PALSA PLUS	Practical Approach to Lung Health and HIV and AIDS in South Africa
PEPFAR	US President's Emergency Plan For AIDS Relief
PHC	Primary Health Care
PLHIV	Person/People living with HIV
PMTCT	Prevention of Mother to Child Transmission (of HIV)
STI	Sexually Transmitted Infection
STRETCH	Streamlining Tasks and Roles to Expand Treatment access
TB	Tuberculosis

UCT **University of Cape Town**

UFS **University of the Free State**

VCT **Voluntary Counselling and Testing**

Introduction

Antiretroviral treatment and HIV care in context: Nurses in South African PHC

Sister Vermaak knows how many patients come to the clinic to get their antiretroviral treatment for HIV (ART); there are 411 ART patients currently registered at the clinic. Christen Primary Health Care clinic (PHC) provides ART to a rural township in the Free State province, South Africa. The availability of ART in the clinic results from a combination of strategies being implemented across many low and middle income countries (LMICs): decentralisation of ART to lower level health facilities, integration with existing programmes and then task shifting of responsibilities for care to nurses. The Free State province has pioneered this experience of developing ART and HIV care access. This experience focuses on trial to increase nurses' role in the delivery of ART and HIV care. The STRETCH trial – Streamlining Tasks and Roles to expand access to Treatment and Care – is a randomised controlled trial of a complex health intervention, culminating in nurse-led delivery of ART in PHC facilities. As a result of the trial nurses are initiating and prescribing ART, and then also providing other aspects of HIV care like Voluntary Counselling and Testing (VCT). For those 411 people in Christen clinic these processes and interventions are now, arguably, transforming the experience of HIV from having to manage rapidly declining health and ultimately death, to living with a chronic disease.

Sister Vermaak and the other nurses in the clinic are perhaps used to the 411 patients on ART being of interest to visiting researchers like myself and from Department of Health officials, yet there are many other concerns for a PHC nurse. Amongst the people waiting for ART are others sat in a long queue for preventative care: vaccines for their children, antenatal care or family planning. People also come for care for TB, diabetes, hypertension, sexually transmitted infections (STIs) and for the many minor ailments and injuries that afflict populations anywhere, but which perhaps beset this group of people more, owing to the setting in which they live: an unequal society in which the social determinants of health are notoriously damaging (Bradshaw, 2008).

ART and HIV care are just one part of PHC. They may take on enormous significance for individual patients, nurses and researchers at varying times, but they are still part of a package of services that are delivered day in, day out. This study focuses on this day to day process of organising and delivering PHC. The everyday routines of a clinic do however lead

to extraordinary outcomes or events of social significance: health restored and maintained, professional satisfaction and happiness, or the generation of physical abuse and fear. The global policy discourses that underpin ART access in PHC clinics like Christen and many others are ultimately made real through these clinic-level routines and the repeated actions of professional nurses and other health workers (Lewin, 2004).

There is evidence that the introduction of ART and HIV care in to PHC has led to positive outcomes for patients, with initial reports that nurses are able to effectively provide ART and HIV care (Fairall et al., 2011). However, there is little understanding of how PHC is organised and delivered in the context of ART and HIV care. The everyday routines through which care is provided are crucial to understanding treatment success, owing to their influence on patient satisfaction, and so adherence and retention in care. Understanding these routines is important for ART and HIV care in particular owing to the ongoing need for monitoring and support, but also for other chronic conditions that are an increasing priority for PHC. Exploring the organisation and delivery of care has also been given greater importance by the suggestion that the availability of ART is motivating nurses to provide more patient centred care (Stein et al, 2007), marking a shift from patterns of care characterised by a narrow, biomedical and task oriented approach (Van Der Walt and Swartz, 2002). In parallel, others warn that ART scale-up could undermine care owing to the complexity of the programme and health system demands, and the potential for diversion of staff and resources from other programmes and health priorities (Schneider et al., 2006, Steyn et al., 2006, Chopra, 2005a) or further task orientation in care delivery as task shifting is expanded (Church and Lewin, 2010). The introduction of ART and HIV care therefore has the potential to profoundly impact on care, yet an understanding of how care is organised and delivered is lacking.

Understanding the organisation and delivery of care

This study responds to the gap in understanding around the organisation and delivery of PHC following the introduction of ART and HIV care. I first of all seek to describe how PHC is organised and delivered in the context of ART and HIV care. I then try to explain these care routines, through giving insight in to the underlying social processes involved. The study

aims to develop knowledge that can inform health services policy debates through the development and application of broader social theory.

The study is set in the Free State province in South Africa. The STRETCH trial of nurse-initiated ART was an opportunity to explore PHC as ART and HIV care is introduced. Through institutional links with the University of Cape Town I was able to spend significant parts of 2009 and 2010 within clinics involved in the trial. From a base in the city of Bloemfontein in the Free State I focussed on four clinics, two involved in the STRETCH trial that had nurses providing ART, and two non-trial PHC clinics that didn't provide ART, but provided routine aspects of HIV care (i.e. HIV testing, treatment for opportunistic infections). This was a chance to see ART and HIV care in context, and to see how ART and HIV care formed part of the broader PHC focus of clinics. I used a multi-site, mixed methods observational approach, based on ethnographic principles; I observed the daily practice of clinics and interviewed nurses and those receiving care, as the basis for a detailed understanding of how care is organised and delivered. I draw on literature and methodology from the sociology of health, health services research and social theory more broadly as a framework for understanding the nature of care.

PHC, ART and HIV care: the limits to patient centred, integrated care and nurses' agency

The principal study findings are that care routines in the clinics studied show important elements of a patient centred, integrated approach, but this is also limited by other aspects of care. ART and HIV care is provided through similar routines to the rest of PHC, but shows some differences by being at times more patient centred. This difference in care supports the suggestion that ART and HIV care may be supporting a shift to more patient centred care (Stein et al, 2007).

These care routines involve specific social processes. I argue that these care routines are shaped by a combination of nurses' agency, clinic orders of interaction and contextual factors including health systems policy and resource shortages. Although nurses' agency to shape care routines is influential, it is limited, leading me to conclude that nurses have the capacity to conduct care (Latimer, 2000). I go on to elaborate on this analysis of nurses'

agency. I explore nurses' complex identity to understand the range of motivations and pressures that are involved in this exercise of agency. My final area of analysis explores the nature of the response to the introduction ART and HIV care; I argue that the differences in care routines reported, indicate a response of a slight change in care. Exploring this slight change in care gives insight in to the constant change and uncertainty in the health system context in South Africa and how it shapes nurses' agency.

My discussion of these findings leads to conclusions relating to theory development and health services policy. I suggest a conceptualisation of patient centred care that responds to the specific context of PHC, in that it addresses the broader dimensions of care beyond the consultation. I also develop understandings of nurses' agency and power as it relates to care. I then suggest a number of policy implications related to supporting more patient centred and integrated care.

The chapters that follow set out how I implemented the study and the findings. Chapters 1 and 2 in Section 1 describe the study context and theoretical basis for the study and then the study methodology. Section 2 has four chapters that present the results of my analysis. Chapter 3, the first of these, presents an account of how care is organised and delivered. In chapter 4 I explore the underlying social processes involved in the care routines, with chapters 5 and 6 further developing this analysis by exploring nurses' complex identity and then the nature of nurses' response to the introduction of ART and HIV care. Chapter 7 discusses these findings and develops theory and policy implications.

Section 1 – Research focus and design

In this first section of the thesis I describe the rationale and approach for the study. In chapter 1 I first provide the context for the study: South Africa and the Free State province, as well as the STRETCH trial that is introducing ART and HIV care to PHC and which the study links to. I then *conceptualise the organisation and delivery of care* and introduce the need for study in this area. I finally consider literature that I draw on in my later analysis, focussing on interactionist and structure-agency theory.

Chapter 2 outlines the study methodology, discussing the study design, and then the specific strategies for generating and analysing data in the clinics I worked in.

Chapter 1 – Study background and literature review

1 Introduction

This chapter reviews the organisation and delivery of PHC nursing, including ART and HIV care, in South Africa and other LMICs, in order to understand its context, its nature and theoretical approaches to studying it. Through the chapter I make several key points that form the rationale for the study and are the basis for my analysis and conclusions: 1) there is an increasing knowledge of ART and HIV care in terms of its clinical outcomes, but little understanding of how PHC is organised and delivered following its introduction; 2) the organisation and delivery of care in LMICs is itself an under-conceptualised field, relating to a general neglect of PHC nursing care in LMICs, and 3) a theoretical approach that allows focus on interaction between clinic actors and the dynamics of structure and agency these are set within is useful for exploring the organisation and delivery of care.

In establishing these points I first explore the study context, the STRETCH trial in the Free State province and the broader policy changes that relate to this. Second, I describe the need to study the organisation and delivery of care and the current evidence available, relating this to the overall study aim and presenting this as the first objective, to describe care. Third, I explore the social theory that has been used to explore related issues, and outline a theoretical approach drawing on interactionist and structure-agency theory which frames my analysis in later chapters, relating this to the second objective of the study, to explain care. I conclude the chapter with a summary of the study aims and objectives.

1.1 Challenges and transformation: PHC and HIV in South Africa

A specific context of resource shortages and a health system facing a range of social and political challenges has shaped the need for PHC and the nurses working there in South Africa, and other LMIC settings, to adopt a central role in the delivery of ART and HIV care. The STRETCH trial in the Free State province is focussed on these changes. In this section I explore the context of the Free State, the state of PHC, the role of nurses and then the specific characteristics of the ART and HIV care programme in the Free State, as a basis for identifying the specific study focus.

1.1.1 The Free State province

The Free State province is landlocked and in many respects remote, but it has nonetheless been pivotal to South Africa's modern history. The area that is now known as the Free State province was originally settled by a number of groups of people, but principally the Sotho, before European settlement. White settlers, including Afrikaaners, travelling from the Cape Colony, the area around Cape Town, established farms and settlements in the area.

Following conflict between Afrikaaner immigrants, Sotho kingdoms and British imperial forces an Afrikaaner republic called the Orange Free State was established in 1854 (Beck, 2000). The Orange Free State eventually became part of the Republic of South Africa and after the removal of the apartheid government became the Free State province.

As with the rest of South Africa, the Free State can be characterised by division and exclusion of the black population from many of the benefits of economic growth and industrialisation; although not the downsides of these processes. The Free State province is mostly rural, with a focus on farming and mining, which have profound influence over broader socio-economic trends: dispersed rural populations, migrant labour and low wage work. Inequality is clear to a visitor. My own experience of living in Bloemfontein, the provincial capital, illustrates this: I lived in a predominantly white neighbourhood, where the local shopping centre took the name of an Afrikaans cultural icon. Houses were ringed by barbed wire, or patrolled by dogs. The peripheral townships populated, apparently exclusively, by black people were some distance away. There was integration within the central business district, but it was still apparently normal for someone to share a racist anecdote with me when I was getting my car fixed. These outcomes can be linked to historical processes of Apartheid, although what is perhaps less commonly recognised is the long historical roots of racial division and impoverishment through colonial and imperial rule (see Thompson, 2001). Full historical exploration of first Dutch and then prolonged British intervention (and exploitation) is not necessary for this study; recognition that division runs much deeper than recent Afrikaaner nationalism is important in establishing the complexity of social identity and relationships.

It is problematic to discuss South Africa solely in terms of inequality and division, despite their intuitive use. Firstly, using this discourse risks perpetuating or simplifying division. The

study does make use of problematic terms to describe people: black, white and Afrikaans, for example. Societal division characterised along these lines has underpinned much violence and injustice, as is clear from any account of South Africa's history. I will use them, recognising they are problematic, but that none the less they are still an important part of the daily discourse in South Africa; furthermore, they can still play an important part in sociological accounts of South African society, with a distinction between this use and that of the apartheid authorities being the recognition of the constructed nature of race rather than it being an essential property (Erasmus, 2008). Framing study in South Africa around these divisions also risks presenting South Africa as 'strange' and not comparable to other settings. Fassin (2007) argues that the experience of South Africa, although 'singular' (ibid., pxi), should be seen as part of a common world with 'convergences and confrontations' (ibid., pxii). Mamdani (1997) is more specific, in actively rebutting South Africa's apartheid history as 'exceptional', instead seeing it as part of the experience of other countries across Africa of indirect colonial rule.

Through my time in the Free State and on previous visits to South Africa I have tried to see it as Fassin and Mamdani implore. Initially it seemed awful that poverty on such a scale could exist in such geographically specific areas and for such a specific group of people; the contrast is appalling. However, the contrast between my own current life in north-east London, and before that in north-east England, with many in the Pakistani or West African communities in these areas is less extreme, but still very real, and also appalling. This is not to downplay the uniquely awful aspects of the history of South Africa and the Free State, but to see the forms of action and behaviour in South Africa as experiences that can still relate to other contexts. This also applies to health care settings. Long queues of patients at 7:30am are common in South African PHC clinics; I have also seen them outside hospitals in east London. Nurses are seen as neglecting patients in South Africa, and this is the same in the UK. This is not to downplay the uniqueness of South Africa, but to draw attention to how similar processes across contexts points to the influence of common, perhaps mundane, social factors as having influence. The horrors of apartheid and colonialism are a significant factor in much of contemporary South Africa, but they can't be seen as entirely determining action.

1.1.2 Change and crisis in PHC

Across South Africa 5.6 million people live with HIV, making it the largest HIV epidemic in the world (UNAIDS, 2010). By the middle of 2011 1.4 million people had initiated ART there (Day et al., 2012). This is, incredibly, only one part of a 'quadruple burden of disease' faced by the country; sitting alongside other diseases and conditions relating to poverty and under-development, chronic diseases and injury (Bradshaw, 2008). The outcome of this burden has been a decline in the health of South Africa over the last decade (Bradshaw, 2008), with average life expectancy falling from 57.0 in 1996 to 51.6 for women and 48.4 for men by 2007 (48.0 for women and 45.2 for men in the Free State) (Day and Gray, 2008). A quadruple burden of disease is one outcome of the dislocation, violence and alienation of contemporary South Africa society. These statistics give some indication of the context and work facing the nurses trying to provide primary health care services.

Post-apartheid health reform

South African Health Minister Dr Aaron Motsoaledi has described the South African health-care system as 'very expensive, destructive, unaffordable and not sustainable' (WHO, 2010, p803). The origins of this system lie in a combination of the apartheid system, inadequate implementation of new policy as well as poor policy. The health system inherited by the post-apartheid government in 1994 was characterised by extreme inequality in access to services (Gilson and McIntyre, 2007) owing to a legacy of care allocated according to power, rather than need (Van Rensburg, 2004a). A legacy is well funded tertiary care (Chopra et al., 2009) but a neglect of rural areas and of preventative care (Sanders and Chopra, 2001). Post-apartheid reform placed primary health care at the core of South African health policy (Department of Health (SA), 1997), making it the underlying philosophy (Van Rensburg and Pelsler, 2004). This reform also included the introduction of free primary health care (Walker and Gilson, 2004) and then other initiatives like the introduction of a patients' rights charter (Van Rensburg and Pelsler, 2004). However, reform has been inhibited by inadequate implementation of new policy due to flaws in state bureaucracy (Schneider and Stein, 2001) and so 'the promise of PHC in South Africa remains largely unfulfilled' (Kautzky and Tollman, 2008, p18).

The scope of PHC

PHC is both a philosophy and strategy (Van Rensburg, 2004c) referring to principles of equity, solidarity and responsiveness to need (WHO, 2008b) but also as the first point of contact and first level of care (Frenk, 2009). In South Africa PHC is principally provided through fixed clinics, i.e. not mobile, of varying sizes and staffing (Van Rensburg, 2004c). In the following chapter I describe the Free State clinics I worked in with some depth, but they were all of a similar size and located within or immediately next to specific communities and locations that they served. The provision of PHC at these clinics focuses on a 'comprehensive service package' (ibid). This is a standardised set of services to be provided at the PHC level and that should be delivered in a holistic way, i.e. not separate vertical programmes but part of a 'one-stop' approach (Van Rensburg, 2004c, p422). These services, as listed out in figure 1.1, largely focus around specific disease areas.

Figure 1.1 The PHC service package

PHC programmes included in the comprehensive PHC service package	
Non-personal health services:	Occupational health, health promotion, environmental health
Disease prevention and control:	Chronic diseases, geriatrics, disabilities and rehabilitation, oral health, communicable diseases
Maternal, child and women's health:	Women's health and genetics, child and youth health, nutrition
HIV/AIDS/STIs and TB:	HIV/AIDS, STIs, TB
Health monitoring and evaluation:	Health information, HSR and EPI surveillance and research coordination
Mental health and substance abuse:	Hospital and community mental health; child, youth, women and family mental health; substance abuse and prevention
Gender issues:	Violence and sexual abuse

Adapted from Van Rensburg 2004

1.1.3 Nurses in PHC

Nurses are the largest cadre of health workers in South Africa: with fifty six thousand professional nurses, twenty seven thousand enrolled nurses and thirty six thousand nursing assistants working in the public sector in 2011 (Day et al., 2011). The distinction between professional nurses and then enrolled (or staff) nurses and enrolled nursing assistants in South Africa reflects the training programme followed, with professional nurses completing a four year degree or diploma, enrolled nurses two years and nursing assistants one year of training (Van Rensburg, 2004b). Professional nurses are 'qualified and competent to

independently practise comprehensive nursing in the manner and to the level prescribed and who is capable of assuming responsibility and accountability for such practice' (Department of Health (SA), 2008, p5), with enrolled and assistant nurses working under their supervision.

As a consequence of these numbers, nurses provide the bulk of health services in the public sector (Van Rensburg, 2004b) and have been described as the 'backbone' of the South African PHC system (Fairall, 2005, p15), with PHC in South Africa largely considered nurse-based (Kautzky and Tollman, 2008, p22). In the clinics I worked in it is nurses who are central to the provision of care, with doctors and other health workers less numerous and often making infrequent visits to clinics.

The relative numbers and centrality of nurses mustn't however obscure the absolute shortages and pressures facing nursing. Such is the shortage, it has been labelled a crisis by the government (Department of Health (SA), 2008), with current estimates that South Africa lacks 22,352 professional nurses (Department of Health (SA), 2011a). These absolute shortages also include inequities between rural and urban areas (Matsoso and Strachan, 2011). The shortages of nurses represent a range of factors (Department of Health (SA), 2011a) but include migration to other countries, leaving the profession due to dissatisfaction and then also burnout. HIV itself is also an important factor, with estimates that almost 16% of the health workforce are living with HIV (Ncayiyana, 2004). The direct impact of health workers dying due to HIV is compounded by the indirect impact of burnout, frustration, sick-leave and worker attrition caused by high workloads (Marchal et al., 2005). The overall pressures on health worker numbers has led to human resources being considered a bigger barrier than financial resources to efforts to making ART available (Marchal et al., 2005, Stein et al., 2007).

Pressure on numbers sits alongside other challenges for the nursing profession of concerns about the quality of nursing care and its broader image. Government reports have highlighted how nursing is not seen as worthwhile by young people, with nurses no longer being revered in their communities (Department of Health (SA), 2011a). This can be linked to media coverage, like stories recounting how nurses have sent patients away without

treatment (Skade, 2010) and stories of misconduct and incompetence (Oosthuizen, 2012) with nurses portrayed as culprits (Meiring, 2010). These negative images and conceptions of nurses are not a recent phenomena however; nurses have long faced unpopularity in their communities, reflecting their perceived role in the functioning of the apartheid state (Marks, 1994).

1.1.4 The ART and HIV care scale-up: decentralisation, integration and task shifting in PHC

In this context of a PHC system facing challenges and then a range of pressures on nurses, South Africa is seeking to make ART and HIV care available across the country. Important context for this is the delay and denial of the South African government in adopting and implementing a comprehensive response to HIV. Oversight and distraction by other issues under the Mandela administration morphed in to denial of the problem by the Mbeki administration (Kautzky and Tollman, 2008, p25). Despite currently rapid moves to make ART available, the initial delay has made the problem all the more urgent. While ART is commonly the focus for these debates, my study is also concerned with HIV care more broadly, which encompasses the process of testing for HIV, and pre-ART care such as regular monitoring of HIV and treatment of other opportunistic infections. I outline here the policy response and interventions involved in this scale-up of ART and HIV care.

The first phases of the ART programme focussed on hospital based care, with government policy restrictions and the initial costs of drugs making these programmes small scale. Doctors were central, being the health workers who initiated and prescribed ART, albeit with nurses referring patients and providing initial stages of HIV care, such as counselling and HIV voluntary counselling and testing (VCT). Providing ART through doctor and/or hospital focussed models of care faced problems of a lack of doctors (Colvin et al., 2010) leading to bottlenecks and low coverage of ART, with many dying before they could start ART (Fairall et al., 2008b). The rising demand and challenges of a fragile health system in South Africa and elsewhere led to demands for new strategies for providing ART (Calmy et al., 2004, Van Damme et al., 2008, Van Damme et al., 2006). In response to these challenges of access and supply of doctors the Free State province Department of Health sought a bigger role for nurses in providing ART (Uebel et al., 2011).

Nurse led ART and HIV care: PALS PLUS and the STRETCH trial in the Free State province

The Free State province's efforts to increase nurses' role in ART and HIV care have focussed on two interventions, both subject to controlled trials: PALS PLUS and STRETCH. Practical Approach to Lung Health and HIV and AIDS South Africa (PALS PLUS, see appendix 1) is a programme of in-service nurse training linked to the use of guidelines on the diagnosis and treatment of common respiratory diseases and HIV and AIDS (Fairall et al., 2005) . PALS PLUS was the subject of a controlled trial involving 15 clinics in the province during 2004-2005. Trial results have demonstrated improvements in client care, with TB detection and prescription of antibiotics as part of routine HIV care both increasing (ibid.). The PALS PLUS programme is now being implemented across all nine provinces in South Africa (KTU, 2012). By February 2012 16,161 health workers across South Africa had been trained on PALS PLUS, in 1,746 health care facilities (KTU, 2012).

The STRETCH trial builds on PALS PLUS. STRETCH is an intervention to support nurse-led ART (Fairall et al., 2008a) which involves provision of a clinical guideline, training, and redefining clinical roles (KTU and DoH, 2007). PALS PLUS is a prerequisite for training for nurses aiming to initiate patients on ART (KTU, 2012), with nurses using a clinical guideline adapted for initiation and prescription of ART. The programme allows doctors to focus on clients with complex needs; specialist HIV nurses to initiate, monitor and prescribe ART; generalist nurses to undertake pre-ART HIV care and for community health workers (CHWs) to foster community awareness of the programme, including drug readiness training. The trial focussed on 31 clinics, with 16 included in the intervention with nurses initiating and prescribing ART and then 15 control clinics (that remained with a doctor led model of care) (Fairall et al., 2008a). Figure 1.3 overleaf summarises these roles in the STRETCH programme, as compared to a doctor led model of care, and then with sites without ART.

The STRETCH intervention represents a combination of processes of decentralisation from hospital to primary care level, integration with existing services and task shifting of responsibility. Decentralisation is the transfer of responsibility to peripheral levels (McIntyre and Klugman, 2003); in this case, care being shifted from hospitals to PHC clinics. Integration is the combination of service functions, with the aim of providing services

packaged together (Briggs and Garner, 2006); in this case, the integration of ART and HIV care (understanding that as a service) with other services, such as TB, hypertension or diabetes care. Task shifting is the redistribution of tasks among healthcare teams, with tasks moved to health workers with shorter training and fewer qualifications to make more efficient use of available human resources (WHO, 2007a); in this case, responsibility for initiating and prescribing ART from doctors to nurses. The overall effect of these policies is to place nurses at the centre of providing ART and HIV care in South Africa.

Figure 1.2 Primary Health Care nurses and their roles in HIV prevention, treatment and care in the Free State province

Delivery model	'Nurse-led' model PHC ART in STRETCH	'Doctor-led' model PHC ART	Non-ART PHC site
Possible roles	Doctor Initiation and on-going monitoring and prescribing of ART for clients with complex needs	Doctor Initiation and on-going monitoring and prescribing of clients with ART	
	Specialist ART Professional nurse Initiation, on-going monitoring and prescribing of clients on ART without complex needs		
	Professional nurse HIV testing, counselling, treatment of OIs, routine care	Professional nurse HIV testing, counselling, treatment of OIs	Professional nurse HIV testing, counselling, treatment of OOs, refer to HIV treatment site
	Enrolled/Staff/Auxiliary nurse As for prof nurse, under supervision	Enrolled/Staff/Auxiliary nurse As for prof nurse, under supervision	Enrolled/Staff/Auxiliary nurse As for prof. Nurse, under supervision
	CHW Drug readiness training, community awareness	CHW Community awareness, home based care	CHW Community awareness, home based care

Results from the STRETCH trial emphasise that nurses can effectively provide ART at the PHC level (Fairall et al., 2011). This positive role for nurses is supported by evidence from other settings in South Africa and across LMICs that are implementing strategies centring on integration, decentralisation and task shifting that increase nurses' role in ART and HIV care. (Sanne et al., 2010, Wood et al., 2009, Colvin et al., 2010, MSF, 2009, Ford et al., 2006, Shumbusho et al., 2009, Vasan et al., 2009, Assefa et al., 2012). In the context of health systems in South Africa and elsewhere facing pressures of health worker shortages and high demand for ART and HIV care these strategies for increasing nurses' role are initially producing positive results and offer much promise.

1.2 The organisation and delivery of PHC in the era of ART and HIV care

In this section I turn to explore how, despite compelling evidence around good clinical outcomes for patients related to nurses' roles in ART and HIV care, there is a lack of clear understanding of how care is organised and delivered. This gap comes despite the organisation and delivery of care having implications for patient experiences and satisfaction, and in turn on adherence and overall care outcomes. It is this that I set out to explore in this study. After conceptualising the organisation and delivery of care, and then outlining literature in this area, I demonstrate the need for research in this area.

1.2.1 Conceptualising the organisation and delivery of care

Nursing is often understood to focus on caring (Mortimer, 2005), which is seen as *distinguishing nursing from medicine and its focus on diagnosis and treating* (Walby and Greenwell, 1994). Despite the apparent centrality of this concept to nursing, there are *ongoing struggles to define and theorize care* (Mortimer, 2005). Caring has been described as 'acts, conduct and mannerisms enacted by professional nurses that convey concern, safety and attention to the patient' (Greenhalgh et al., 1998, p928). Caring can also be seen as a process of emotional labour, involving nurses managing their emotions and outward appearance in order that patients feel a required emotional response (Smith, 1992, citing Hochschild, 1983); with some then linking emotional labour to the *practice of biomedicine* (Fitzgerald, 2008). Alternative approaches see care as centring on a sustained relationship with patients (Davies, 1995 citing Graham, Finfgeld-connett, 2008). *Challenges in defining*

nursing and care reflects how nursing is diverse and the product of situated interactions (Allen, 2001); correspondingly, nursing cannot be reduced to a universal list of tasks. One outcome of this recognition of diversity is of the need to define and understand nursing care locally, and through this study I will approach nurses' care as all activity nurses do in providing services and attending to patients.

To understand the organisation and delivery of care from a sociological perspective means to understand how the aspects of care are arranged in space and time, and the meaning of these arrangements. Care organisation and delivery can be understood at a range of levels: the macro, meso and micro level (Fulop et al., 2001); the macro being, perhaps, the level of a national health system and its governance, the meso level of an individual institution or group of institutions, and the micro being the scale of interactions between health workers and patients at the 'bottom' of the system (Gilson, 2012). At this level, the concern is with patients and providers sharing a clinic space and setting, and of how they act and relate within it, in the process of giving and receiving care. Reflecting the discussion on caring above and as I also explore below in discussing frameworks for the organisation and delivery of care, action at this level can involve a wide range of activity. Rather than seek to define a particular set of actions or tasks, I approach the organisation and delivery of care as comprising specific 'routines, behaviours and ways of working' (Greenhalgh et al., 2004) that need to be understood locally. I see these routines, behaviours and ways of working as repeated patterns of actions. For the sake of brevity, I refer to routines' throughout the study. I explore this conceptualisation of routines through the rest of this section, and contextualise it within specific frameworks.

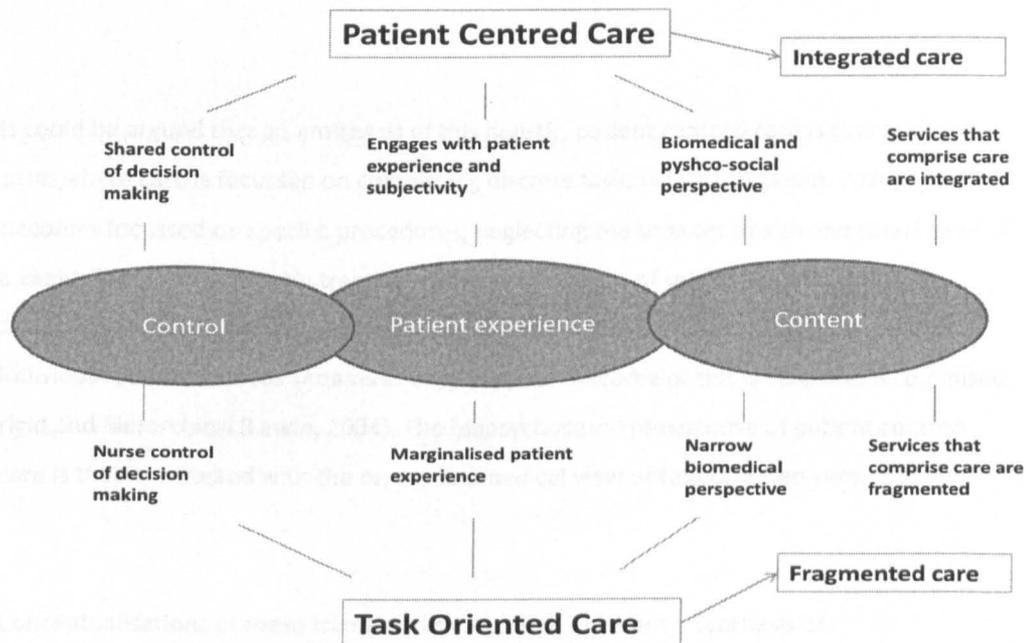
Frameworks for describing the organisation and delivery of care

A range of conceptual frameworks can be used to describe these routines that comprise the organisation and delivery of care, even if they aren't necessarily presented using this terminology. Different approaches have different purposes. Some are abstract and are best understood as broad discourses or paradigms (e.g. quality of care) and only relate loosely to the specific tasks of providing care. Others are intended to provide specific guidance on who should conduct specific clinical tasks, where and when, and principles of how these

tasks should be approached. Others are more analytical and seek to understand underlying patterns within care.

Here I present a framework that I use to describe care in the clinics (see chapter 3). The framework draws attention to key dimensions of care and their characteristics that can be related to care routines. I focus this around the contrasting frameworks of patient centred, integrated care and then task oriented, fragmented care, and the core overlapping dimensions of patient experience, control and content of care. In particular, I draw on conceptual work in the area by Church and Lewin (2010), Mead and Bower (2000) and Bensing (2000). Figure 1.3 summarises this framework.

Figure 1.3 A framework to describe the organization and delivery of care



Patient centred and task oriented care

Patient centred care is a dominant paradigm within literature on organising care (Bensing, 2000). This broad philosophy of care centres on sharing control of consultations and decision making, and focusing on the patient as a whole person rather than reducing them to a body part or disease (Lewin et al., 2009). Although it has a range of meanings they all emphasise a need for care to centre on an individual patient's needs (Kitson et al., 2012).

These varied meanings reflect the divergent origins of thinking behind patient centred care. Patient centred care has a long history, emerging from early distinctions between patient orientated medicine and illness oriented medicine (Balint, 1969); a distinction that can be seen as distinguishing patient centred care from a biomedical model of care (Mead and Bower, 2000). Key strands of the debate focus on medicine in particular, but it is also central to debates in nursing (Kitson et al., 2012) with equivalent terms of 'person centred nursing' (McCormack and McCance, 2006). The core idea of the nursing process encapsulates these same principles (Smith, 2012) through an approach of nurse and patient identifying problems and their causes together, and then planning and implementing a response (Aggleton and Chalmers, 2000, citing Yura and Walsh, p14). Although evidence linking patient centred approaches to improved outcomes is mixed (Pilnick and Dingwall, 2011) it is linked with increased satisfaction with care (Lewin et al, 2009), which is crucial in fostering adherence and regular care.

It could be argued that an antithesis of this holistic, patient centred care is task oriented care, where care is focussed on completing discrete tasks (Church & Lewin, 2010). Care becomes focussed on specific procedures, neglecting the broader health and social need of a client (ibid) and ultimately treating a patient as a series of unit tasks (Dingwall et al., 1988). It indicates a mechanistic approach to care, with a focus on the task rather than individual patients' needs (Adams et al., 1998). An outcome of this is care that is routinised, rigid and hierarchical (Lewin, 2004). The biopsychosocial perspective of patient centred care is then contrasted with the narrow biomedical view of task oriented care.

Conceptualisations of these frameworks vary. Here I present a synthesis of conceptualisations of patient centred care and task oriented care based around the common ideas of patient experience, control and content of care, including a consideration of integration of care within this last component of content. I review each of these ideas in turn to identify the specific elements that I focus on in my following analysis.

Patient experience

The first dimension I consider is around how care engages with and recognises the patient's experience of an illness and care. Mead and Bower refer to seeing 'the patient as a person', to understand the personal meaning of the illness and so see the patient as an 'experiencing individual rather than the object of some disease' (2000, p1089). This conceptualisation of the patient experience is however narrowly focussed on their experience of an illness, which I broaden to include the patient experience of care, as included in McCormack and McCance's framework (2006), reflecting the broader aim of patient centred care of providing care that address a patients individual needs (Kitson, 2012). Contrasting dimensions of this patient experience can be seen in the patient centred engagement and valuing of the patient experience, as contrasted with the marginalisation of the patient experience in task orientation (see Lewin 2004) with an impersonal, hierarchical and distant approach (Adams et al 1998). In my later analysis I explore how care routines engage with patients, and see them as experiencing individuals, or, in contrast, involve distance and a lack of engagement with patients' experiences.

Control

Control is seen by Bensing (2000) as one of the two core dimensions of patient centred care, referring to the patient's right to decide over interventions. Shared responsibility (Mead & Bower, 2000) and shared decision making (Lewin, 2009) are equivalent to this. The recognition of imbalances in control over care implicitly assumes an analysis of power within a relationship, with power understood as the capacity to act (a concept I explore in section 1.3 below). While an in-depth analysis of power isn't necessary within the framework of patient centred care, it is nevertheless crucial to identify where the focus of power lies, with control understood as the power to act and get others to act. The approach of patients taking, or sharing, control over care corresponds to ideas of patient empowerment. ART and HIV care has been promoted as part of a paradigm of rights and empowerment. This centres on a 'new contract' between clients and providers with non-hierarchical relations (Robins, 2005, Schneider et al., 2006). This shift from a prescriptive to a partnership approach to care (Mayers, 2005) reflects the challenge of supporting a person on ARVs. In my later analysis I explore care routines for evidence of either shared

control or patient control typical of patient centred approaches or the hierarchy and provider centred decision making typical of more task oriented care.

Content

The content of care refers to 'the choice of topics that could, or should be addressed, according to patients' needs and expectations' (Bensing, 2000, p21). This equates to whether care approaches just the biomedical dimensions of patients' issues, or also psychosocial dimensions. A task oriented approach would view care narrowly, focussed on biomedically defined tasks, as opposed to a biopsychosocial perspective of patient centred care. An element of this content of care is how the delivery of care can be organised in to discrete services (see section 1.1.2 above), with services representing a particular disease focussed area of care. While this represents a biomedical orientation to care, it can also lead to a narrow content of care, with care focussing on specific services rather than addressing a patient's full needs. Patient centred care can then be extended and include ideas of integrated care (Church & Lewin, 2010) with efforts taken to combine or link separate services, where care is organised around these. The focus on specific tasks is in turn linked with care that can see services fragmented, where services are separated and poorly coordinated, leading to a narrow range of topics being addressed in a consultation. This overlap between patient centredness and integration is why I have included it in my analysis. In the analysis that follows I explore whether services are combined within consultations and how this links to a division of labour across a clinic, reflecting how as a phenomena it addresses how work is allocated between nurses.

Analysing care

As I summarise at the end of the chapter, I use this framework of patients' experience, control and content to describe care in the clinics studied, and to conclude whether it relates to patient centred, integrated care or task oriented, fragmented care. Framing analysis around these ideas of patient centred and task oriented care reflects their key position in understandings of health care, as well as their past use in analysis of nursing in South Africa as I set out below. Despite the utility of the framework, it also has limitations, which I discuss through my analysis in chapter 3. The principal limitation reflects how these ideas have emerged from either analysis of consultations between doctors and patients, or

hospital based nursing. There is correspondingly a need to develop understandings of patient centred care as it applies to PHC nursing in LMICs. In the following discussion I relate this framework to existing accounts of care, in order to understand the context and need for the study.

1.2.2 Nursing care in the pre ART and HIV care era

The organisation and delivery of nursing care in South Africa in particular, and other LMIC settings generally, has previously been described as task oriented. Here I review literature of care from studies conducted (but not necessarily published) prior to 2004/5 as this was the period when the ART and HIV care programme was initiated on a large scale.

Studies of TB care in PHC services in South Africa focus on this task oriented approach to care. Routines of patients seeing a succession of health workers with care broken in to separate tasks, delivered by nurses at different stations; this 'conveyor belt' indicates a mechanistic approach to care, and creates care that is excessively routinised, impersonal and involves little attempt to engage with patients (Lewin, 2004). Indeed, these routines act to separate nurses from the psychosocial needs of patients (ibid.). Study in similar contexts has overlapping conclusions, reporting how verbal communication between nurses and patients is minimal, with cues from patients hinting at broader problems being ignored and nurses focus on administrative aspects of care (Van Der Walt and Swartz, 2002). The focus of nurses care is ultimately on a disease, rather than the person (Van Der Walt and Swartz, 2002). This narrow focus to care has also been indicated in how care focuses on clinical services rather than health promotion and counselling (Lush et al, 1999). Overlapping with this task orientation is the fragmentation of care in to distinct services. Services are focussed on to particular days, in an effort by providers to control their workload (McIntyre and Klugman, 2003) but with the outcome of limiting the availability of services on particular days (De Villiers et al., 2005) and so requiring patients to potentially make multiple visits to a clinic.

Patients' experiences give further insight. Patients report nurses scolding and insulting them (Fonn et al., 1998), being hostile (McIntyre and Klugman, 2003) as well as being

abusive, physically (Jewkes et al., 1998) and verbally (De Villiers et al., 2005, Abrahams et al., 2001). Such abuse can lead to fear amongst patients and then non-attendance at clinics, as well as frustration and dissatisfaction with care (De Villiers et al., 2005). These problems are then compounded by long waits and problems accessing care (Van Rensburg, 2004c, Davies et al., 2002, De Villiers et al., 2005, Bachmann and Barron, 1997) .

Relating these descriptions of care to the framework just described, these routines can be seen to largely ignore an individual patient's experience of illness and care, involving hierarchical relations with power and decision making invested in providers and a narrow content to care, with little integration of services. These routines in care are not isolated to South Africa. Similar patterns have been reported in other low income settings (Mathole et al., 2005, Lindelow and Serneels, 2006, Archibong, 1999) as well as in high income settings (Maben et al., 2006, Adams et al., 1998). However, there is a need to be wary of negative portrayals of care. Organisations do vary and some clinics provide good care in difficult conditions (Schneider et al., 2006). The relatively small volume of research on the organisation and delivery of primary care nursing in these settings is grounds for caution. A principal concern is that past research cannot necessarily be read as a comprehensive portrayal of practice, with the risk that small samples are the basis for broad generalisations about past characteristics of care. For example, the reference by Jewkes et al (1998) highlighting nurse abuse of patients in South Africa draws attention to an important and previously ignored issue, yet without context there is a danger that the prominence of this reference in a limited field of research places too much emphasis on negative aspects of care (as in its reference in support of a claim of 'rampant mistreatment of patients' (Freedman et al., pS80). Despite the need for caution, the available literature characterises care as being task oriented and fragmented.

1.2.3 Nursing care in the era of HIV treatment and care

In this section I discuss empirical literature reporting on nursing care in LMICs following the introduction of ART and HIV care (and so including the introduction of VCT and routine HIV care before starting ART). A study that guided the focus for this study reported on nurses' accounts of care in the Free State province, South Africa and how the introduction of ART was leading to nurses providing more patient centred care (Stein et al., 2007). Following

initial stages of the ART programme, but before nurses began initiating ART, nurses reported that they were seeking to counsel, support and empower patients and trying to integrate this holistic patient-centred approach in to primary care (ibid). These reports suggested that the ART programme, through motivating nurses, was fostering a shift from task oriented to more patient centred approaches to care (ibid).

A possible shift from task oriented to more patient centred care is also referenced in the context of nurses and voluntary counselling and testing in Kenya, where nurses are being motivated by their new role (Evans and Ndirangu, 2009) and also in Zimbabwe where nurses are trying to improve relationships and support adherence linked to a respectful approach towards patients (Campbell et al., 2012a); accounts supported by patients who report good care (Campbell et al., 2011a). Positive accounts of nurse-led HIV care in South Africa (Cleary et al., 2012) and Ethiopia (Assefa et al., 2012) also support this. Although not specific to nursing, the uptake of patient centred care within HIV care is also reported elsewhere in South Africa (Pienaar et al., 2006). Other specific evidence focuses on both provider and patient satisfaction with the general quality of care (Orner et al., 2008, Amanyire et al., 2010, Wouters et al., 2008), reports of improvements in provider attitudes and relationships (Squire, 2007, Morin et al., 2008) and that care is well integrated (Price et al., 2009).

Alongside positive accounts of care are indications of the continuation of routines linked with more task oriented and fragmented approaches. ART care has been linked with hierarchical, authoritarian provider relationships (Robins, 2008) as well as providers insulting and stigmatizing patients (Squire, 2007) and lacking compassion (Fried et al., 2012) with little progress on integration of services (Mall et al., 2012, Uwimana et al., 2012, Sorsdahl et al., 2010). Further to this, nurses elsewhere have reported concerns about the quality of their care (Evans and Ndirangu, 2011), which links to other challenges of long waits (Were et al., 2008, Wringe et al., 2009). There are also specific reports of task oriented nursing in South African hospital settings (Fassin, 2008). In summary, although there is some evidence of patient centred care approaches this is far from clear.

1.2.4 How is care organised and delivered?

From this conceptualisation of the organisation and delivery of care and the literature in the area two themes emerge: firstly, of historical patterns of care indicating a tendency towards task oriented approaches; and secondly, of a possible shift to more patient centred approaches in the context of ART and HIV care. Understanding how care is currently provided and whether it is following more patient centred approaches relates to a range of priorities, as outlined below, and so is the focus for this study.

Describing how PHC is currently organised and delivered now that ART and HIV care is available is crucial to understanding prospects for patient satisfaction with care, and patient adherence and retention in care. Understanding these routines is crucial for ensuring the success of any health care encounter, but is arguably especially important for ART and HIV care owing to the repeated interaction needed by patients with health care services, owing to the ongoing need for monitoring and adherence support. A continuation of task oriented approaches may ultimately undermine the possibility for successful treatment outcomes. The challenges currently reported in adherence to ART and retention in care programmes (Cornell et al., Dalal et al., 2007, Ferguson et al., 2012) have many causes but addressing the organisation and delivery of care is a key element of this. Understanding the organisation and delivery of care can guide both the ongoing development of ART and HIV care programmes as well as broader efforts to strengthen PHC in South Africa for other chronic conditions.

Although I am not explicitly concerned with understanding processes of change, describing how care is currently organised and delivered and comparing with past research will allow insight in to this. Stein et al (2007) suggested that more patient centred care was the result of nurses' increased motivation, which relates to the meaning and significance ART and HIV care hold for nurses; understanding whether nurses' motivation in relation to care is being maintained, and what influences it, will also be useful to track the ongoing impacts on nurses and how to support them. Understanding how care is currently organised and delivered will also link to policy debates around how the scale-up of ART and HIV care could have significant impacts, with potential for unanticipated results and broader ripple effects. There have been many warnings that ART programmes could undermine already fragile

health systems (Schneider et al., 2006, Parikh and Veenstra, 2008, Steyn et al., 2006, Chopra, 2005a, Philips et al., 2008). Although these reforms could have negative impacts, the ART scale up has also been described as a 'remarkable opportunity' to leverage benefits across the health system through enhancing infrastructure and systems and boosting morale of staff (El-Sadr and Abrams, 2007, p566). Understanding clinic level processes of delivery can inform these broader debates on health system change.

Research in this area will also contribute to conceptual development in what is an under-theorised field. I outlined a framework of patient centred, integrated care above, on the basis of this being a dominant approach within the field, and of how other studies in the area have approached similar enquiry. I orientate the study around this framework, while accepting that it is problematic, owing to its origins in different contexts. An additional issue I therefore aim to address is how ideas on patient centred care and integration can be usefully applied in PHC settings such as those I study.

In this section I have outlined and introduced the aim of the study to understand the organisation and delivery of care and introduced an analytical framework I will use to describe care. In the next section I consider approaches to developing sociological insight in to these care processes.

1.3 Approaches to explaining care

In this section I turn to focus on the second objective of the study, to explain what is involved in these routines of care that my first objective identifies, in terms of the social relationships and processes involved. A theoretical aim for the study is to therefore use sociological concepts to give insight in to the health service and policy challenges just described. In this section I first review the literature that shaped the original study question and initial data collection and analysis. Reflecting the nature of the study phenomena under question, much of this literature involved in-depth qualitative study, including ethnographic approaches. Following in this line of literature, I also adopted a study design based on ethnographic principles. An initial feature of this approach was to identify foreshadowed problems in the literature (Atkinson, 1995): issues to consider as I

began data generation and analysis, rather than a rigid theoretical framework (I outline the methodological choices and basis for this in greater detail in chapter 2). I discuss these foreshadowed problems in the first part of this section. I then move on to discuss a theoretical framework around which I present my later analysis where I seek to explain care. This framework focuses on interactionism and structure and agency, key themes in the sociology of health and illness and social theory. I conclude the section by summarising this theoretical literature and how this informs my analysis in later chapters.

1.3.1 Foreshadowed problems

These foreshadowed problems reflect key themes identified in my initial literature review as explaining patterns in care and of being a potential focus for understanding any changes brought by the introduction of ART and HIV care: nursing identity and culture; nurses' professional relationships with other clinic staff and patients; the clinic context, and nurses' experiences of HIV and ART. Although not resulting from a systematic review of the literature, these themes overlap closely with themes identified in other related reviews; for example, Griffiths (2003). I outline each of these themes, showing how they either provide a theoretical insight in to care processes, or could in turn provide an indicator of wider changes following the introduction of ART and HIV care.

Nurses' professional relationships

Nurses' relationships with patients have already figured as a key conceptual focus in understanding patient centred care; for that reason they will be an analytical focus in this study. The literature discussed in sections 1.2.2 and 1.2.3 above also highlights the frequently problematic relationships between nurses and patients. The introduction of ART and HIV care may also offer specific avenues for this relationship to change, as reported by Stein et al (2007) in their study. A second key relationship for nurses in South Africa is their subordinate position to medicine (Marks, 1994). This subordination and the shape of nursing-medicine relations are also profoundly gendered (Davies, 1995, Walby and Greenwell, 1994) reflecting wider understandings of women's role as 'care-givers' (Benjamin, 2000). This has fostered understandings of nursing as 'anti-academic' and that nurses should remain 'faithful carriers-out of doctors orders' (Dingwall et al., 1988). This

directly influences nursing practice with nurses taught to take orders from doctors and not given the skills to work autonomously (Petersen, 2000). The ART programme and task shifting is a challenge to these existing professional relationships and understandings of nursing practice.

Nursing identity and nursing culture

Patterns of task oriented care in South Africa have been linked to particular aspects of nursing culture and nurse identities. Particular norms and cultural understandings within nursing in South Africa can be linked to poor quality care; for example, understandings that 'proper' work only involves that done publicly (Lewin, 2004), of ill health having individual rather than social causes (Marks, 1994) or where nurses feel abused by the poor conditions of their services and resort to abusing patients themselves (Schneider et al 2006).

Experience from the UK has shown that efforts by nurses to adopt more client-centred approaches to care are frequently 'sabotaged' by the organisational pressures of time or staff shortages and by fellow professionals who socialise nurses into a dominant nursing culture that values speed, efficiency and hard physical tasks rather than talking to clients and offering support (Maben et al., 2006). These norms then become assimilated as particular identities that underpin efforts to create difference and distance from patients. For example, nursing cultures promote understandings of 'subordination' that foster authoritarian attitudes towards patients and understandings of higher social status that underpin a power difference (Petersen, 2000).

The clinic context

The discussion under section 1.1.2 above highlighted the resource shortages facing South African PHC, as for care in many other LMICs. Material conditions of low resources and staff shortages can lead to high workloads within clinics. Specific patterns of care that seek to impose order on what can seem chaotic conditions are the result (Jewkes et al., 1998, Lewin, 2004, Van Der Walt and Swartz, 2002). Other resource challenges can also be a likely cause of stress for health workers. A specific example from the Free State province is of a 'moratorium' on ART from November 2008 to April 2009, as the study was being planned, where no new patients started on ART as a result of over-expenditure of the provincial health budget (I refer to this again through the thesis). More prosaically, the physical layout

of the clinic infrastructure shapes care, with care being done publicly if there are few private facilities available (Lewin,2004) and bureaucratic process of forms and guides can shape consultations (Petersen, 2000).

Nurses experiences of HIV and ART

The notion that ART is inspiring hope and so shifting nurses practice raises the importance of the social dimensions of HIV, and how this too figures in the possibility for wide scale change. ART scale-up has been linked to global discourses of hope (Bernays et al 2007), related to how ART is changing the social experience of AIDS, with people being able to rejoin family life and start work (Castro and Farmer, 2005). In the South African context, there is also the added issue of the past government denial of the link between HIV and AIDS and the unwillingness to make ART available through the public health care system (See above). Without recanting this long history, it is nonetheless important to highlight that AIDS in South Africa has involved an 'epidemic of disputes' (Fassin, 2007, p30). In this context, Stein et al's report of ART inspiring hope is one example of how understanding the meanings nurses attached to ART, HIV care and HIV will be fundamental to understanding care provision.

Nurses' relationships with HIV involves more than a professional concern, with nurses themselves living with HIV. Despite a predicted prevalence amongst South African health workers of 15.7% (Ncayiyana, 2004) there are few programmes to respond to this (Uebel et al., 2007). Furthermore, nurses fear stigma from their own colleagues (De Vries et al., 2011). HIV related stigma is a major challenge in communities in South Africa (Campbell et al., 2005a); that nurses are also involved in relaying this stigma highlights they are a central part of the communities they work with in providing care. This is further supported by nurses usually acquiring HIV through the community, rather than through occupational injury (Uebel et al, 2007). It is clear that biomedical discourses around ART and HIV care are not the only influence on nurses' interpretations of HIV. These personal experiences of HIV are a key consideration through the study, and involve specific methodological steps to try and explore them. I discuss this in further depth in chapter 2 where I set out my methodology for trying to explore the experiences of nurses living with HIV (NLHIV).

These foreshadowed problems provided ways of understanding and focussing on potentially influential social dimensions and process of care. They were a focus for initial data collection and analysis, but not exclusively. Through my data collection and analysis I sought to explore and develop these areas, eventually developing these ideas and others within a broader theoretical framework.

1.3.2 A theoretical framework for explaining care

As I referred to above and explore more in the following chapter, I sought to respond to the specific clinics and ground my analysis in the data I generated, holding the foreshadowed problems just described in mind, but also seeing what other issues emerged. I adopted a theoretical approach synthesising interactionist and structure-agency theory. This seeks to understand social phenomena from the view of social actors, and sees actors as having agency and specific relationships with structure, the latter not being entirely determining. This approach responds to an overarching question or problem I posed to myself throughout the study: what level of influence did nurses have over the clinic routines? Were their actions shaped by the resource shortages that were widely discussed by both the nurses, and in wider literature? And how could this be understood with relation to notions of compassion and other meanings attached to care? This problem reflects the longstanding sociological issue of how to understand 'bad' outcomes, in the context of 'good' intentions (e.g. Garfinkel, 1967); how to understand the precise role of nurses – their agency - power, control and compassion together at the same time? A question that, I argue, cuts to the heart of nursing. In short – what is nurses' agency with relation to these routines?

The approach I outline here, and build on in my analysis in chapters 4,5 and 6, focuses on key theoretical concepts of interaction, structure and agency. The synthesis of the literature I set out here is the result of iterative consideration of existing literature and my data and how they could usefully combine. My study question of whether care was patient centred or not automatically involved sensitivity to issues of power, owing to the prominence of concepts of control in this literature, as discussed above. Another theme that shaped my approach is the influence of health workers in shaping and translating health system processes in implementation (Blaauw et al., 2006, Walker and Gilson, 2004,

Rajaraman and Parker, 2008). As analysis progressed I explored these initial themes with reference to two areas of literature: the first, interactionist study of healthcare, and then secondly, structure and agency in social theory generally, and as used in development studies in particular. The framework that emerged from this, and which I discuss below, is a pragmatic synthesis of these areas of literature. It provides a way to present key aspects of my data in a coherent way, and in the process point towards possibilities for a fuller synthesis of these areas of literature. I introduce this framework by exploring interactionist theory, before moving on to discuss structure, agency and power.

Healthcare as interaction

The role of interactions in healthcare institutions is a key theme in ethnographic studies of health (Bloor, 2001). These interactionist approaches see healthcare as constructed at the micro-level through everyday social interaction, rather than being a social fact that acts to determine action (McDonnell et al., 2009). An implication of this perspective is of social actors continuously establishing and renewing the tasks they perform and relationships with others (Friedson, 1976). Interactionist approaches have been used extensively to understand the organisation and delivery of health care and related services (Strauss et al., 1963, Dixon-Woods et al., 2006, Atkinson and Housley, 2003, Strong, 2001); I follow this tradition to explore how nurses, and other actors, are involved in producing and shaping care routines.

Interactionism approaches social action as guided by the meanings people attach to them (Hodson and Sullivan, 2008). A frequently cited demonstration of the importance of meaning for understanding social action is in Ryle's distinction between a twitch and a wink (Geertz, 1973) and how understanding the meaning attached to the movement of an eye is crucial to a full understanding. Action and interactions do have meanings, but they are not however linked in a straightforward way, or 'behaviour and belief are not always synonymous' (Moore and Sanders, 2006, p11). People do have beliefs and these do relate to action, but people can act without an awareness of beliefs or have conflicting beliefs (Benton and Craib, 2001). There is therefore a need to be cautious in understanding how these meanings relate to acts, and to see them as conditioning acts (Scott, 1985) rather than directly producing them.

Interactionist approaches focus on the actions of individuals, but this is not to assume that there is complete freedom to act. There are in fact patterns in interaction, with rules of conduct (Dixon-Woods et al., 2006). These rules are 'shared understandings' (Strauss et al., 1963). Rules here can therefore be seen as corresponding to understandings of culture and identity, raised earlier as foreshadowed problems for the study. This knowledge of what is socially acceptable or proper behaviour has also been referred to by Goffman as presenting particular social 'orders' (Burns, 1992). Strong's (Strong, 2006a) analysis of doctors' consultations is an example of analysis of these rules of behaviour, where he sees that in consultations doctors have the role 'experts' and mothers as 'good'; it is that both follow these roles that the consultations is accomplished smoothly, with both working to exclude anything that would undermine these roles. I follow Strong further in how he develops Goffman's idea of social encounters having a ceremonial order, with his conceptualisation of there being multiple orders. Strong (ibid) sees consultations as having a bureaucratic format, charity format or private format. In my later analysis I build on this idea of rules forming an order, and of there being multiple orders.

These rules of interaction express power relations (Dixon-Woods et al., 2006, citing Goffman) with orders linked to a balance of power (Strong, 2006b). In the analysis cited above of consultations with a doctor, doctors have a position of authority but this varied according to the patients, with patients often adopting a passive role but also able to in certain orders influence doctors (ibid). Interactionist approaches tend to view power as disbursed, a more nuanced approach than that of understandings of medical dominance (Nugus et al., 2010) that arguably frame much analysis of healthcare in low and middle income settings (Sheikh and Porter, 2011); approaches that others have seen as simplistic (Mosse, 2005). This conceptualisation of power rests on Foucauldian perspectives of power being exercised in relationships and not a property people possess, and that power is productive as well as repressive (Mulcahy et al., 2010).

A widely cited idea in interactionist study is the idea of care as a negotiated order (Strauss et al., 1963). This theory sees care routines emerging through negotiation, in interaction, amongst health care actors, whether doctors, nurses or patients. The implication of this

negotiation is of clinic level routines involving processes of bargaining and struggle. Some have suggested limits to the utility of ideas of healthcare involving a negotiated order; with suggestions that analysis of medical dominance isn't allowed for (Regan, 1984) and correspondingly the role of compulsion or coercion in interaction (Svensson, 1996). Both these critiques seem to rely on an excessively literal interpretation of 'negotiation', based on a dictionary based definition grounded in open bargaining. Strauss's original conceptualisation does allow for tension (Strauss, 1978) and so instead sees negotiation as a broader sociological process, grounded in interaction. I do not dismiss the idea of negotiation -it provided an initial conceptual guide for the analysis I discuss later - but instead present the idea of nurses' conducting care (Latimer, 2000) as a useful development of the idea of a negotiated order. Latimer argues in an ethnography of nursing practice in a UK hospital that nurses are central to ward organisation, yet they are constrained, leading to the metaphor of an orchestral conductor. Latimer's analysis was not intended to evolve negotiated order ideas, with Strauss's work and ideas of negotiated order not referenced. However, I argue that it retains the core ideas of a dynamic network of relations in which interaction takes place, with rules of action formed amongst them, but allows for a more focussed understanding of agency suitable for this setting and work of nurses. I return to this concept below, in discussing structure and agency.

Structure and agency: interaction in context

Interactionist approaches have been criticised for neglecting the role of structural factors in shaping social action, with the implication that action can be understood as driven by the individual (Regan, 1984). Alternatively, some analysis has been seen as dealing with structure as 'vague context' and not meaningfully integrating structure with analysis (Pappas, 1990, p199). Early iterations of my analysis that I present later in chapter 4 were vulnerable to this critique: they lacked a consideration of broader influences on nurse action; I focussed on interaction and meaning and treated the clinics, implicitly, as isolated from the outside world and that nurses were free to shape the routines in the clinics.

A neglect of structure in interactionist work isn't inevitable however. For example, leading theorists in interaction work like Strauss et al engage with structural issues, through conceptualising negotiation as happening in structural contexts (Regan, 1984).

Nonetheless, a critical focus on interaction does bring a micro-scale orientation to analysis, which can potentially neglect the role of structural factors. My theoretical framework therefore takes care to centrally draw in structure to an analysis of interaction and agency. An effort to combine interactionist and structure-agency theory is not novel (Fine, 1993, Dixon-Woods et al., 2006), and I do it with caution, reflecting how concepts of structure and agency are arguably already present in aspects of interactionist study (Atkinson and Housley, 2003). My approach therefore is to use structure-agency theory to supplement or frame the areas of interactionist thought I have already discussed above, and on the basis that this particular combination of approaches usefully guide analysis of my data, rather than necessarily offering theoretical innovation.

In setting out this synthesis I first of all discuss structure, and the two structural dimensions of rules (linking back to rules of interaction) and then context. I then discuss agency and relationships of power (again, linking back to power in orders of interaction as above). I finally discuss structuration: how agency and structure combine.

Structure

Structure is a central feature of much social research, especially in health. Notions of structure as political and economic factors at the macro level that shape health outcomes are prominent (e.g. WHO, 2008a). Structure usually refers to social institutions or 'systems', 'forces' or 'currents' and 'regular, relatively fixed, objective, and generalised features of social life' (King, 2005, p215). These understandings of structure are evidently broad, and a tendency towards a lack of conceptual clarity perhaps understandable. Social theory focussing on this field has resolved this in part through distinguishing between different levels of structure. Strauss (1978) distinguishes between negotiation context and structural context. Giddens (1984) distinguishes between rules and resources and more recent approaches like that of Long (2001) between field and arena. These efforts in varying ways seek to understand the constraints on individual action, and overlap to a considerable degree. Drawing from this literature I conceptualise two dimensions of structure – orders of interaction and context – which I discuss in turn.

(Structural) orders of interaction

I build here on my earlier conceptualisation of how interaction involves rules, which in combination can be understood as forming an order. The association between rules as I discussed above in shaping interaction and as a structural phenomena is more than a convenient overlap in terminology. For Giddens, rules refer to procedures of social interaction (and cites Garfinkel, a key interactionist thinker) (Giddens, 1984, p18). These rules forming orders I discussed above can therefore be seen as structuring social action, in that they provide an established way of acting in social encounters. These rules are followed, because they are the established norm. In my later analysis, I explore how the clinic routines I describe are produced in action by agents following rules as part of orders of interaction, which provide structures of norms and understandings that guide action.

(Structural) context

The idea of structural context I adopt closely reflects Strauss et al conceptualisation, of structural context being what negotiations (i.e. interactions) are situated in (Strauss, 1978), and so includes negotiation context, but each can influence each other (ibid). This then implies a macro-level, or higher order, understanding of structure, distinct from the structural rules of action. Giddens has a related conceptualisation of resources as a key element of structure, alongside his conceptualisation of rules (1984). These resources can be 'material, symbolic, cultural, cognitive or discursive' (Atkinson and Housley, 2003, p172). I avoid Giddens's terminology of resources for two reasons. A first, minor, reason is that in the context of resource shortages, confusion is likely when referring to resources as social structure. A second, major, reason, is that in Giddens' approach the notion of there being macro structures that can profoundly circumscribe local level action is not clear, when he says how these resources are the basis for power and for social action (1984). This reflects caution based on critiques of Giddens as having an optimistic view of agency of being able to overcome constraints (Cleaver, 2007 citing Greener). Although I see structural context as being made up of material, symbolic and discursive resources my understanding follows Strauss, and views it as providing a macro-level set of structures that provide resources and boundaries within which local level rules of action are developed and enacted, with these rules then in turn mediating context. This relationship becomes clearer following my discussion of agency.

Agency

Agency refers to capability, and the 'power to be the originator of acts' (Cleaver, 2007, p226). It also has the dimension of meaning and reflexivity (ibid.). Agency therefore is about intention and capability, and can be understood by whether an individual could have acted differently (Giddens, 1984, p9). Whilst interactionist work may not frame analysis in terms of choice and capability, the focus on micro-scale action and understanding actor's meanings and the power relations they are in offers conceptual overlaps. I outline my conceptualisation of agency by considering its dimensions of being networked, the nature of power, and then move on to discuss how it relates to structure.

Key to my understanding of agency has been the idea, which I found prominent in development studies literature, of agency as relational (Cleaver, 2007, Connor, 2012) and how agents exist in networks (Long, 2001) (an idea also raised by King (2005) in context of broader discussion of social theory). In this line of thought, individual actors' agency is not only understood as operating within structures, but also as situated within social relationships, which also shape and enable action. Agency can therefore be seen as networked and situated (Connor, 2012, citing Elias). This notion of agency as relational has overlaps with a focus on interaction and negotiation, as previously discussed. They both draw attention to how action is embedded in social relations. Agency can therefore be defined with reference to the relationships in which action takes place in.

An understanding of agency as relational corresponds to my conceptualisation of power as a property of relationships, and then how this power forms the capacity dimension of agency. Latimer's notion of nurses as the conductors of care builds on this, seeing power as relation, and as oppressive as well as productive (Latimer, 2000). However, a criticism of Foucauldian analysis and governmentality on which Latimer builds is how it removes agency from analysis by placing power and control solely in the effects of discourse (Freundlieb, 1994). Latimer uses two metaphors, the first of an orchestral conductor, and the second of an electrical conductor. The first is more useful for implying agency, the second less useful, implying a role of discourse in guiding action and denying agency. I focus on Latimer's first metaphor. I develop the idea of nurses' power in this agency based

on the ideas referenced above of power as relational and disbursed. I add to these ideas a typology of power as 'power over' and 'power with' (Göhler, 2009, Chambers, 2005). Chambers uses terminology of 'uppers' and 'lowers' to refer to people's power; uppers have power over, which can be seen as negative, in that it limits others field of action (Göhler, 2009) but this power over can also be used to empower others, and so have power with others (Chambers, 2005); the outcome of this analysis is for Chambers to compare the role of power over and power within development relations, with the former he sees power as counterproductive and the latter about trust, mutuality and collaboration. In my later analysis I explore how nurses have both power over and power with others.

Agency and structure, structuration

Theory around the role of structure and agency in producing social action, can focus on processes of structuration: i.e. agency is constituted by structures, and in turn structure is constituted by agency (McDonnell et al., 2009, p122 citing Giddens, 1976) . The exercise of agency in action is therefore constrained and enabled by structures, yet these structures can in turn be remade, as well as shaped and changed, by the exercise of agency. This is what Giddens calls the duality of structure (1984). It is the relation of agency to structure where variations in conceptualisations of agency are clearest. For Giddens, structuration is more agency oriented, whereas for other theorists like Bourdieu, social and physical structures have a greater role in defining our behaviour (Hatch and Cunliffe, 2006). The relation between agency and structure can also relate to the extreme positions of rational individualism and determinism (Connor, 2012), extreme positions of whether action results entirely from the individual or is shaped by exterior forces. I resolve this on the basis that the extent to which agents can adapt and shape structures is an empirical question (Lewis et al., 2003). I don't presume a particular relationship and instead seek to identify specific links between these different forms of structure and agency through exploring how orders are enacted by nurses exercising agency, and in so doing mediating context.

Understanding care routines through order, context and agency

On the basis of this theoretical approach I analyse the care routines I later describe in the clinics. The approach can be summarised as: care routines involve nurses exercising agency in interaction, to enact orders, that in turn mediate context. I explore the foreshadowed

problems of nurses' relationships, identity, the clinic context and experiences of within this framework.

1.4 Understanding the organisation and delivery of care in the era of ART and HIV care

Through this chapter I have outlined the basis for the study focus, of aiming to understand the organisation and delivery of PHC nursing in the context of ART and HIV care, within the Free State province, South Africa. I have shown how there is a gap in the literature and why this gap relates to both areas of policy concern for health services, as well a theoretical gap in understanding but also a pressing policy issue.

I approach this aim with two specific objectives:

1 To describe care in PHC: using the framework of patients' experience, control and content around patient centred and task oriented care I will describe care. Owing to the nature of care as comprised of microscale interactions this focussed on in-depth, ethnographic approaches to study. My study isn't intending to primarily study processes of change, although the conclusions can be used to comment on that. Following that, I will also comment on the reported shifts to more patient centred care.

2 To explain care in PHC: I will then try and establish the underlying social processes involved in these care routines identified, with reference to the foreshadowed problems and theoretical approach just described. A purpose here is to develop sociological insight to support insight in to these health services issues, but to also develop theory within a relatively underexplored area.

This study address an issue of importance to understanding the overlapping needs of a successful ART and HIV care programme, PHC and how to support nursing. These three areas of focus are a concern not only in South Africa, but also across other LMIC settings.

Chapter 2 - Methodology

2 Introduction

I used a mixed method, multi-site observational approach based on ethnographic principles to explore the question of how PHC is being organised and delivered in the context of ART and HIV care. This in-depth and sustained approach allowed me to engage with the detail of care routines in the clinics, and to identify and explore the social processes involved in these routines. The study involved in-depth study of four clinics, including clinics delivering ART (as part of the STRETCH trial) and clinics providing standard HIV care only. Within these clinics I observed care routines and interviewed nurses, as well as clinic staff and patients; I also made separate efforts to explore the experiences of nurses living with HIV. Data generation and analysis were iteratively combined, leading to a grounded theorisation of care in the clinics studied. In the rest of this chapter I outline the basis of this approach, and how I implemented it.

In the first section of this chapter I outline the considerations behind the overall study approach; I consider the key elements of the study design, epistemological assumptions, the role of reflexivity, ethics and then significant relationships that shaped the study. The following sections explore the detail of how the study was implemented. I first of all outline the specific steps followed for data generation. This focussed on clinic observation and then interviews with nurses, with some interviews with patients and other clinic staff. The third section of the chapter outlines the approach to analysis. Here I outline my analysis strategy of combining inductive and deductive approaches to coding and interpreting data, to produce a grounded account of clinic routines and the social processes involved in sustaining them.

2.1 Study approach

The study has been conducted on the basis of a series of philosophical assumptions and practical considerations of how to address the study question. I discuss these here, before moving on to outline the detail of study implementation in section 2.2.

2.1.1 Study design

This study design was shaped by ethnographic approaches to research. Ethnography has been extensively used to study nursing care and broader health service and system issues in both high income (e.g. Charles-Jones et al., 2003, Quirk et al., 2004, Savage, 1995, Smith, 1992, Atkinson, 1992) and low and middle income settings (Harrowing and Mill, 2010, Van Der Walt and Swartz, 2002); with an increasing trend in the number of studies (O'Byrne, 2012). A broad definition of ethnography is of it being 'small scale social research that is carried out in everyday settings; uses several methods; evolves in design throughout the study; and focuses on the meanings of individuals' actions and explanations, rather than their quantification' (Savage, 2000, p1401, citing Hammersley 1990). A complimentary definition that emphasises the researcher's role is that 'the distinctive feature of ethnography is that it demands contextualised experience-near, on the ground, up close and personal research' (Singer, 2002, p92). The design of this study departs from traditional ethnography such as found in anthropology with its expectations of immersion of several years in the culture and language of those being studied (Silverman, 2006, p71). I instead adopted a more focussed approach. Ethnographies of healthcare have been described as 'focussed', owing to their purpose of answering specific questions and generating knowledge expected to be of use for health professionals (Roper and Shapiro, 2000, p7, citing Muecke, 1994). Others have seen this focus as leading to 'miniethnographies' (Kleinman, 1992) - not disparagingly – owing to their focus on the specific world of a patient (or of health care providers, in this case). These miniethnographies can bring valuable insight to health services research through allowing study of the complexity of health services (Huby et al., 2007). In this methodological context, I sought sustained, in-depth study of a small number of clinics, accepting the limitations imposed by my lack of familiarity with local languages and that I wouldn't be in the clinics for a number of years. Based on this, my study can be most accurately described as a multi-site, mixed methods observational study, building on ethnographic principles of being small-scale, flexible in response to the study context and engaging with the meaning of social action.

Within this framework, the study design was determined by the particular study setting, the approach to sampling, the methods for data generation and analysis, the iterative combination of data generation and analysis and finally a necessary flexibility in conducting

the study. I reflect on each of these in turn. This provides a basis for discussing the detail of the methods used in following sections.

The study setting was determined by my institutional links with the team at UCT who were leading the PALSA PLUS and STRETCH trial interventions in the Free State province. Through these links I was able to base myself in the Free State and study clinics there. The trial allowed study of PHC clinics who were adopting nurse-initiated ART, as well as facilitating links with the Free State Department of Health to allow access to other clinics as I also sought to include clinics not providing ART, but just general HIV care. This inclusion of different clinics was intended to allow exploration of any differences raised by ART and HIV care's role within PHC. I reflect below on the specific relationships involved in how I worked with the STRETCH trial team, and how this influenced sampling.

Sampling with respect to clinics, nurses, staff and patients was driven by a pragmatic and considered use of approaches. Initial sampling was purposive, with clinics selected on the basis of the needs of the study (Coyne, 1997) in this case to understand, in-depth, the care routines across PHC clinics. My sample included two clinics providing ART, as part of the STRETCH trial, and then two clinics providing general HIV care. I included this variation on the basis that comparison would allow insight in to how ART and HIV care formed part of the broader PHC focus of clinics. An initial 'foreshadowed problem' was that there may be important differences between urban and rural clinics and large and small clinics (with the overlapping assumption that urban clinics would be larger than rural clinics). This led to an initial aim to focus on one urban and one rural clinic each providing ART and urban and rural clinics not providing ART, on the basis of a judgement that this would allow reasonable time in each clinic reflecting the broader logistical constraints of the study. Sampling with respect to interviews initially sought to be purposive, trying to include nurses with a range of work experience and then patients with differing reasons for visiting the clinic. However, interviews with nurses evolved to be more opportunistic, partly because it seemed to be assumed by the nurses that they should all be interviewed (and some sought me out when in the clinics on this basis) and equally arranging interviews proved challenging and so I sought to maximise any opportunity that presented itself.

Data generation sought to understand both the clinic routines and their underlying social processes. The complex, dispersed and often hidden nature of both these routines and social processes involved in them led to a focus on both observation and interviews within clinics. This combination of data allowed varying perspectives on care routines, leading to a more comprehensive analysis as well as insight in to the varying meanings attached to them. I explore issues of triangulation in section 2.3. Within these perspectives I sought to include those of nurses living with HIV. This reflects the discussion in chapter 1 about how these experiences are neglected in research and could give valuable insight in to both the support needs of nurses and the delivery of care. Owing to ethical considerations this followed an approach of distributing study information through intermediaries to engage with nurses beyond the clinics, rather than directly exploring it in the focus clinics. I outline specific ethical considerations and approaches to sampling for this below.

The study iterated between data generation and analysis. The overall effect of this iteration was to give the study a 'funnel structure' with progressive focus developed over time (Hammersley and Atkinson, 1995). I adopted this initially open approach on the basis of my literature review – as set out in sections 1.2 and 1.3 above – not suggesting a clear conceptual framework on which to describe and explain care. The absence of a clear conceptual framework led me to seek this focus in response to the specific clinic contexts, whilst using ideas of patient centred care and the foreshadowed problems discussed in section 1.2 to guide my emerging study. Iteration functioned at two levels: the first focusing on a constant process of reflection on my data as it was collected and then efforts to explore emerging hypotheses. The second level involved incorporating distinct periods for analysis between separate phases of fieldwork, as summarised in figure 2.1. I would spend several months or weeks in the Free State province, visiting clinics, before returning to the UK to reflect on my data. These periods in the UK were an opportunity for more intense analysis and to formulate hypotheses for consideration in later data generation.

Figure 2.1 Study process overview

Time	Study activity
Sept 2007 – Jan 2009	Study development
Feb 2009 – May 2009	Round 1 Data generation and analysis – South Africa
June – Oct 2009	Analysis - UK
Oct – Dec 2009	Round 2 Data generation and analysis – South Africa
Dec 2009 – Feb 2010	Analysis – UK
March 2010	Round 3 Data generation and analysis – South Africa
April 2010	Analysis – UK
May 2010	Round 4 Data generation and analysis – South Africa
May 2010 – August 2012	Analysis and writing - UK

PHC clinics are dynamic and complex environments, with a range of ongoing activity; my analysis sets this out in chapter 3. This environment also shapes the approach to research. The study was ultimately conducted within a context, and working with people, over which I had little influence and which shaped specific possibilities for the study; ultimately my control of aspects of the study was limited and I had to make a ‘virtue of necessity’ (Fine et al., 2008). As I discuss below, data generation was shaped by what was feasible under the constraints of a busy clinic and the wishes of nurses. Whilst frustrating in terms of trying to achieve specific objectives, this reflects the social reality of the clinics studied and is an unavoidable aspect of research. Rather than seeking to oppose these external constraints, I engaged with them as a necessary part of the research and reflect on them for what they can say about the issues I am studying and the broader social context.

2.1.2 Epistemology

The aim of this study is to inform health services policy, and in particular to support efforts around the ongoing scale-up of ART and HIV care and strengthening of PHC. This implies specific assumptions about how reality can be understood (epistemology). A prominent

theme within ethnography is a social constructionist perspective that views reality as a social product generated through interaction (Rosen, 1991). This position is within the broad interpretivist paradigm, rejecting natural science and positivist approaches to the study of social reality and understanding people as 'complex, unpredictable and able to reflect on their behaviour' (Green and Thorogood, 2009, p13). However, at an extreme this position can lead to a relativism that sees the products of ethnography as themselves relative and therefore having no more value than other accounts of the world (Hammersley, 1992). Instead, I work within an interpretivist and social constructionist paradigm, and follow a subtle realist approach that accepts there are limits to the extent reality can be understood, but that reasonable claims to truth can be made about it (Brewer, 2000 and citing Hammersley 1990, Hammersley, 1992, Silverman, 1993, Mays and Pope, 2006). The implication of this position is that I accept people construct their accounts of the world, and that analysis of these accounts can then give insight in to the meanings they reveal for those relating them, but they can also give insight to the phenomena to which they refer (Hammersley, 1992). In other words, nurses' and patients' accounts (and my own observations) give insight in to both the nature of care routines and their meaning.

In accepting the constructed nature of accounts of the world there is a need to be critical of the assumptions involved in their production and judge the insight they give to reality (Hammersley, 1992). A first consideration based on this is that the data gained through interviews and observation is a social product, shaped by specific relationships between the researcher and respondents, and so only partially gives insight in to a broader reality. This recognition underpins my use of the term 'generation' rather than 'collection' of data; my data was generated in the interaction between my respondents and myself, it wasn't waiting to be collected (Rhodes, 2012). This social nature of data points towards the need for reflexivity, which I discuss in the next section. Further to this reflexivity, is the need to critically explore the influence of the context and conditions in which the data and accounts are generated, to understand influences on it and so to guide how it can be interpreted.

A study can be judged on its reliability and validity (Silverman, 2010). Reliability refers to the extent to which repetition would bring similar results (Green and Thorogood, 2004, p193-4), or more specifically, demonstrating the extent to which data are assigned to the

same categories on different occasions (Hammersley, 1992). I seek reliability through trying to demonstrate how my data supports the concepts and theories I describe (and I discuss this below in 2.3). Validity, which sits within reliability (Hammersley, 1992), engages with 'truth' (Silverman, 2010); validity judges the extent to which an account represents the phenomena in question. I seek to demonstrate validity through following rigorous procedures for analysis, and providing transparency on them; I set these out in section 2.3 below.

An extension of this discussion is the use of the knowledge produced. I approach the study on the basis that a description and analysis of the organization and delivery of care in a focussed sample of clinics in a particular context can provide knowledge useful in other settings. I do this on the basis of conceptual generalisability: that the concepts 'can inform understandings of similar contexts or issues' (Green and Thorogood, 2004, p198). The detailed description I present of the specific clinics in later chapters I do not claim as being necessarily of use in understanding all PHC clinics in the Free State province, or South Africa, but the concepts I generate – whether descriptions of care routines or insight in to rules of interaction – I present as being of use in giving insight in other settings.

2.1.3 Reflexivity

Reflexivity – reflection on the influence of the researcher – rests on understanding that 'researchers are part of the social world they study' (Hammersley and Atkinson, 1995, p16). This influence over research can take many forms, reflecting the complexity of an individual's experience, and recognising it is central to a full recognition of a study's strengths and limitations. Recognizing this influence is essential to the process of rigorous analysis and producing credible accounts. Rather than trying to eliminate the researcher's influence, we should seek to understand them so that the influence of the researcher then becomes a part of analysis (Hammersley & Atkinson, 1995). A full outline of my biography is not a practical or desirable undertaking in the context of a PhD. Instead, there are key aspects of my beliefs, identity and experience that are the focus for reflection through this chapter and the study for how they have influence over the data generated and my interpretations of it. I discuss here key points that are foundational to the entire study, and these form a foundation for a detailed consideration in section 2.1.5 below about the

specific relationships that were central to the ongoing implementation of the study once designed. My focus for reflexivity here is on my 1) past study, 2) research and then 3) work experience, and finally 4) my institutional background in the UK and with the London School of Hygiene and Tropical Medicine (LSHTM) and how that links to the University of Cape Town (UCT) STRETCH trial. I go on to reflect on my gender and racial identity in more detail, and the specific issue of my language abilities.

My previous experience of studying the social sciences informed the theoretical choices that I initially outlined in section 1.3 in the previous chapter. I have previously studied human geography and then development studies; both areas of study involving a range of social science disciplines. This study has variously drawn on anthropology, sociology, politics and economics; latterly, my study also particularly focussed on dimensions of power, and how it manifests in developing country contexts. The outcome of this prior study for this research was in shaping my perspective towards combining *micro and macro* perspectives, and a sensitivity towards particular analyses of power. The theoretical framework discussed in section 1.3 doesn't draw significantly on past literature and references I was familiar with, but the antecedents in terms of the underlying assumptions of what shapes phenomena are clearly evident.

My prior study was broad based but didn't involve considerable qualitative methodological experience, shaping the potential for data generation. An element within this is my status as a research apprentice, if social research is understood as a craft needing knowledge and skills (Kvale and Brinkmann, 2009). Conducting ethnography can be seen as a 'socialising experience' in that it develops or leads to internalising a set of assumptions central to understanding 'human social reality' (Singer, 2002, p88). Through the course of the study my understanding of the research process evolved. Having to initially defend my research approach from more positivist critiques – both in the UK and South Africa – was useful, but also led me to adopt a distant position, initially not engaging with the value of my own experience in allowing me to understand and interpret what I was trying to understand. As the research unfolded I gained a more nuanced position of how to understand, and approach understanding, social reality. This relative inexperience doesn't undermine the

credibility of the study, but will explain specific decisions made and how some opportunities were missed.

Before the research I had also worked in South Africa and the UK on HIV related issues. In South Africa I had supported the implementation of HIV prevention interventions in township settings. Related to this I had worked on HIV policy within an international NGO in the UK. In combination this work experience gave me a background in the specific context of South Africa and the HIV treatment programme there, as well as fostering an orientation towards a health service focus in the research, rather than solely serving theoretical outputs.

My study and work experience shaped how I initially came to do the research through allowing me to take up a position with the LSHTM, with the purpose of doing PhD research around issues raised by the changing role of nurses in the South Africa HIV treatment and care programme. Through my position at LSHTM, and specifically through professional relationships of my PhD supervisor, I was able to link with the University of Cape Town who were managing the STRETCH trial. Although my study links to the work of UCT and the STRETCH trial and they provided considerable support, I was not a formal part of their trial or work. It was through these personal links that I was able to investigate the changing role of nursing, rather than through a direct and central position within one of the implementing institutions (ie UCT or the South African national or provincial departments of health). This peripheral institutional position with UCT meant that I largely implemented the study independently and had little visible backing or support for the study when in the clinics I worked with. I discuss in more detail below how this peripheral position impacted on opportunities for data generation through shaping relationships with key gatekeepers, the process of accessing the clinics and my relationships with nurses.

My experience in work and research is also a reflection of my political and ethical beliefs: a concern for social injustice, a recognition of the role of structural factors in shaping this, and an acceptance of universal human rights including access to healthcare. These beliefs have directed my gaze through the research, drawing it to some aspects of the clinics and not others, and will have led to an initial favouring of some explanations over others.

Ultimately, I agree with the position that 'social science would not be worth a moment's attention or labour if it had no political role' (Fassin, 2007, pxxiii). Such beliefs are not remarkable, especially in the context of research oriented towards health services in resource poor settings; acknowledging them and their role on analytical decisions is however a necessary step in rigorous analysis.

My gender, racial and social identity will have shaped what was said to me, and also shaped my interpretations. There is a widespread recognition that personal characteristics of a researcher mediate what unfolds in front of them (Bell, 1999). Although identity is understood as influencing research, it's influence is little understood (Agar, 1996). My status as white, British, middle-class, male and a non-nurse made me in many respects an outsider; I did not have an appearance, the languages, technical skills or health need that would allow me to blend in with those around me. This will have had impacts on data generation. With people less able to clearly identify with me it is likely that they would initially be wary of me, less likely to openly discuss issues I wanted to explore, and likely to adapt their behaviour to keep certain practices hidden (such as what could be considered 'bad practice', fearing I may be more likely to report this to other authorities). However, it is possible that an 'outsider' identity supported data generation because respondents found it easier to reveal their accounts without fear of negative outcomes if they are unlikely to have future contact with the researcher (Letherby, 2003). This argument is reflected in my data: nurses were often very open about the 'bad' elements of their practice. In addition, by not speaking Afrikaans and Sotho I may have come across as less threatening or imposing in contexts where fear of white people was still reported to me by nurses, as I may have been understood differently from white South Africans. The influence of identity on data generation is not simple or stable, and in different moments of data generation my outsider identity will have had different impacts. In trying to understand this impact there are there are key axes of my identity on which I reflect in understanding the influence on data generation and interpretation, namely the role of gender, race and class. In section 2.1.5 I reflect on these points in detail when considering my relationships with nurses and others in the clinic.

My identity not only shapes others perceptions and behaviour towards me, but also what I can understand and interpret owing to my lack of Sotho and Afrikaans in particular. Language mediates much communication, and meaning, and so not being able to speak what are widely used languages in the clinics will have denied me first hand access to much of what is spoken about directly between nurses and patients. An example of the limits this imposed on the study is when an Afrikaans nurse said patients referred to her as 'goa' in the waiting areas, which I later found out is a term from the apartheid era used to insult white people; there were potentially numerous instances of these interactions within public areas of the clinic which I was unable to understand. This lack of Sotho and Afrikaans meant there were instances where I was reliant on checking my observations of activity in the clinics with others, making cautious interpretations of my observations and also relying on second hand accounts. Although a limitation, the findings I develop still have value based on how English is still a core language in the clinics, being spoken by virtually all of the nurses fluently, even if it was a second language. In addition, much of what happened in the clinics happened without direct verbal communication (as I explore in chapter 3, there are numerous unspoken rules, which my analysis sought to uncover). Finally, the amount of time I spent in the clinics I was able to explore and verify interpretations of social activity that centred on Sotho or Afrikaans speaking.

The last main consideration is my emotional experience of being in South Africa. The experience of conducting research can be stressful for the researcher, which in turn has implications for processes of data collection and analysis. Roper and Shapiro (2000) suggest the need to record the initial loneliness of being away, to acknowledge how it may colour your impressions. Here is an extract from my fieldwork diary, towards the start of data collection, describing a drive I had taken out of Bloemfontein on a day off:

'[I have] a feeling like everything in South Africa is a bit barren and sterile. Many places feel a little like there isn't enough people to make things work – in X the whole place seemed like some poor imitation of a tourist resort, awful and soulless – and just hot with a bleached sky, it is very hard to imagine any kind of community forming and thriving – just dislocated people trying to eke by. Or at least that's how it seems – at the moment I find it impossible to imagine any joy in these places, or, if there is joy, it is in small groups, inside, and not in the street.'

I had spent considerable time in South Africa before with previous work and more generally read around and reflected on contemporary South African society. My references to 'feeling' and 'seems' highlight that I was consciously recording this knowing my opinion was likely fleeting but could influence the wider conduct of the study. An example of how my sense of alienation in South Africa potentially fed harsh interpretations of the clinics can be seen in my early analysis: my initial observations and notes are full of references to the waiting time or the conditions in which patients are waiting. This partly reflects that waiting is a very public activity and so easy for me to observe. It also reflects that seeing patients wait for hours angered me a little, and I became frustrated at some nurses, a result of my then emerging understanding of what was underlying the organization and delivery of care. This frustration likely limited my engagement with what nurses were saying. This initial interpretation however evolved, and I became more sympathetic to the nurses; more able to engage with their perspectives and to understand their situation, rather than perhaps quickly judge. Emotions of the researcher can cloud perception, but can also evolve. Reflection on this is key to effective analysis.

2.1.4 Ethics

My approach to ensuring an ethical conduct of the study focussed on both set procedures and principles of conduct. Formalised processes can do much to ensure effective ethical conduct, and prevent the risk of psychological or social harm that social science research can raise (Molyneux et al., 2009). However, I conducted the study on the basis that how to treat people within a research relationship is no different from the values that should operate in everyday society (Murphy and Dingwall, 2001). Throughout the study I was aware that I was a potential disruption or burden within the clinic and that my presence reflected nurses' willingness or tolerance of me being in the clinic. This sense of being a burden was heightened by research literature reporting nurse burnout and dissatisfaction in South Africa (Engelbrecht et al., 2008) and from time spent with the STRETCH research team who adopted a general approach of sensitivity towards a profession they understood as needing support and of being under pressure. I was also aware that anyone involved in my research was unlikely to directly benefit (beyond myself). Lastly, I was troubled by the inherent deceit of ethnographic approaches to research, of developing and continuing relationships on the value they can bring to research (Hobbs, 2001, citing Ditton). Following these points, my fieldwork was not just an ethics of ensuring consent and access, but

sought to respect the ongoing routines and lives of the people with whom I was trying to work.

I outlined above my caution in gaining access to the clinics, with ethical conduct focussing on providing information about the study to nurses, clinic staff and patients, and emphasising that their participation was optional. Appendix 4 contains the documents that I used as part of the process of gaining access to the clinics, and subsequently in interviews. When interviewing I would give information sheets and consent forms, in whatever language was appropriate. Some nurses and patients did decline to be interviewed after reading through the study information sheets. Conversely, with some interviews nurses or staff would start talking before I had even sat down; in these instances I would pursue the interview and get consent after, on the basis that nurses themselves had chosen to be interviewed and with my presence in the clinic were already aware of the research. Both processes indicate that those involved did not feel obliged to participate. I was still acutely aware of the potential power I held to pressure those I was working with. I would try and avoid pressuring nurses for interviews and would ask managers if they were at all worried about my presence or how I was approaching the study, continually emphasizing that I was flexible in how I conducted myself within the clinic.

The process described above for seeking to include nurses living with HIV in the study followed these same principles. I ensured anonymity and confidentiality for all potential interviewees, and that any disclosure of an individual's HIV status would remain entirely within their control. I did not seek details from the gatekeepers, and instead waited for voluntary responses to the information I distributed through key contacts. Overall, efforts to engage with the perspectives of nurses living with HIV were unsuccessful, in that I didn't conduct any interviews. This result also reflects a necessary ethical caution and illustrates the rigour of the ethical procedures in place.

This effort to adopt ethical principles through my conduct had the effect that there were times when data collection would have been facilitated by me being more assertive, for example through being more insistent on interviews or through repeating questions. A more aggressive approach to data collection could have yielded more data. However, it

would likely have disrupted clinic routines more than I already was, and it may have jeopardized the relations I was building as well as potentially jeopardizing the 'field' for future researchers, as well as representing a level of disrespect and insensitivity in an environment which I had little experiential understanding of. I also chose not to observe consultations; this reflected an ethical position of not wanting to interfere with patient care. Although some nurses did offer me access to their consultations, I declined. Others have argued that what patients say in a consultation is recorded anyway and so a researcher may simply make a patient less relaxed (Strong, 2006). This is possibly true in a UK setting, but in a South African PHC setting where the dynamics of my gender and race are additional challenges I feared that I would undermine communication, particularly considering the challenges of discussing issues like HIV and problems around disclosure that my presence would raise. The reverse is also possible: patients may have felt more comfortable with an extra person and it may have encouraged nurses to provide better quality care. However, on balance the position I adopted is I believe supported by my data from patients and nurses that patients are often unwilling to raise issues and communicate freely in consultations (See chapter 3).

A consideration when writing my analysis concerned issues of confidentiality and anonymity for those involved. Small clinic samples from specific geographic locations raise risks of participants' identities becoming apparent through presentation of their accounts. This risk led to me to specifically seek permission from every interviewee to be quoted, with permission being 'opt-in'. Very few nurses chose to 'opt-in', perhaps reflecting a rushed consideration of the form, or a sense they had no control over the research encounter. This was an issue I could have raised further with nurses to try and secure their permissions for this. However, in a context of consent already being gained for the study on initial visits, an awareness of my precarious position of control over the research process within the clinic and a respect for nurse autonomy led to me not pursuing consent for direct quotation. Rather than being able to use extensive quotes from nurse accounts to illustrate my analysis, I paraphrase these accounts but then also quote specific words or terms nurses use where these give important insight in to the nature of the phenomena and serve thick description. This combination allows my interpretation to be supported by nurses' original meanings, and navigates between the pressure to convey participants' accounts and then respect for ethical permissions and anonymity.

2.1.5 Being in the clinics: relationships with UCT, the clinics, nurses, staff and patients

In this section I build on the foundational principles of the study outlined so far, and discuss the key relationships that shaped the study, in terms of how I accessed the clinics and then the relationships with nurses, clinic staff and patients. Social research studies social relations, but also proceeds through them. This fact, common to all social research, is perhaps especially marked in sustained observational study owing to the duration of contact with research subjects. I explore these relationships here to show how my relationships with these nurses and the specific contexts shaped the data generated. I outline the process of accessing the clinics to explore my relationship with UCT and the STRETCH trial before going on to reflect in detail on my relationships with specific nurses, clinic staff and patients. I raise a number of considerations, and relate these to my identity of a 'lone outsider' with respect to the institutions I worked with, the clinics and the nurses I spent most of my time talking with.

Accessing clinics

My access to the clinics studied was governed by my relationship with UCT and the STRETCH trial management. As described above, I came to do the research through my position at the LSHTM and the links this allowed to UCT in South Africa. In turn, UCT's work to implement the STRETCH trial meant they had strong links with the Free State Department of Health. Dr Kerry Uebel, the STRETCH trial manager, was an employee of UCT but based in the Free State and worked from within the provincial Department of Health in Bloemfontein. I was introduced to her by the team at UCT and she was instrumental in introducing me to key contacts within the Free State department of health, and then on to the clinics. Kerry ultimately functioned as a key gatekeeper for my study; I relied on her in establishing the study within the Free State department of health, and then in turn to access the clinics, and as a consequence this relationship was a defining influence on the study, as I set out below.

Kerry was instrumental in establishing the study but herself held a particular position within the Department of Health. She managed the STRETCH trial, a free standing project

within the Department of Health, and although she worked with and through the bureaucracy there she held a position of relative autonomy it seemed, owing to her ultimately being UCT staff. In negotiating my study within the Department of Health and in arranging clinics for me to visit and potentially study we worked with full permission and acknowledgement of the Dept of Health. However, we worked within and through the dept bureaucracy, rather than with the active and deeply engaged support of key stakeholders. As a consequence the study had no unequivocal and vocal endorsement from key figures, that was in turn transmitted on to the clinics. Although Kerry had some authority over the clinics, this was through personal relationships and her position as a doctor and manager, rather than us having clear Dept of Health institutional backing. I return to the effects of this below.

Kerry's gatekeeper role was particularly influential in choosing the sample of clinics. When selecting clinics I outlined the criteria for my sample, as discussed above, and Kerry suggested four clinics, two STRETCH sites and two other PHC clinics that she was familiar with. The two ART clinics were, by Kerry's admission, clinics where the trial (and therefore ART) was 'working', even if not necessarily successful. This is in contrast to clinics in the trial where there were major problems in starting nurse provision of ART. The clinics suggested as study sites could perhaps automatically be seen as 'better' clinics. Although potentially a bias, it also reflects that any 'problems' in implementing the STRETCH programme would have been overcome and any problems that did emerge would be of a systemic nature (Pienaar et al., 2006, p6). Ultimately, Kerry shaped the clinics I studied, based to a degree on our discussion and agreement, but it did mean that I was not seeing nurse led ART 'failing', and so my study is oriented towards what ART and HIV care can achieve in relation to patient centred care, rather than towards exploring negative outcomes; this conforms with the study aim, but requires recognising so that the study conclusions aren't interpreted as a comment on how ART and HIV care are provided generally.

The process of accessing clinics and securing their permission to study them was also shaped by Kerry. Permission to access all clinics was sought after an initial introductory phone call from Kerry, or myself. I would then visit to explain the study and seek their

permission to study their clinic. This initial visit (the first few I was accompanied by Kerry, but for the majority I visited by myself) would generally be brief (perhaps half an hour maximum). When I arrived – I usually arranged these initial meetings for the afternoon when clinics were often quieter – the entire clinic staff would often come to a meeting. I would give everyone an information sheet on the study (in English, an abbreviated version of the interview information sheet – see appendix 2 for an example). I would then briefly outline the study, what it would involve for them and then explain it was voluntary.

The four principal clinics – what I have renamed as Aangekom, Ba Banyane, Christen and Dula clinics – showed some subtle variation in how I negotiated access, although all agreed. There was no open resistance to the study from Aangekom, Ba Banyane and Christen, with some nurses being very positive. In the initial meeting in Aangekom the nurses seemed subdued, with nurse manager of the clinic being positive, but little obvious enthusiasm from others. In Ba Banyane clinic the manager agreed to the study without any questions; I actually encouraged her to discuss and reflect on it. Immediately after this she said there were some patients she was having trouble with and asked Kerry to see them, suggesting my study was potentially viewed as a way for her to access help for patients or other resources. In Christen clinic, the ART nurse was very positive, the others seemed largely uninterested. Dula clinic was the only clinic where I was questioned about the study, and particularly on what the benefits would be for them. I responded that their clinic was unlikely to gain any direct and immediate benefit, although I hoped that my study would influence the broader Free State health system and so potentially they would benefit through that. I would then call back in a few days to see if they had further questions and to see if they were happy to be involved. I was aware of the potential for clinics to feel coerced in to accepting me in to the clinic and so insisted that nurses discuss it amongst themselves and that I would call in a few days time. It is likely that some nurses lacked enthusiasm initially, and throughout the study, and that any consensus decision to accept me in the clinic actually reflected the views of more senior staff. I didn't however hear any reports from nurses – directly, or indirectly reporting the views of others - of active resistance or opposition to my study. Any perception that I was coercing clinics or nurses is undermined by the three clinics that I approached to be included in the later stages of fieldwork that declined to be involved. One actively said no, whilst two others simply didn't

return my calls, suggesting a more covert 'resistance' to the project or at least that they weren't compelled to participate.

This process of accessing the clinics ultimately demonstrates how Kerry, as principal representative of UCT and the STRETCH trial, shaped the study as it was established and in initial access to the clinics. The role of Kerry in shaping this, and then my own solo efforts to access the clinics overlapping with some support from Kerry, also underline the absence of clear institutional backing from the Department of Health, an issue I return to below.

The clinics

The four principal clinics I summarise in figure 2.2 below. To ensure anonymity the clinic names have been changed; I chose names to evoke my experience of the clinics and following the approach used by clinics themselves of names conveying positive sentiments or prominent aspects of the local place, and also used a mixture of Afrikaans, English and Sotho words, reflecting the mix and combination of languages common in the Free State. Also included are an outline of the staff in each clinic and a summary of changes during the fieldwork. The majority of staff – including all nurses - were full time, although some – e.g. lay counsellors – worked part-time. The majority of nurses were professional nurses, with the clinic managers also professional nurses (alongside clinical duties they also had managerial responsibilities).

Figure 2.2 The four focus clinics for the study

Clinic	Role in ART programme	Clinic Description	Summary of nursing staff	Summary of other clinic staff
Aangekom Clinic	No ART	Large, urban clinic on the periphery of a major urban centre. Large township area close by.	6 Professional nurses including the clinic manager (with 3 leaving, and then being replaced during the fieldwork), 1 enrolled nurse	2 session doctors (left during the fieldwork), 1 receptionist/clerk, 1 general clerk, 1 pharmacy assistant, 3 general assistants, 1 cleaner (varied), 2 lay counsellors (1 left, another returned from maternity leave)
Ba Banyane Clinic	No ART	Very small clinic in a small, rural settlement, 45 minutes drive from a major urban centre.	3 professional nurses including the clinic manager	1 cleaner, 1 occasional volunteer for reception, 1 occasional volunteer for general duties
Christen Clinic	ART - STRETCH site	Medium, periurban clinic in a township area, 30 minutes drive from a large urban and industrial centre.	4 professional nurses including the clinic manager, 2 nursing assistants (1 left)	1 lay counsellor (Changed), 1 receptionist, 1 clerk (changed), 2 cleaners
Dula Clinic	ART - STRETCH site	Large, urban clinic in a township area within a large town.	8 professional nurses including the clinic manager (gaining 1 nurse during the fieldwork), 1 nursing assistant	2 lay counsellors, 5 clerk/reception staff, 3 pharmacy assistants, 1 visiting pharmacist, 2 cleaners, 1 gardener

The clinics themselves varied considerably. Aangekom clinic was on the periphery of a large city, although was isolated, with the nearest housing some several hundred metres away. They had a sign in the front signalling it had been built since the regeneration programme (i.e. post apartheid). Inside it was built around a central waiting area, which was filled with rows of plastic chairs. To one end was a corridor with consultation rooms on both sides, at the other was the TB room and then administrative offices, the staff room and reception. The reception faced over the waiting area, through a small hatch with a window across it. In summer the clinic would be hot, as well as dusty, even with the front door and windows wide open. In winter the clinic would be cold, as they all would be, with nurses and patients normally still wearing their large, thick coats as they worked.

Ba Banyane was also a relatively new clinic, built on the very edge of an isolated township. I had to drive some distance to get there, although it was still close enough to the nearest city for people to commute there for work. The clinic building was very small, compared to the others. There was a waiting area that could fit around 15 chairs, then two consultation rooms and a reception. There was an adjoining temporary building, which had a staff room and a couple of offices, but the space was not fully used. The clinic was at the entrance to the township, opposite another government building. By the entrance to the clinic there was a bench, a place where I would often sit for a few minutes, as would other patients, and watch the township community come and go.

Christen clinic was also on the edge of a township. This township was several hours drive from Bloemfontein near an industrial centre. My overriding sense from the weeks I stayed there was of it representing the bleakest, cruellest aspects of the South African political economy. Heavy industry originating in the apartheid era had developed, with accompanying pollution and social dislocation as people moved there. That there was a holiday resort close by seemed to me almost laughable, or it would have been if it were not true. Such a harsh description can easily be dismissed as the musings of someone unused to seeing the contradictions of the global economy, from which I benefit, up close; this is partly true, although I have never spoken to anyone who was positive about the area. The clinic itself was new, and similar in size to Aangekom clinic, if only slightly smaller. A waiting area with a reception facing on to it, joined a long corridor with consultation rooms coming off it. This corridor itself had no external windows and so could often be quite gloomy and dark. Christen clinic was the first of the clinics, along with Dula, that was involved in the STRETCH programme. Although not signposted as such, one end of the corridor was used exclusively for ART, with the 'ART nurse' having her consultation room there, and a group of around five chairs formed a smaller waiting area.

Dula clinic was in the middle of a township, which itself was adjoining a large town. This was again several hours from Bloemfontein and so I would spend several weeks in the town in total. The clinic itself was very old in parts, to the extent that there were clear holes in the roof. There were also new extensions, with the 'ART side' being the newest of these.

The clinic was also the largest of the four focus clinics, although not significantly larger. A small initial waiting area, led on to two differing corridors; one of these led to the 'ART side', the other to another waiting area with a pharmacy, and then in turn on to another corridor which was termed by some the 'mainstream side'. The ART side had a wooden bench in the middle surrounded by consultation rooms, with double doors leading outside to where patients would often congregate. The mainstream corridor had windows along one side and consultation rooms along the other, with a bench for patients to wait on along the window side.

This initial sample of four clinics was supplemented by an additional six clinics for the 3rd and 4th periods of data collection, summarised in figure 2.3. I again worked with Kerry, the STRETCH trial manager. I originally asked for an additional 8 clinics, to include 6 ART PHC clinics (four STRETCH, two doctor-led ART) and then 2 non-ART clinics; including a variation in urban and rural settings. This was purposive, with the basic intention of exploring whether my emerging ideas around care and explanatory factors existed in other clinics. From this list five clinics agreed to participate, and I subsequently approached an additional clinic to make six. Time constraints limited including others. A weighting towards ART clinics allowed me to explore ART in more detail. Data collection in these clinics was not as intensive or for as long duration as the initial four clinics, this reflects that these clinics were intended to test the emerging ideas gained from the original four and to give depth to study themes.

Esita was the largest clinic I visited, dwarfing Ba Banyane, and was newly built; this one clinic had been built to bring together three separate clinics which had each separately served the white, black and coloured communities. Fontein clinic was a marked contrast, being in a renovated old house. Both were in, or on the edge, of small towns. Geheim was similar in size to Aangekom, and like Ba Banyane was in a relatively isolated township. Hantle and Ithuta were also in township areas, but on the edge of a major city. Joyful was in a small town, and the clinic itself was in a suburban area, although this adjoined a large township and it was the people who lived there who mainly used the clinic.

Figure 2.3 The six additional clinics included in the study

Clinic	Role in ART programme	Clinic description
Esita	ART – STRETCH site	Large clinic on the edge of an isolated town, 2 hours drive from a major urban centre. Clinic set in an area of poor housing.
Fontein	ART – doctor-led, no nurse prescription or initiation	Small clinic in a rural, isolated town, 2 hours drive from a major urban centre. Clinic set in the middle of the town.
Geheim	ART – STRETCH site	Medium sized clinic, in a township area, 30mins drive from a major urban centre.
Hantle	No ART	Large clinic in a township area in a major urban centre.
Ithuta	ART – STRETCH site	Very large clinic, with facilities for surgery, in a township area of a major urban centre
Joyful	ART – doctor-led, no nurse prescription or initiation	Small clinic in an isolated town. Clinic set in the middle of the town, close to a township area.

The nurses and clinic staff

The data I generated within the sampled clinics was mediated through the relationships I had with nurses and the other clinic staff. As I described in section 2.1.3 above, my identity within the clinics was that of an outsider. In this section I explore the specific implications of this in terms of specific relationships with nurses, and show how I sought to manage my identity within the clinics and overcome challenges and limitations.

To aid discussion of these relationships whilst maintaining confidentiality I have renamed the nurses – as with the clinics above - using Sotho for the black nurses and Afrikaans for the white nurses (following my discussion in chapter 1, I use those terms aware that they are problematic). Nurses were referred to by their surnames and with the prefix ‘Sister’, with the exception of the one male nurse. I also include other clinic staff that I had regular conversations with, or who figure highly in my data in other ways.

Figure 2.4 The nurses in the four focus clinics included in the study

Nurse (Prof Nurse unless stated)	Impressions
Aangekom	
Sister Terene (Clinic manager)	Sister Terene left the clinic in the course of the fieldwork, and so although she was friendly we never developed a close relationship.
Sister Marais (Staff nurse)	Sister Marais was very forthcoming with her opinions on the clinic, which often focussed on her colleagues. Although there never seemed to be open hostility towards her, she seemed isolated within the clinic. As a result, she was willing to voice opinions to me and be very open, but I sensed a similar reluctance to relate to me as she did with some of her colleagues.
Sister Botala	Sister Botala and I rarely talked and I sensed she was wary of me.
Nurse Tefo	Nurse Tefo was the only male nurse in the four clinics, and this common identity likely played a role in allowing us to talk quite freely. Our relationship wasn't however notably different to what I had with some other nurses.
Sister Fourier	Sister Fourier and I often spoke, and of the nurses in Aangekom she was likely the nurse I was friendliest with (she hugged me when I came back for the second period of fieldwork for example).
Sister Kopo	Sister Kopo joined and left the clinic in the course of the fieldwork and we rarely spoke.
Sister Metso	Sister Metso joined the clinic during the fieldwork, and I rarely talked with her.
Sister Molao	Sister Molao joined the clinic during the fieldwork, and I rarely talked with her.
Sister Kwena	Sister Kwena joined the clinic towards the end of my fieldwork. In our interview she seemed irritated by me and on the few occasions we met she was generally distant.
Sister Andrews	Sister Andrews was friendly towards me, but was rarely willing to talk at length. My overall impression was that she was quite willing to humour me, but she found my position in the clinic strange.
Dorothy (Receptionist)	Dorothy and I spent a lot of time talking, when I would share admin work with her. I generally considered her the social focus of the clinic, being very confident and friendly with all the nurses. Although we spent a lot of time talking, there was also a form of social distance, evident in how she would ask to borrow money, or for me to driver her places (I would jokingly resist both).
Ba Banyane	
Sister Habore - (Clinic manager)	Sister Habore and I talked a lot, with me giving her lifts to the clinic being a factor in this (she asked, and I considered it both polite and useful for the fieldwork). Her general demeanour through much of the fieldwork was of being exhausted and frustrated by her work and a result of that was how she would often talk work with what I considered candour about her work and what she considered bad sides to it.
Sister Peo	We were friendly, but Sister Peo often seemed distant.
Sister Pretorius	Sister Pretorius was very approachable and willing to engage in my research. She had a long sick leave in the course of the fieldwork which limited our relationships, and left her generally exhausted and distant when she did return to the clinic.
Esther (Cleaner)	Esther spoke Sotho only, and so our communication was limited; she was however very friendly and open towards me.
Christen	

Sister Seporo - clinic manager	Sister Seporo was supportive of the research, but reluctant to prioritise it. Towards the end of the fieldwork her husband was seriously ill, and this seemed to distract her when she was at work and consequently our relationship was respectful but not close.
Sister Vermaak	Sister Vermaak was very supportive of the research, willing to be interviewed and talk about her work.
Sister Kgaolo	Sister Kgaolo initially seemed unapproachable and cold, but as the fieldwork developed this seemed to reflect a level of shyness and perhaps being distracted by family illness outside the clinic.
Sister Thabo	Sister Thabo often seemed very distant and at times wary of my presence in the clinic, I never understood precisely what was involved in this beyond my role as a researcher.
Sister Ngata (Nursing assistant)	Sister Ngata was open and friendly with me.
Sister Pono (Nursing assistant)	Sister Pono spoke little English and so we often had little more than small talk
Dula	
Sister Fula (Clinic manager)	Sister Fula was very approachable and optimistic, and seemed to welcome the research in the clinic.
Sister Mamdala	Sister Mamdala was friendly at times but also seemed distant at others.
Sister Nomkhula	Sister Nomkhula was very friendly and confident initially, and we seemed to form a close friendship, linked in part to her having lived in the UK. In the second and third periods of fieldwork she seemed more distant and the initial friendliness waned.
Sister Sehlwela	Sister Sehlwela was friendly, but often seemed distracted.
Sister Sediba	Sister Sediba seemed wary of my presence in the clinic.
Sister Setempe	Sister Setempe was friendly, but, we rarely spoke in any depth.
Sister Kgaba	As above.
Sister Setala	As above
Sister Lejwe	As above
Sister Meso - Nursing assistant	As above

My relationships with the nurses across the clinics varied, from warm friendships through to wary distance of me. There were several nurses I would consider I formed friendships with, or who became 'key informants': in Aangekom I spoke frequently with Sister Fourier and Nurse Tefo as well as Dorothy the receptionist. In Ba Banyane I spoke with Sister Habore most, based upon me often giving her a lift to the clinic in my car. In Christen I spoke most with Sister Vermaak. In Dula I would chat with several of the nurses, but there were none with whom I felt comfortable to regularly approach to ask questions and have

discussions with. Although I would talk to nurses a lot about the general workings of the clinic, I also spoke about a whole range of topics, relating to life in South Africa generally, and my life in the UK. At times this was a considered effort to get to know nurses, and also to understand their responses and reactions to some issues. At other times I would be tired and drained by the research, a long drive, the hot weather or being a long way from home, and in these instances I would instigate aimless chatter about the weather in the UK, or my family as that was all that seemed appropriate, rather than what could feel like an interrogation of tired nurses on aspects of their work. These reactions or judgements that I made happened in the context of specific relationships: I responded in particular ways to particular nurses.

I always sought to be friendly and approachable with the nurses, but this was not always clearly reciprocated. Often this may have been because of a lack of time in the context of a busy clinic, at other times the social distance or lack of confidence on their part, or just a general lack of interest: Sister Andrews in Aangekom and Sister Mamdala in Dula always seemed distant and aloof. There were also some nurses from whom I sensed a reluctance to talk with me throughout the fieldwork: Sister Thabo in Christen and Sister Sediba in Dula clinics in particular. This interpretation may be misplaced, or at least I never really understood any specific reason for any antipathy. One encounter in Aangekom illustrates these more distant relationships. I was in the staff room and Sister Molao and the pharmacy assistant came in, they offered me a drink and we chatted about the upcoming football world cup for a couple of minutes. They then shifted to talking in Sotho and largely ignored my presence. This episode encapsulates the sense of many of my relationships with nurses: of being polite and friendly towards me, but able and willing to ignore me.

When in the clinics I tried to present myself as always willing to adapt to what the clinic staff needed, and to help with small tasks where I could. I was careful to dress smartly, but without wearing – what I considered - expensive clothes (or watches). I kept my phone in my pocket, avoiding checking it or having it on display. However, I was clearly wealthy, relatively speaking. The nurses would have known I had travelled to South Africa, and they would see my car (even if inexpensive) parked outside the clinic. This is not a cause of social distance with nurses necessarily. The car I drove was often the least valuable outside a clinic when parked alongside those of the nurses. Nurses would also hold or display mobile

phones and jewellery very conspicuously. Despite my efforts to blend in, there was an obvious division with nurses relating to my precise purpose in the clinic. Some considered that I may be 'evaluating' them. I tried to convey that was not my purpose, and that my research was more general and not oriented to identifying or addressing specific shortcomings. Any difference between academic research and programme evaluation is however largely meaningless if you are on the receiving end – your work is still being scrutinised.

An obvious dimension of my relationship with the nurses was my identity of a white, British male and a non-nurse, whilst the majority of the nurses were women and black, with three white Afrikaans nurses (Sisters Fourier, Pretorius and Vermaak). As I referenced above, I was, in some respects, an obvious outsider. This had some clear impacts on relationships with nurses. Not being a trained healthcare professional meant conversation about clinic challenges and decisions, which nurses spoke to each other about, was removed from our relationship. Similarly, the absence of shared experience in terms of having grown up and lived in similar communities is another potential factor in any distance. Indeed, the identity of a white male in South Africa I considered to carry powerful historical connotations of power and control. I consciously sought to overcome this by presenting myself as deferential and respectful, trying not to impose on nurses or disrupt their work (beyond the imposition of being in the clinic in the first place) and also regularly stating my wish not to impose. That I might be a nurse or doctor was another misconception I anticipated and I sought at initial meetings with nurses to clarify that I had no healthcare training. By placing myself in a position where I sought not to impose and occupy a position of authority I hoped to overcome more damaging aspects of being an outsider, and to prevent nurses viewing me as a threat. That nurses often didn't feel compelled to be interviewed indicates a level of success at this. That I was able to engage most nurses in small talk regularly also indicates my presence in the clinic was not openly resisted. Overall, I considered that although some nurses were wary, the majority of my relationships with nurses were friendly if also formal and at times distant.

A particular dimension of this outsider identity was my lack of knowledge of Sotho and Afrikaans, as discussed in 2.1.3 above, languages used by many of the nurses and the

majority of patients as they went about their work in the clinics. There is the danger that my language limitations in effect exclude people from participating in the study (Murray and Buller, 2007). This was the case with Sister Pono in Christen clinic; her English was limited, meaning that our interview was brief and lacked in-depth discussion. However, that this was an isolated issue – with Sister Pono only – highlights how English was still a central language for nurses, and which the majority were articulate and competent in. Often communication between nurses was also in English, as well as occasionally in Afrikaans and Sotho (but principally English). Further to this, none of the nurses complained about talking in English, beyond occasional struggles to translate a particular word, or engage with my accent. My lack of Sotho and Afrikaans is certainly a factor in shaping my data and how I can interpret it, but it didn't fundamentally limit my relationships with nurses, and so allowed much data generation.

As well as personal dimensions and language, nurses' views of my study and identity as a researcher and how these were framed by their broader views of research influenced the data generated. I explore here firstly how some nurses showed slight scepticism towards research generally, second, their view of my study as a secondary concern in relation to their wider work in the clinic and, last, how aspects of the study design may have limited nurses willingness or ability to provide in-depth accounts of their work.

Some nurses expressed some scepticism towards the broader practice of research, which may have limited their willingness to engage with my study. Clearest expression of this scepticism came from the clinic manager in Ithata, who expressed concern about people doing research and then not reporting back to them. Any concerns about previous research studies were not widely voiced; indeed, Christen clinic was the only other clinic that reported being involved in research, and that was only in brief comments without any criticism clearly implied. In Dula clinic at my initial introductory meetings, there was open questioning of how the research would benefit them, indicating they weren't assuming it was necessarily a good thing for their clinic to be involved and that it would lead to positive outcomes. The other clinics didn't display this same questioning, although that doesn't mean nurses didn't quietly harbour these attitudes. My response to any initial scepticism of research was to acknowledge the limitations of some research practice in terms of not

taking care to communicate the purpose and likely benefits involved for participants, and consequently I sought to present a nuanced picture of how my research would have impact, on them and on health policy and services broadly.

A view nurses seemed to hold of my research in particular was of it being another work task to be done, and of being secondary to other work in the clinic. Generally, my interviews were done after nurses had seen all the patients, something I actively acquiesced in, but which nonetheless clearly illustrates how my research was prioritised below other concerns. This not only limited time for interviews, but also meant that nurses were often tired at the end of a day's work when I interviewed them. This position of my work as a secondary priority will have been compounded by my peripheral position within UCT and the Dept of Health and not having any visible institutional support for my study (as discussed in 2.1.3 above). The absence of this clear prioritising from other authorities within the Department of Health will also have potentially reduced nurses' willingness to prioritise my study above other concerns. In summary, my study, and specifically being involved in an interview, was something else to be done, and not necessarily something to commit energy and attention to.

The iterative, flexible study design may also have limited some nurses' efforts to engage with the study, and to provide in-depth accounts. The design of the study of achieving progressive focus meant that the initial focus also wasn't clear to the nurses, beyond my stated interest in their work across the clinics. For nurses who saw my research as an important project they would potentially have been enthusiastic to support my study, but in the absence of a clear focus – to them anyway – would not have been able to clearly direct their enthusiasm and to construct accounts of their work. The open nature of the study also frustrated some nurses. When interviewing Sister Kwena she seemed irritated by the open nature of the questions: my question of 'what impact has ART had on the clinics' was met by a short 'in what way' and then a short exchange where I emphasised I was keen to engage with her thoughts. On reflection, if a nurse was both willing to give up her time and to support a research effort that she considered was going to address an urgent health service issue (how to support PHC and ART) then to be faced by my open questions could be potentially frustrating. The iterative, flexible design was extremely valuable in bringing

specific, unanticipated insights, but may have shaped nurses responses by limiting their ability to construct accounts to respond to a specific focus, and in some respects 'help me'.

My presence as a researcher may also have impacted on nurses' behaviour. What I observed of clinic routines may have been shaped by the 'Hawthorne effect' of people changing their behaviour in response to being studied (Green and Thorogood, 2009). Sister Pretorius in Ba Banyane clinic commented on how my being in the clinic meant the other nurses arrived at work on time, rather than their usual late arrival. This comment is in the context of a long standing conflict between Sister Pretorius and Sister Habore, which I discuss below. Similarly, patients' accounts of nurses shouting at them didn't fit with the infrequent times I heard nurses shouting; this could reflect an aspect of patients accounts (that I discuss below under analysis), or that nurses were adjusting their behaviour in response to me being in the clinic. Although I likely had some influence, this is impossible to ascertain with any certainty, and although I explore and consider it through analysis I follow other researchers in judging that with the time I spent in the clinics and the other demands on professionals it is likely I didn't have a significant impact on normal practice (Pitchforth et al., 2010, Leonard and Masatu, 2006). From episodes and actions I did witness it would seem that nurses often weren't concerned about me witnessing apparently 'bad' practice: for example, the isolated instances of nurses shouting at patients, reception staff reading newspapers even though patients were waiting, or patients being sent home despite assurances this was not standard practice.

Patients

I didn't develop close relationships with patients, as their presence in the clinics was more fleeting, even if I did come to recognise some patients and we might exchange friendly greetings and nods of recognition. Overall I was an obvious contrast with patients. It was likely assumed by many that I was a doctor; several patients did at times refer to me as 'doctor' when passing and saying hello in the corridor as demonstration of that (I would always quickly insist I was not a doctor). The language barrier with most patients prevented much informal interaction, although I did have some conversations with patients whilst in the waiting areas, where I could explore their experience of care with some depth. These conversations were also at times initiated by patients, indicating I was perceived as

approachable and not threatening to at least some of the patients. When doing formal interviews with patients I worked with a translator when necessary, who would provide simultaneous translation; some interviews with patients I was able to do in English. As I explain below, these interviews were brief and intended to give more insight in to the more in-depth accounts I was able to get from nurses. Translators 'are active producers of research' (Temple, 2002, p845) and can be seen to provide a level of analysis through how they interpret respondents accounts. This work with a translator did allow challenges of my lack of knowledge of Sotho to be overcome to an extent, although there are still challenges in assuming the data produced from translated interviews allows direct access in to meaning. As such, I am cautious in my analysis in how I interpret patients' account, and don't place analytical emphasis on the superficial nature of the discourse (ie words used). As I explore in chapter 7, working closely with a Sotho speaking fieldworker would have allowed these language challenges to be overcome, even if financial constraints didn't allow that for this study.

Any social distance with patients I sought to overcome in a range of ways: by smiling at patients as much as possible, or through being deferential in how I behaved around the clinic (standing aside, holding doors). However, this was limited by the fact that I had a different level of permission to patients to move around the clinic: I could sit in reception, I could go in to the clinic at lunchtime, early or after hours when patients weren't allowed. There were a couple of instances in Ba Banyane clinic where young men visiting the clinic tried to get my attention, in a way that I interpreted as mocking and potentially threatening. On one of these occasions Esther, the cleaner, walked out and called a passing police car to deal with the men (boys is perhaps more apt); needless to say, this was not the sort of attention I wanted, especially as it was one of my first days in the clinic. That Esther responded in this way likely reflects a sense of responsibility she felt towards the clinic, and then me as part of that.

Managing the outsider identity

Throughout this section I have explored how my relationships with gatekeepers at UCT, nurses within the clinics and then clinic patients focussed on my position and identity of being an outsider. This identity of outsider involved several dimensions: first, my identity as

male, British and a non-nurse who doesn't speak Sotho or Afrikaans, and second, my institutional identity of being on the periphery of UCT's work, and having little visible institutional support for my study within the clinics. This outsider identity shaped the study by complicating access to the clinics and by closing off some areas of enquiry through imposing some limits on my relationships with nurses and patients. However, it also gave me a specific perspective on the work within the clinics, and also allowed me to develop specific relationships with people in the clinics, that in turn allowed insight that an 'insider' identity would have limited. Throughout this section I have also demonstrated how I sought to manage this outsider identity, to mitigate any limitations and to develop relationships that would support data generation. In the next section of the chapter I explore in detail the specific methods that I implemented within the context of these relationships.

2.2 Data generation

Data generation was organised around the framework I have described in section 2.1: a combination of interviews and observation used for a sustained period in a small number of clinics, with data generation guided by a process of progressively developing focus on study findings. In this section I discuss in detail how I implemented the two methods of data generation, observation and interviews. I first discuss observation and then secondly my use of interviews, and for each I outline first the key principles and then the detailed process of implementation.

The dataset resulting from my data generation is summarised in figure 2.5 below, which highlights the key characteristics of the data: over 250 hours in the clinics, 34 interviews with nurses, 6 with clinic staff and 21 with patients. This quantification of the data set demonstrates the breadth of data gained across the four clinics. There are also key qualities of the dataset that I demonstrate through the discussion below, and in presenting my findings through the results chapters that follow: data that allows a combination of perspectives on clinic phenomena, data that focuses on the detail of clinic routines as well as the context for these routines of nurses' lives and the clinic environment, and data not bound by a preconceived framework and instead that reflects an effort to engage with the specific clinic contexts and their diversity. As well as data extracts in this chapter I have also included additional material in appendix 4 to illustrate the nature of the data set.

Figure 2.5 Summary of data collected

Data collection	Round 1: Feb-May 2009	
	Observation and time in the clinics (number of days/hours)	Interviews
Aangekom	34 (85 hours)	8 nurses, 1 members of clinic staff, 8 patients
Ba banyane	21 (54 hours)	3 Professional nurses, 5 patients
Christen	15 (34 hours)	5 professional nurses, 2 members of clinic, 5 patients
Dula	21 (60 hours)	7 professional nurses, 3 members of staff, 3 patients
Esita Fontein Geheim Hantle Ithuta Joyful	In total, 19 visits (29 hours)	11 nurses
Total	258 hours	34 nurses, 6 clinic staff and 21 patients

2.2.1 Observation

The process of generating data through observation was principally driven by a concern to develop a progressive focus on study findings, overlaid with considerations of my identity and role in the clinic and then finally how I sought to be flexible and adapt to the clinic contexts in response to how I perceived them; I discuss each of these three considerations in turn below. After discussing these three foundational considerations I move on to describe in detail the process of being in the clinic and observing to generate data.

Developing focus

My approach to observation in the clinics was driven mainly by a concern to move from an open and unstructured approach to observation, to a more focussed and structured approach to support the development of well evidenced findings. Reflecting this, phase 1 of fieldwork involved me trying to record whatever seemed of significance for understanding important clinic routines, but also to be open to anything that could help in understanding these routines. Observation at this time was then in some respects an opportunity to be in the clinic, to experience it, and to also develop relationships with nurses that could support the effort to implement interviews. Phase 2 of fieldwork saw a slight progression towards more structure to my observation, with efforts taken to explore specific themes, such as patient arrival times and experiences of waiting that had seemed of significance in early

fieldwork. Phase 2 was also still an opportunity to record new and unanticipated events and actions. Phase 3 and 4 of the fieldwork saw a greater focus to observation, in terms of an effort to note and count certain phenomena and to ignore others; for example, noting how often consultation room doors were left open, whilst not engaging with issues around the clinic filing and information systems which I decided not to explore. I also reduced the overall emphasis on observation as a method to generate data, and instead placed more emphasis on interviewing nurses, on the grounds that interviews were a better opportunity to explore possible meanings, as well as providing a route to check my emerging findings gained through observation.

My identity: observer-as-participant

The role I sought to adopt in the clinics was that of an 'observer-as-participant' (Green and Thorogood, 2009, p133 citing Gold); rather than observing with no interaction, I would, in various ways, interact with the clinic staff and patients and participate in the daily life of the clinic. In the initial stages of phase 1 of the fieldwork I would just observe the clinic and try and ask questions and have passing conversations with nurses. Observing the clinics was however difficult, with much care being private – ie held behind closed consultation room doors - and busy waiting areas limited me further in where I could actually sit in the public areas of the clinic. Overlapping with this challenge was an unease I felt about my position and lack of a clear role within the clinic (stemming from my peripheral position I discussed above); not having any obvious purpose is a stark contrast with the hectic and chaotic nature of nurses' work and the ill health and occasional desperation of many patients. Any unease I felt was often highest when sitting in the waiting areas. A principle concern I had was that I was disrupting the waiting system; my lack of Sotho meant I was unable to fully comprehend and explain myself to patients, and so couldn't understand the waiting systems or explain I was not aiming to join it. In response to this 'lack of purpose' I offered to help. When I first suggested this to Sister Terene in Aangekom clinic – the first clinic I observed - she immediately asked me to help Dorothy in reception. In Ba Banyane, Christen and Dula clinics I also offered, and so across the four clinics I did varying administrative tasks, although this was not 'full time' when I was in the clinic and more ad hoc. Work could include helping to register patients on arrival or with filing. This work gave me a clearer justification for being in the clinic, it felt, and also allowed me to be in reception and participate in what were often the main meeting points for nurses. This allowed me to see

many of the 'back office' functions of the clinic (filing, paperwork, use of the phone, processes for arranging tests) as well as allowing me to make passing conversation with nurses. This was important in building relationships and likely supported the openness and candour often evident in interviews that would follow.

The identity of observer-as-participant was shaped and limited by my lack of Sotho, the dominant language in the clinics. The majority of patients were Sotho speaking, as were many of the nurses; although several nurses spoke little or no Sotho, instead speaking Afrikaans or languages like Xhosa and Tswana. My lack of Sotho meant I was unable to directly engage with all the activity in the clinics, reflecting my discussion in 2.1.3 above, and was instead limited in some instances to recording descriptions of events, to explore their meaning at a later date. For example, one day I was sat in a busy and loud waiting area. A nurse shouted in Sotho across the waiting area at a specific patient, quite bluntly it seemed to me, and without smiling; the patient then shouted something back and followed the nurse in to a consultation room, again, without smiling. From my position immersed in the culture of the UK, this could suggest that there was an argument or indicate poor communication and relationships. This could also reflect particular patterns of language and relations and their meaning, that don't hold across cultural settings. A critical caution in interpreting behaviour is a key part of any social research but throughout my observation I had to elevate this caution, reflecting my linguistic and cultural naivety. As such, in making any notes I would attempt (as much as is possible) to separate description from my initial interpretations; I would literally write, in this instance, 'nurse shouts across to a patient' and alongside this indicate a potential signal of poor communication for me to explore later. I would then sometimes later ask the specific nurse involved or someone else (sometimes in other clinics) what had happened or what they thought about it. This reflects my awareness of how preparing field notes involves processes of construction and interpretation (Atkinson, 1992) and to reflect on this to foster validity. Much of the conversation between nurses in the 'back office' areas of the clinic was however in English and so I was able to observe this more directly, and to access meanings being attached to specific events or actions.

Flexibility

Following the ethnographic principles underpinning the research I sought to be flexible and to adapt to the clinic contexts. The first dimension of this flexibility was in how I adapted observation to my efforts to get interviews. As I discuss below, interviews were difficult to schedule in advance, and so part of the purpose of observation was to be in the clinic and to develop opportunities for interviews. For example, observation of public areas of the clinic could be interrupted without notice by a 30 minute interview when a nurse came and found me and told me they were available, and after which I would continue observation. Alternatively, I might be doing an interview, and people might be coming and going from the room, or there might be activity I could hear outside, which I would also note. Observation and interviewing were therefore not entirely distinct activities, with my time in the clinics shifting between the two. I also adapted observation to what I considered to be the needs and interests of nurses and patients. As mentioned in the discussion in section 2.1.5 around ethics, I sought to avoid disrupting care, and to be a burden on those I was working with. As a result I chose not to observe consultations, and would also avoid standing in parts of the clinic at busy times when I would disrupt waiting systems.

Being in the clinics

Observation involved me visiting the clinics alone and spending time in the public areas of the clinic. On average, I would spend around two hour periods in a clinic for each visit, sometimes going back to the same clinics twice in one day. Within these periods of observation I would observe public areas of the clinic, have informal conversations with staff, help with minor administrative tasks and also conduct interviews. Observing for approximate two hour periods was intended to allow me to maintain my focus and concentration, through ensuring I had time away from the clinics to reflect and refresh myself, and to ensure I had sufficient time to make notes.

I initially observed each clinic for an extended period, later switching to an approach of visiting a different clinic each day. In the first period of fieldwork I visited the four clinics sequentially, staying in each for an approximate period of two weeks. As I was unfamiliar with the contexts and the nurses, I considered that this intensive focus would allow me to immerse myself in the detail of the clinics and to build relationships with the nurses. In the

following periods of fieldwork I instead went to a different clinic each day, or for just two days in a row in the case of Christen and Dula clinic which were a considerable distance from my base in Bloemfontein. This shift in approach was intended to allow me to pursue ideas across the clinics and to facilitate comparison. I also sensed it made me less of a burden on clinics. It also allowed me to remain fresh, rather than staying away from my central base in Bloemfontein. I found being alone for two week blocks in isolated parts of South Africa emotionally difficult, and so I latterly tried to avoid doing this.

Figure 2.6 below summarises the time spent in the clinics to indicate the time spent observing. As above, observation and interviews were not distinct activity, and so within the time indicated is included time spent interviewing nurses and patients. Christen and Dula clinics were much harder to access, being several hours drive from my base in Bloemfontein. As a result I spent slightly less time in those clinics, and in the final rounds of data collection made isolated visits as a way to check if any major changes or issues had arisen, and to try and get interviews that would allow me to explore emerging themes. Aangekom clinic was much easier to access, and I would often combine a visit there with visits to other clinics. Ba Banyane was much smaller with correspondingly less staff and less patients, and so I judged that I could correspondingly spend less time there whilst still being able to gather data that would allow description and exploration of clinic routines. With over 250 hours spent in all the clinics, the data gained from observation allows a detailed insight in to life within the clinics.

Figure 2.6 Summary of time observing and being in the clinic

	Round 1: Feb- May 2009	Round 2: Oct – Dec 2009	Round 3: March 2010	Round 4: May 2010	Totals
Clinic	No of days/hours	No of days/hours	No of days/hours	No of days/hours	
Aangekom	11 (47 hours)	11 (19 hours)	7 (12 hours)	5 (7 hours)	34 (85 hours)
Ba banyane	7 (28 hours)	8 (15 hours)	4 (8 hours)	2 (3 hours)	21 (54 hours)
Christen	9 (22 hours)	5 (11 hours)	0	1 (1 hour)	15 (34 hours)
Dula	9 (33 hours)	8 (21 hours)	4 (6 hours)	0	21 (60 hours)
Esita		1 (1 hour)		2 (4 hours)	3 (6 hours)
Fontein		1 (1 hour)		2 (4 hours)	3 (6 hours)
Geheim			1 (2 hours)	1 (3 hours)	2 (5 hours)
Hantle			3 (1 hour)	3 (2 hours)	6 (4 hours)
Ithuta			Initial visit	1 (half an hour)	1 (half an hour)
Joyful			1 (2 hours)	3 (6 hours)	4 (8 hours)
				Totals	258

When in the clinics I would aim to observe the public areas of the clinic, moving myself around to try and engage and observe with as much different activity as possible. This sampling across time and the clinic space meant I was variously sitting or standing in waiting areas, the clinic reception, staff rooms and offices and then adjoining corridors, as well as outside the clinic. Regardless of where I was, I would observe what was going on, but then also have brief conversations with nurses, clinic staff and occasionally patients. During all visits I would try to combine observation with interviews. Interviews usually happened in the afternoons, when the clinics were quieter, and so I generally made sure I was in the clinic from 2pm onwards.

Opportunities for observation were more limited than I had anticipated when planning the study. Similar studies in South Africa (e.g. Lewin, 2004) had found many aspects of care provision to be public and so easy to observe. That this wasn't the case in the clinics I studied reflects different trends in the actual physical layout of the buildings and how it was used. There was a focus on consultations with patients in private rooms, limiting what I could observe of the care process. This was compounded by busy clinics, with staff often too busy to engage in passing conversation or for me to ask questions. In addition, waiting areas were often full, with people standing. My presence actually sitting in the waiting area not only risked disrupting routines and causing confusion, but also quite literally taking a

seat from the seriously ill. These limitations and observations led me to spend significant amounts of time in the reception areas or back office areas of the clinic, like staff rooms, which still allowed a good view of many public areas of the clinic. However, there were then areas of the clinic relatively neglected: in Aangekom clinic there was a particular side corridor where I would only walk through briefly, or find excuses to walk through; in Dula clinic a separate outside building of just one room was used for care for chronic conditions, and it took me a little while to feel comfortable asking the nurse if I could observe her work in there. Although what I observed had some limitations the length of time I spent in the clinics meant I still had a broad coverage of clinic events and processes.

I used observation to generate data through taking brief notes when in the clinics to be later written in to longer field notes. I carried a small notebook and pen in my pocket, and would make brief notes as I was in the clinic; this would often be just a few words on what I had observed, although sometimes I wrote longer reflections if time allowed. I would also note analytical reflections, but separate these interpretations from the detail of what I was actually seeing and hearing. There were many instances when I felt making notes would be intrusive. In common with many ethnographers, trips to the toilet would be used in order to quickly make a few notes. I did however try and leave my notepad in public areas to reduce suspicion it may generate (Brewer, 2000). The obvious corollary of this was an element of censorship in what I recorded (e.g. instances of apparently bad practice by members of nursing staff), although I would later record these when I typed up my notes at length in the evening. I would use the brief notes made during the day to type up longer fieldnotes. I would try and type these notes up as soon as possible, within a few hours of being in the clinics usually, but at most within 24 hours. An average day in a clinic would lead me to write approximately 1000 to 1500 words of notes, although this varied considerably.

The field notes I made on the basis of my observation had specific characteristics. This extract below illustrates some key aspects of my approach:

"I arrived at about 1:30. The clinic was deserted this time as I walked in. Sister Habore was in reception arranging the computer - it had stopped working and she was trying to figure out whether it was the computer or the extension lead (it turned out to be the extension lead). She said the dust in the clinic

sometimes caused problems for the computer. I helped her with the computer a little bit, and then I sat down on one of the chairs leading towards the consultation rooms.

Four young men (approx 20years) came in to the clinic. They were laughing and joking a little, and it seems they just wanted condoms - which they all took, and all said hello to Sister Habore and seemingly exchanged pleasantries. They all also chuckled and smiled in my direction, in a conspiratorial 'yeh, we want condoms' sort of way. After they left I said to Sister Habore that it was good they were coming in for condoms. She said that we didn't know what went on in privacy though, and whether they would be used. We had a short conversation about this - I referred to my experience in SRH and how it is one thing to give people condoms, and quite another to get them to use them. She said that in South Africa (based on her general experience, not from what specific patients had told her) there was the problem that men who were the breadwinners would often refuse to use condoms.

I asked about the patients coming in the afternoon when two of them turned up. One patient turned up, but when she saw us through the glass door she smiled and sat down outside, another woman joined her a few minutes later. Sister Habore said that they can come anytime, she referred to it as one of their rights as patients, to be treated at anytime when the clinic was open. However, she said she discouraged them from coming in the afternoon because if there was an emergency then they may not be seen."

This extract illustrates a number of themes in my observation data: 1) The variation and detail of clinic life: that Sister Habore was fixing a computer was something I had never seen before, and is the sort of mundane clinic activity that interviews would likely not have captured, and gives contextual insight in to the pressures and challenges nurses faced. 2) Clinic exchanges: the interaction between Sister Habore and visitors to the clinic, like the four young men, are recorded cautiously reflecting limitations of language, but then I was also able to reflect on these exchanges sometimes with staff. 3) Exploring emerging themes and issues: the final paragraph shows how I used observation to explore analytical themes, in this case trying to understand the scheduling of care, a key focus in my analysis in chapter 3; the late arrival of patients is also something I tried to explore in interviews. This extract, and those included in appendix 4, give an insight in to the data gained through observation and how I was able to access the detail and context for nurses work, as well as engage with specific care routines as well.

2.2.2 Interviews

The majority of interviews were with professional nurses in the four clinics, but I also sought interviews with other clinic staff, patients and professional nurses who are living with HIV, which I discuss separately. I consider interviews to include both the formal, recorded conversations, as well as extended conversations with nurses during observation where I would take extensive notes. I first of all outline key considerations around sampling and arranging interviews and then the semi-structured approach and how that was linked to efforts to be flexible and develop rapport. I then go on to discuss key features of how the interviews were implemented within the clinics.

Sampling and arranging interviews

The focus for interviews were professional nurses. I had originally planned to be purposive, seeking to interview nurses both directly involved in delivering ART and generalist PHC nurses as well as nurses with different levels of experience based on their length of service and staff category. However, owing to the small size of the clinics, the limitations on who was available for interview and my own lack of control over large parts of the process, the strategy increasingly became opportunistic and engaged with who was willing and available. This reflects how I interacted in the clinics: I would observe the clinics and also make it clear to nurses that I was available for interviews whenever they were free. I usually suggested the afternoon, as this was when the clinics were often empty of patients. This also echoed what many nurses said, as well as Kerry. I would then be in the clinic from at least 2pm and if a nurse was available (i.e. not obviously providing care to a patient) I would ask for an interview, or nurses would approach me saying they were available. An additional need to be opportunistic was to support field relations: it became very clear that all nurses expected to be interviewed – some welcoming it, others seemingly more begrudging. However, it became clear that the choice wasn't necessarily mine as to who I could interview.

I approached study of the specific issue of how nurses living with HIV experience their work through adopting a parallel sampling strategy, alongside interviewing nurses from the sampled clinics. As I discuss below, there are complex ethical issues related to exploring HIV status and the stigma involved. In several interviews nurses raised the general issue of

nurses living with HIV or referred to other nurses they knew living with HIV, allowing me to explore aspects of the issue. However, none discussed their own status. Rather than rely solely on nurses spontaneously and voluntarily disclosing their positive HIV status I adopted a 'snowball' approach (Browne, 2005) of trying to interview openly HIV positive nurses in South Africa through reaching out via key informants and contacts in the department of health in the Free State. They took information on the study and distributed it amongst nurses they knew to be HIV positive, inviting them to contact me; there was no direct contact from me, and I was never told to whom the information was given (the letter I gave out to be distributed is included in appendix 4). I also spoke to the Treatment Action Campaign and the Aidslaw project, two prominent civil society groups in South Africa. They didn't have contact with any HIV positive nurses. I also contacted the HIV clinicians' society and a contact there offered to pass on information (through personal rather than institutional contacts). I lastly sent information around a popular email listserve for people working on HIV in South Africa. This approach didn't lead to any interviews, or even initial contacts and expressions of interest. I reflect on this briefly below when discussing ethics, and also in the following chapters.

Interviews with clinic patients and other clinic staff were purposive, although with clinic staff this became opportunistic, again reflecting the realities of who was available and willing to be interviewed. I sought interviews with patients as a way to bring insight to the data I was collecting from nurses. Although patients' experiences of care would give valuable insight, there were logistical and resource challenges associated with this and so I elected to conduct a small amount of interviews. In Aangekom, Ba Banyane and Christen working with a translator I would approach patients as they were leaving the clinic. We approached a range of people (young/old, men/women, pregnant women/not, ART/non-ART) to try and get a broad perspective on experiences in the clinic. In Dula Clinic I was unable to arrange a translator and so instead asked nurses to introduce me to patients who spoke English and who would be interested in being interviewed. I also spoke informally to patients in the corridors during clinic observation.

Semi-structured approach, flexibility and rapport

The interviews were typical of the iterative, reflexive framework outlined earlier. The interviews were semi-structured (see appendix 5 for example interview schedules). I had a list of issues to be covered although the interview was open-ended and free to pursue themes that were raised in discussion. Although I retained the power to shape interviews and the issues covered, I was frequently relatively powerless to determine the length and location of interviews and so the extent to which I could cover the issues I wanted to. I would often let interviews last no more than 45 minutes as sometimes nurses would start to look tired and occasionally evidently lose interest. Nurses would also sometimes say they had twenty minutes available (or less). I adjusted interviews to these demands, as to try and do otherwise would risk field relations, which I needed to maintain in order to get repeat interviews with the same nurses. Interviews were also interrupted or curtailed by phone calls, patients arriving at the clinic or other events, leading me to constantly reformulate what I planned to discuss during an on-going interview, but also trying to explore any significance of these emerging events. At other times nurses would be hungry and exhausted in trying to fit in an interview, and I would end these early, sensing it was unfair and not wanting to jeopardize field relations. In later periods of data collection to try and work around these constantly shifting timetables for interviews I would make a list of questions that I would prioritise during an interview, with others that were less important that I would be willing to not explore.

The adaptation of interviews at short notice and as they were being conducted was not simply a response to nurses' control, but something I also actively managed and agreed with, representing a recognition of the many pressures nurses were under. I was aware that my study and an interview with me was another demand on nurses' time. In line with this, I shaped the interviews in several ways, to adapt to (what I perceived as) the needs and position of control of nurses. The first few days in a clinic I made the interviews short, in an effort to ease myself into the clinic and not to give an impression that the research was especially onerous. I was also influenced by Oakley's feminist approach to interviewing (Oakley, 1981), in that I sought to overcome hierarchy and see establishing rapport as essential. This recognizes that it can be necessary to engage with interviewees and discuss personal issues (*ibid*). This also reflected that nurses were interested in me – an outsider visiting their clinic – and so I considered it only fair, ethically, to allow nurses 'in to my

world', as a counterpoint to them letting me in to theirs. An example of this was an interview where a nurse mentioned her own experiences of going for a HIV test, I then also referred to my own experiences of testing as a gesture to reciprocate the honesty and candour she was showing towards me. I was also reluctant to be antagonistic and explore 'bad practice' in any direct way. I sometimes shied away from asking questions in these areas as they seemed too confrontational, and would only ask them if they fitted easily with the existing flow of conversation. Additionally, there was a risk of desirability bias in any response and so occasionally not worth raising. For example, it was difficult to talk about issues of patients being sent home early, or nurses shouting at patients. Instead, I would wait until these issues were raised by nurses themselves, or, I would explore issues through framing them as something I had seen in other clinics.

Being in the clinic and doing interviews

Figure 2.7 below gives an overview of the interviews I conducted, showing how the total of 34 interviews with nurses, and then interviews with 6 other members of clinic staff and 21 patients were spread across the sample of clinics, focusing on the four original clinics.

Figure 2.7 Summary of interviews across the clinics

Group	Four focus clinics	Six additional clinics	Interviews
Nurses	23	11	34
Clinic staff	6	0	6
Patients	21	0	21

Figure 2.8 gives a more detailed outline of the interviews conducted, also illustrating the repeat interviews I was able to do, and also highlighting how the first round of data collection was a focus for interviews in the four focus clinics, and then much less in later stages (and consequently more observation, as above). The interviews in the six additional clinics in the later stages were then an opportunity to explore emerging themes.

Figure 2.8 Detail of interviews

	Round 1: Feb-May 2009	Round 2: Oct – Dec 2009	Round 3: March 2010	Round 4: May 2010
Clinic	Interviews	Interviews	Interviews	Interviews
Aangekom	Nurses: 7 Sisters Terene, Marais, Botala, Tefo, Fourier, Kopo and Andrews. Clinic staff: 1 One lay counsellor Patients: 8		Nurses 2: Sisters Fourier and Nurse Tefo (both repeat interviews)	Nurses: 1 Sister Kwena
Ba banyane	Nurses 3: Sisters Habore, Peo and Pretorius Patients: 5		Nurses: 1 Sister Habore (repeat)	
Christen	Nurses: 4 Sisters Seporo, Vermaak, Ngata, Pono Clinic staff: 2 Clerk and a cleaner Patients: 5	Nurses: 1 Sister Kgaolo		
Dula	Nurses: 7 Sisters Fula, Mamdana, Nomkhula, Sehlwela, Sediba, Setempe, Kgaba Clinic staff: 3 Nursing assistant, clerk and a pharmacy assistant Patients: 3		Nurses: 1 Sister Fula (repeat)	
Esita				Nurses: 3
Fontein		Nurses 1		Nurses 1 (repeat)
Geheim				Nurses: 3
Hantle				Nurses: 1
Ithuta				Nurses: 1
Joyful				Nurses: 2

Interviews in the early rounds of data collection followed a similar format. I would ask a nurse if she had time for an interview, or they would approach me when they were free. We would then usually use their consultation rooms, or a clinic office for the interview; this meant that the majority of interviews were done privately, although this wasn't always possible, and there were often interruptions, reflecting how interviews were still done in clinic work time. Appendix 5 gives examples of interview schedules that I would use to

guide my questions. I didn't follow these schedules rigidly, instead I combined discussion of specific areas with efforts to pursue specific issues raised by nurses. The interview extracts in appendix 4 illustrate how I used this structured approach alongside open-ended and responsive questions. Interviews ranged in length, but averaged approximately 45 minutes.

Interviews in later phases of fieldwork were more structured towards exploring emerging themes. These interviews would normally start with a general, opening question ('how is the clinic') before moving on to explore areas of practice I was seeking to explore. This was structured around, for example, exploring issues of how services were (or were not) integrated, or how the patient waiting system varied day by day. Questions would also often be framed through experiences in other clinics, e.g. 'another clinic I have worked in X happens, does it happen here?'; this was especially the case when I was trying to explore instances of 'bad practice'.

In later interviews, I also began to directly explore some issues that I had avoided openly addressing in early stages of the research. For example, I avoided open reference to the hypothesis that ART and HIV care may be fostering more patient-centred care, instead referring to the potential for broad change in care. This was out of an effort to reduce desirability bias. In later stages I openly explored this idea, suggesting it as one possible change. For clinics that I was returning to I also gave transcripts of our first interview to each nurse. I had done this in the hope of encouraging reflection as well as a spirit of transparency, but more realistically as a way to spur interest and engagement in the research. This didn't seem to work; it wasn't clear whether nurses read them, or at least none showed keen interest. A possible factor in this is the nature of the interview content, of nurses largely recounting their everyday work in the clinics.

There were instances in the later stages of the research where nurses chose not to have interviews recorded. This then required me to take notes during the course of the interview. Reflecting my lack of shorthand skills and the need to maintain the pace of the interview, the notes I made were often brief and acted as reminders for when I wrote up the interview later on that day. In analyzing these texts I focus on the involvement of my

interpretation in these accounts of interviews. It is likely my recollections were influenced by the emerging ideas that were shaping the questions in the conversations.

In the later stages of the research I struggled to interview nurses. For the third round of fieldwork (which was then planned as the final period), I aimed to conduct interviews in the four original clinics as well as the new clinics. Despite visiting the clinics, and making myself available as I had through the early stages of fieldwork, I was rarely able to get interviews. There are a range of reasons for this: with broader health system changes and initiatives the clinics did have additional demands, notably a nationwide immunization and then HIV testing campaigns; staff were also on leave or out of the clinics for training courses; and in the clinics I returned to there was likely a loss of interest and enthusiasm for the study. A further dimension to any loss of interest is that the research may have served nurses' purposes after the first interview: they had had an opportunity to voice their frustrations, complain or discuss their anxieties and stress. A corroboration of this point is the enthusiasm for the study from many of the clinics in the increased sample, who showed the same enthusiasm as the original four clinics did at the start.

Interviews with clinic staff – clerks, pharmacy assistants etc – were conducted as with nurses; I would make myself available in the clinic and staff would either approach me or I would ask them for an interview if they looked available. Interviews with patients were more structured than interviews with nurses and clinic staff; this was in an effort to keep interviews short, but also reflected the overall purpose of gaining an additional perspective on general clinic functioning, rather than exploring the nature of specific routines. Interviews generally lasted around 15 minutes and followed a structured schedule (see appendix 4) intended to get an insight in to their overall perspectives and experiences; as I have described elsewhere this was to provide critical insight in to nurses' accounts and my own observations. The translator I worked with provided simultaneous translation within interviews, allowing me to explore and follow up on occasional issues raised.

Transcription and preparation of data

Transcription of audio-recordings of interviews involves decisions about what is and isn't important for analysis, in effect being a process of translation (Green and Thorogood, 2009, p101). I transcribed to ensure an accurate recording of what is said, according to the purpose of the analysis, and so didn't note lengths of pauses or emphasis on certain words. I transcribed several interviews myself to begin with, later employing a professional to do this, which I then checked to ensure validity and consistency of the data.

2.3 Analysis

My analysis strategy can be summarised as a thematic analysis that aimed to develop theory grounded in the study contexts. Through my analysis I sought to develop an understanding of care grounded in the specific clinic contexts I had visited; I aimed to develop theory that accounted for these specific contexts, rather than imposing a preconceived framework and consequently risking neglecting engaging with the breadth of the unexplored work of nurses in PHC in low and middle income settings. A second key feature of the analysis, based on ethnographic principles, was aiming to achieve progressive focus of the analysis through the course of the study, with analysis beginning with data generation, and interacting with it (Hammersley & Atkinson, 1995). A third key feature was a thematic approach to analysis (Ezzy, 2002), based on an inductive approach of deriving analytical concepts from the data, rather than imposing concepts on the data (ibid), with data and existing theory in dialogue to avoid forcing data in to existing theory, and instead working to integrate existing theory in to an emerging theory (ibid). In the rest of this section I elaborate on this approach to analysis: first by clarifying each of these key principles of being grounded, progressively achieving focus and combining existing theory with the emerging theory; secondly I outline more detailed considerations and analytical strategies of coding, constant comparison, triangulation, deviant case analysis and reflection; lastly, I account for how I actually implemented and used these principles through the process of analysis.

2.3.1 Analysis principles

My reference to developing theory that is grounded is based on achieving theory that is derived from my data rather than an overarching and preconceived hypothesis (Nugus, 2008, p191, citing Punch). I distinguish this 'grounded' approach from the more specific approach of grounded theory (Glaser and Strauss, 1967, Charmaz, 2006). Grounded theory follows specific steps, notably of theoretical sampling and ongoing combination of data collection and analysis until saturation (Green and Thorogood, 2009). Although I iterated between data collection and analysis, as I outline further below, I differed from other aspects of grounded theory as I considered them not practical considering the limitations placed on my study, i.e. continual data collection until analysis was complete wasn't practical.

Analysis was driven by an overall understanding that it should follow a funnel structure, becoming increasingly focused over time (Hammersley & Atkinson, 1995). This progressive focus involved an initial open stage of analysis where a range of conceptual categories were developed and explored. This open analysis was then replaced by an effort to develop firmer conceptual categories and explore theoretical explanations (ibid). Ezzy's account of thematic analysis can be seen to operationalise this effort to achieve progressive focus, moving through stages of open coding, axial coding and finally selective coding (I elaborate on these ideas below). I build on this idea of three stages in coding to outline key steps in my analysis: an initially open approach, followed by efforts to develop focus, and lastly prioritising linking ideas and testing the analysis. Each of these steps of analysis involved distinct approaches, as I outline in section 2.3.3 below.

My analysis sought a theoretical understanding of the clinics and care through combining existing theory with my own emerging analysis. This combination of existing and emerging theory reflected "an ongoing dialogue between data and theory" (Ezzy, 2002, p93). This dialogue was driven by the principal concern that my description and explanation of the clinics should be driven by the specific contexts, and not be forced in to pre-existing categories and theory. As I described in my initial literature review, I sought to avoid imposing explanations on the clinic, and instead tried to respond to the detail of the specific contexts. Existing theory was therefore used on the basis of how it could serve an

understanding of the specific context, and was adapted to the data, rather than the data being forced to fit the theory. This approach has the effect of reconstructing existing social theory (Burawoy, 1991), where an effort is made to improve theory when it is challenged by a particular area under study. For example, ideas of patient centred care shaped the initial study question, but the process of analysis involved this theory being adapted to fit with the specific clinic contexts (I explore this in chapter 3, emphasising the need to consider issues of scheduling care, and discuss in chapter 7 an alternative conceptualisation based on this). The dialogue between data and theory also involved theory that hadn't originally been considered in designing the study. This process involved emerging ideas resonating with existing theory, with this existing theory then taken on, modified and ultimately integrated in to the ongoing analysis (Ezzy, 2002). The role of agency and structure in my final analysis reflects this approach, as initial ideas around agency that emerged from my data were further developed as I engaged with this literature and then returned to my data to further explore this.

Whether I was concerned to use theory that I considered at the start of the study, or theory that emerged as relevant later on, there was a constant process of iteration between my data and literature to develop the concepts that analysis focussed on. Concepts that emerged from my data were refined by insight from existing literature. I would then explore these potentially refined ideas with reference to my data, and adapt accordingly. For example, in chapter 4 I explore the influence of structure at different levels; this process of identifying structure at the level of clinic rules and clinic context involved the consideration of a range of conceptualisations of structure and agency, and how they would be useful in interpreting my data. The ideas of Strong and Giddens were what I eventually focussed on, after exploring how they would allow me to get insight in to the breadth of my data. The overall theoretical framework I outlined in section 1.3 in the previous chapter is the outcome of this process of identifying theory that resonated with initial ideas, and then taking it on and adapting it to correspond to the specific characteristics of my data set. In summary, analysis of my data was primarily driven by a desire to respond to the detail of what I was generating, with existing theory being adapted and used to explore where useful.

2.3.2 Analysis strategies

Before discussing the detail of the process of analysis I here outline key strategies which built on the principles just described: the coding and management of data, triangulation between data sources, constant comparison, deviant case analysis and then reflection and feedback.

Constant comparison

Constant comparison is central to ethnographic analysis (Kleinman, 1992) and is a process of exploring whether data fit the emerging categories (Elliot and Lazenbatt, 2005) and so developing the properties of a code/category (Ezzy, 2002). As a process this ensures that the concepts I discuss and present through my analysis account for my data. For example, an area I discuss in chapter 5 in exploring nurses' agency is around how nurses are unsupported. I originally had an open code with a range of data around how nurses felt unsupported and 'abused' by the broader health system. I was using this to question and explore the idea of nurses being independent practitioners and how they were actually in a difficult or subordinate position. As I continued to explore the data I focussed it in to two more specific themes, about nurses being neglected, and then nurses being controlled.

Deviant case analysis

Exploring deviant cases in comparison to emerging ideas is a key principle of challenging and developing insights (Green and Thorogood, 2009). On one level careful consideration of deviant cases was integral to forming, and changing, the concepts I was trying to work with. As an example, Esita clinic was the first of the additional clinics I visited, and their claim to have fully integrated ART with other services was a marked contrast with the other clinics, where my emerging conceptualisation of care focussed on nurses having individual services they focussed on. This apparently different approach in Esita clinic led me to reconsider nurses' accounts from the original four clinics. The experience from Esita made me realise that nurses had different and varying understandings of integration, and eventually I developed a local, more emic understanding of integrated services. On a second level considering deviant cases led me to more in-depth insight of the concepts I was considering. For example, an open conflict between Sister Habore and Sister Pretorius

in Ba Banyane clinic initially seemed 'exotic' or deviant, but as I considered it more it actually revealed core aspects of nurses' professional relationships and how they had little power and control over each other.

Triangulating data

Multiple methods – in this case interviews and observation - allow triangulation to cross-check findings (Bryman, 2004, p545). During analysis I coded interview and observation data together, including it in the same categories and analytical scheme, on the basis that all data regardless of method allowed insight in to the phenomena I was focusing on. When apparent contradictions emerged I used these as an opportunity for engaging with the complexity of the phenomena and to also consider further analysis. An important example of this was how patient accounts of care were often negative, with nurses often more positive: this points towards the need to reflect on the social processes and context underpinning these accounts, leading to reflection on the period of data collection, salient issues with influence as well as my own relationships with nurses or patients. Conflicting accounts also point towards additional complexity of the phenomena under question or that the same phenomena have different meanings for those involved.

Feedback and reflection

As my analysis progressed I received comment and feedback on initial ideas and writing from supervisors and other colleagues, leading me to reconsider aspects of my thinking. A significant event in this process was when I returned to South Africa to present initial findings and draft recommendations to the clinics, in tandem with attending a social science conference (Guise, 2011). This didn't necessarily function as 'respondent validation' on the basis that respondents' comments on an analysis should be treated as another form of data rather than as giving validation (Hammersley & Atkinson, 1995). Instead, I saw it as an opportunity to get additional perspectives on my initial conclusions and to explore the feasibility of my draft recommendations, and – perhaps primarily – as meeting an ethical responsibility to convey to the nurses and clinics I worked in that their time and commitment to the study was being translated in to rigorous research and that I was seeking to support health care and nursing, rather than just furthering my own research ambitions. I developed a summary report of my initial findings on care, linked to draft

recommendations (the report is included as appendix 5). This was purposely written to be concise to foster both nurse and Free State Dept of Health engagement with it if they were willing to. I visited as many of the sampled clinics as was possible in the short time I had available and discussed it with nurses. Although I reported back in part out of a sense of responsibility towards the nurses I had worked with, I also felt responsibility towards the broader integrity of research and so did include critical comments, although framed – as throughout this thesis – in a fashion where I sought to convey the nuance and complexity of apparently ‘bad’ phenomena. I would occasionally avoid raising these areas, or would avoid leaving the reports lying around in clinics where I feared my critical comments may be read out of context. Another key element of this process of reflection and feedback was the production of initial drafts of chapters that accounted for the analysis, and on which I sought feedback from supervisors and colleagues.

2.3.3 The process of data analysis

The process of analysis involved three separate steps, each with distinct characteristics in terms of what I was trying to achieve and how I responded to the data. I have labelled these steps according to what I was trying to achieve in each: open analysis, followed by a stage of developing more focus and lastly efforts to link and test the emerging ideas. These aspects of analysis were not entirely distinct, they had some overlap, but it is a useful heuristic device to present them in this way to highlight the evolving analysis. I discuss each of these parts of analysis in turn and use examples from my data to illustrate the process through them.

Open analysis

The first stages of analysis were open, in the sense of involving me thinking broadly to generate ideas, to familiarise myself with the data, and to find ways of breaking up the data and thinking about it (Charmaz, 2006). This open approach dominated the early rounds of data generation, through 2009. I tried not to restrict my thinking at this point, allowing many new ideas to emerge based on initial reflections on the data. I moved through the data by analysing the interview and observation data for each clinic in turn, ie Aangekom clinic, then Ba Banyane clinic, representing the order in which I collected it.

I approached the data by reading transcripts and listening to interview recordings (including during the long car journeys to the clinics – visits to Christen and Dula clinics could involve journeys of several hours per day). I also organised my data – in the form of transcripts of interviews and my observation notes – within Nvivo software. Using this software I could easily record initial ideas for codes. Coding is in essence the labelling of sections of data that relate to a theme. I generated codes through a combination of: 1) creating codes that related to concepts and themes induced from the data (for example issues around patient waiting quickly emerged as a key theme in my data that I hadn't clearly anticipated before the study started); 2) using codes derived from existing theory and literature, including from my foreshadowed problems (for example, I tried to link aspects of my data to ideas of nurse identity like with nurses making conspicuous displays of their relative wealth within the clinic and seeing this as a possible strategy to maintain distance from patients); 3) identifying indigenous or in vivo codes in terms of using the ideas that nurses or patients used (for example, the idea of nurses 'fast laning' patients, which referred to them treating patients very quickly); 4) looking for repetitions and regularities (for example I grouped together all my notes around when patients were arriving at the clinic, to start recording the flow of work through the day).

Whilst identifying codes I was also starting to develop analytical memos. These memos focused on short reflections and ideas on what may be happening in the data. Through these memos I started to explore further my ideas around how care was being provided, the foreshadowed problems and then how these could be used to explain care, and then also exploring higher order theoretical ideas. An example of the latter is how ideas of patient agency within the clinics started to emerge early, and so I would code fragments of data at a code for patient agency, and then also make brief notes within a memo in Nvivo. These notes were not developed in to coherent arguments, but functioned as a repository for general ideas.

An illustrative example of this open period of analysis is in how I coded and recorded ideas around ideas of scheduling care. How care was scheduled in terms of being ordered through the day and week is a key focus for my discussion in chapter 3 where I describe the

patient centredness of care. The final coding of data around scheduling care emerged from this process of open, then more focussed and then linking and testing the analysis, and I use this as an example through this section to demonstrate how the analysis progressed. In the initial open period of analysis I hadn't yet gained focus around the idea of 'scheduling care'; I instead had a range of codes that related to specific aspects of when patients arrived at the clinic, when the clinic was busiest, and what factors might be involved in this, but these were listed as 'free codes', in that they weren't clearly grouped together in a clear structure. I was focussed more on developing ideas about what may be happening within the data, and making notes for memos. For example, in a memo exploring work flow and care being focussed in the mornings, I made the following notes:

nurses tell patients to come early

Perhaps one reason for nurses keen to get patients out the clinic early – so they can do/catch-up with admin – nurses did speak about admin a lot, although not clear what or how much they actually do

what makes nurses think admin tasks are more important than patient care? sense of wanting control over the clinic? under pressure - valuing stats because they illustrate how hard they work?

This sort of early analytical thinking was very open, in that it wasn't closely tied to a comprehensive analysis of the entire data set, but was a set of ideas for me to note and return to.

Focussing the analysis

As data generation progressed, and in particular in the period immediately after it finished, analysis shifted to trying to develop more focus on the key themes and concepts relating to the study question. The open period of analysis had led to a range of ideas, in this focussing period I sought to explore which of these ideas held significance and related well to the breadth of the data, and also started to focus further data generation on these ideas. I also started to explore with more focus how emerging ideas fitted with other existing literature.

This focussing was achieved through a different approach to coding. The open phase of analysis had led to a proliferation of codes, and so my attention shifted more to collapsing codes in to each other, and forming codes in to 'trees', with codes integrated around core

categories (what can also be called axial coding) (Ezzy, 2002). I also moved back and forth across the data set, in contrast to the chronological approach of early analysis. This movement between the different clinic data sets was intended to support exploring ideas, and so I would more often scan through transcripts and notes to explore my data for its fit with particular codes.

To return to the example from above: at this stage of my analysis – April 2010, as data generation was finishing - the coding around what progressed in to scheduling care was becoming more structured, and I had formed a tree code around these ideas of workload. I was unclear on how to conceptualise care at this point, and was using the general idea of ‘macro organisation’, with sub codes referring to different areas of care scheduling I was focussing in on. This tree code had been developed through combining separate free codes together, if I considered that they related to the same phenomena. Figure 2.9 below summarises this early tree code structure, with the lower tiers of codes referring to different aspects of the phenomena of how workload appeared in the clinic.

Figure 2.9 Early tree code for data around scheduling care

Macro organisation		
	Work load and flow – patients being in the clinic	
		Ordering patient attendance by day
		Ordering patient attendance through the day
		Prioritisation and timing of services

My memos also became more structured, with specific ideas starting to emerge. I rewrote the early notes to become more structured. In a memo for ‘nurses workload – patients being in the clinic’ I structured my earlier ideas around firstly describing the phenomena, then secondly the implications of this, and thirdly around exploring how this could be explained.

The process of developing focus also involved deciding what not to focus on. Many early ideas and codes turned out on further examination to either hold little analytical significance for the purpose of understanding the organisation and delivery of care, or didn’t relate well to the rest of the data. For example, some of my early coding had been

around the forms and paperwork that was used in the clinic. These ideas were originally prominent in my thinking, but I started to consider them as being of secondary importance in relating to the question of how care was organised and delivered, and on reflection started to understand how their prominence was a result of how my early observation would involve large amounts of time spent in clinic receptions.

Focusing the analysis also involved integrating my emerging coding with available literature. A key objective of the study is to describe care in the clinics, and to relate this to the question of the patient centredness of care. As analysis progressed I sought to develop a framework for describing care, based around what I considered significant for the ideas of patient centredness. A key issue I encountered here was how existing literature on patient centred care didn't seem to account well for the specific detail and context of the clinics I was working in. In particular, I was interested in how conceptualisations of patient centred care didn't clearly account for issues of how care was scheduled or issues of patient waiting within the clinic, both areas which seemed to dominate the experience of care. In trying to develop a framework that would allow me to describe the patient centredness of care I progressed through a range of formulations. An early framework focussed on 1) clinic patient flow, 2) clinic scheduling, 3) separation of services, 4) patient registration, 5) patient waiting and queuing, 6) forms, paperwork and filing systems, 7) consultations, 8) nurses' approach to care with patients, and 9) patients' approach to care. As I continued to reflect on my data, and the idea of patient centred care I ultimately ended up with a three part framework of scheduling care, consultations and service integration (which is what I describe in depth in chapter 3).

At this point of analysis I also started to focus in on ideas of structure and agency and how they could be used to explain the patterns of care I was observing. Ideas of nurse and patient agency had formed early in my analysis, but these were not comprehensively linked to my data. I started to gather data around how nurses and patients were shaping care routines; I also developed an increasingly complex conceptualisation of this agency, drawing in ideas and literature around resistance and 'the gift' for example (see chapter 4). This writing was in memos, but also increasingly in very early drafts of the thesis chapters.

Linking and testing

Several months after data collection had finished and as the focus was becoming very clear I progressed more on to developing links across the data and testing and refining the still nascent analysis. I sought to develop firm concepts through testing comprehensively their relevance to the data; I also sought much more to link concepts together and to test relationships between them.

My coding at this time sought to develop the concepts I already had, working through the boundaries and contours of these concepts. This coding was highly selective (Ezzy, 2000), in that it focussed around a set of core categories. Although new analytical ideas were still emerging I chose to ignore these and to instead prioritise the full development of the ideas I already had. I worked back and forth across the data, by now being very familiar with the overall data set, and able to move quickly between data sources to follow up and check points I was developing. Rather than memo writing, my priority at this stage was fully on writing substantial accounts of the emerging analysis in the form of chapters, even though the chapter structure of the thesis continued to evolve. This writing was integral to analysis, highlighting 'possibilities, loopholes, contradictions, surprises.' (Richards, 2009, p50).

By this stage of analysis my coding around scheduling of care had become focussed around specific care routines; this reflects a development from the earlier tree code where data had been grouped around general phenomena like 'ordering patient attendance by day', and was now focused on specific phenomena like the existence of appointment systems. I had also divided my coding in to a structure of whether these routines were more or less patient centred, a division that became pivotal to the write up of the analysis (now in chapter 3). This tree code structure of scheduling care is summarised in figure 2.10:

Figure 2.10 Final coding scheme for scheduling care

Scheduling care	
	Workload description
	impersonal or unresponsive routines
	First come, first served routine – no appointments
	Service timetable
	No triage or prioritisation
	Responsive routines
	Triage and assessment of need
	Times given by nurses - flexibility

As well as coding to develop the core concepts, I also followed a theoretical approach, aiming to gather data around the relationships between categories (Charmaz, 2006). I sought to relate concepts I was developing to each other (Corbin & Strauss, 2008, p198). My overall theoretical approach of explaining care through ideas of structure and agency emerged at this point. The analysis to this point had considered elements of these ideas, but I sought at this stage to clarify the relationships between them. This process simultaneously involved testing ideas, relating these ideas to the existing literature, and then revising ideas. Early drafts of chapter 4 were, I considered on reading it through, excessively interactionist in their focus, and ignored the influence of differing forms of structure. Following analysis therefore focussed on understanding the role of structure.

A conclusion for analysis and then writing about it was determined by theoretical saturation. This involves an understanding of saturation as referring to the relationship between codes and theory, and that coding finishes when a theory is saturated (Ezzy, 2002), as it will always be possible to identify new information in the data (ibid). Different or additional conclusions could be made on the basis of data I generated; particular avenues I could have explored include the detailed functioning of waiting systems and patients role in them. That I haven't pursued those themes within the analysis presented here reflects a need for coherence and focus around one argument, rather than to suggest they lack health service or theoretical significance. The focus here on particular care routines and then particular forms of clinic orders of interaction, context and nurse agency reflects their greater analytical development within the scope of this study, not that they are the only themes evident in my data.

2.3.4 Presenting the analysis

My approach to writing seeks to follow the tradition of thick description (Geertz, 1973). Key tenets of thick description include a focus on context, using vivid detail, documenting unexpected events and comparing researchers assumptions and beliefs with those of the groups studied (Hatch,p196). This writing is also then a key process in ensuring the validity of analysis, and demonstrating this. In my writing I attempt to explore the breadth of the data coded around a particular point, and supplement this with an effort at 'quantificatory statements' like 'always/typically/rarely/never' (Strong, 2006 p181). When presenting nurses' accounts gained during interviews or general observation I often paraphrase in an effort to concisely present information, and use selected terms in 'quotation marks, in line with the limits on quotations during ethical approval (as above, in section 2.1.5). Where I quote from my observation data I also use quotation marks, with the length of the quote indicating the source. Where there are tensions between the different areas of my data I reflect on this, to explore possible factors in this.

2.4 Understanding the organisation and delivery of nursing care

The approach I adopted for the study allowed me to meet the study objectives of engaging with the detail of care routines in a focussed sample of clinics, as well as to explore the social processes involved in these routines. The study followed clear ethical principles and sought to respect the lives, work and rights of the nurses and others in the clinics. In the following chapters I present the results of the analysis this methodology culminated in. The validity of this account of care that I present can be judged on a number of factors. Firstly, the appropriateness of the methods for data generation in relation to the study question: iterative, sustained observation and interviews with nurses that explored their meanings and perspectives provide detailed insight in to the specific clinic routines and contexts. Secondly, the clarity on analytical procedures followed and corresponding caution through the results chapters that follow on interpreting the data. Thirdly, the careful consideration of my identity and role in the research, and how my outsider identity shaped the conduct of the study. On this basis, in the chapters that follow I seek to present a detailed account of care in the clinics, combining the range of data I collected, being cautious of the

constraints of the data and reflecting on the context and issues that have shaped the data and my interpretations of it.

Section 2 – Results and analysis

In section 2 of the thesis I present an analysis of the data I generated. I focus in this section on two objectives: seeking to describe care in the clinics – in chapter 3 - and to then explain the social processes involved in this care – in chapters 4, 5 and 6.

In chapter 3 I describe care across the clinics studied. I present a detailed description of care across the clinics, exploring the scheduling of care, consultations and service integration. I conclude that care routines do show signs of being patient centred and integrated; although this is limited. A second conclusion focuses on ART and HIV care being largely provided within the same routines, but there are some differences indicating it can be more patient centred. These differences relate to how care is provided with a greater intensity of effort, but still following the same principles of other areas of care.

Chapter 4 seeks to explore the social relationships and processes involved in these care routines. I adopt a theoretical approach, outlined in chapter 1, that approaches these routines as produced in interaction between clinic level actors. This interaction is shaped by contextual factors and clinic orders of interaction, with nurses also exercising agency in producing the care routines. The focus of my argument is that nurses' agency allows them to conduct care, rather than control it.

Chapter 5 further explores this analysis of nurses' agency, and focuses on understanding nurses' complex identity. I argue that understanding the range of identities nurses have, beyond the single identity of a professional nurse, gives insight in to the motivations and tensions that nurses manage in exercising agency, and correspondingly, further demonstrates the challenge of day to day work in the clinics.

Chapter 6 develops my analysis of context and agency by exploring the nature of the response to the introduction of ART and HIV care. The identification of slight differences in care in chapter 3 suggests a small change in care since the introduction of ART and HIV care. I suggest this small change gives insight in to the existence of a broader trajectory of change towards patient centred, integrated care linked with wider PHC reforms. A context of constant change around the ART and HIV care programme also gives rise to uncertainty which can be seen as limiting nurses' agency, and correspondingly limiting the potential for changes in care.

Chapter 3 - Care routines in the clinics

3 Introduction

In this chapter I present my first level of analysis and present an account of care in the four principal clinics: Aangekom, Ba Banyane, Christen and Dula clinics. I also draw on data from the additional six clinics to explore the care I describe. The principal conclusions of the chapter are that care across the clinics includes routines indicative of patient centred approaches to care, but these happen alongside more dominant routines that are less patient centred. In addition, service integration is limited, with nurses' provision of care involving a specific service they are allocated. All four clinics show a varying combination of these differing routines. A second conclusion is that ART and HIV care are predominantly provided within these same routines, although with some nurses focussing more effort on ART and HIV care. This difference in effort reflects an intensification of widely held principles, rather than a distinct approach to care. The difficulties nurses found in accounting for this difference, and the tensions inherent in it, I combine in the paradoxical idea of ART and HIV care as 'the same, but different'.

I structure my analysis of care around the framework of patient centred, integrated care discussed in chapter 1. I first of all discuss two dimensions of the patient centredness of care: the scheduling of care and then the process of consultations. I then secondly discuss service integration in the clinics. Within each of these dimensions of care I identify care routines that are involved in care; as in chapter 1 I see these as repeated actions, and so not necessarily a pejorative label (see chapter 1 and discussed in detail below). Figure 3.1 summarises these routines and their overall characteristics. As I present my analysis I explore these routines and relate them to the concepts of patient experience, content and control that sit within the framework of patient centred, integrated care. Although I present these routines as a dichotomy of more or less patient centred, this is intended to facilitate the identification of important characteristics of care and so is heuristic, rather than suggesting care can be neatly divided in this way. The reality in the clinics is of a continuum between more and less patient centred care. As I develop the analysis I also reflect on how characterising care routines as more or less patient centred is problematic. I raise specific issues of how applying patient centred care to primary health care is problematic, as a basis for further discussion in chapter 7.

Figure 3.1 Summary of care routines

Dimension of care	Care routines and their characteristics	
	Less patient centred care routines	More patient centred care routines
Patient centredness of care		
Scheduling care		
PHC generally	<u>Routines that are impersonal and unresponsive:</u> First come, first served routine; daily service focus routine; absence of triage	<u>Routines that respond to individual need:</u> prioritising emergencies and triage; informal appointments; prioritising patient care over administration
ART and HIV care	Same routines	Same routines
Consultations		
PHC generally	<u>Routines that limit consultations:</u> A narrow range of issues covered in consultations; poor communication with difficulty in sharing information and being understood	<u>Routines that lead to comprehensive consultations:</u> A broad range of issues addressed; good communication that is open and responsive
ART and HIV care	Same routines	'Same, but different' routines
Service organisation	Extent of service integration	
PHC generally	<u>Limited integration:</u> Service allocation, with varying ad hoc integration	
ART and HIV care	<u>Limited integration:</u> Service allocation, with varying ad hoc integration (with distinct forms of provider integration around ART)	

In the chapter I first discuss analytical and methodological issues I encountered in developing this account of care, in order to provide a clear basis for the analysis that follows. I then discuss each of the areas of care referred to above. Within a discussion on patient centred care I discuss routines around scheduling care and then consultations. I then discuss the extent of service integration. The chapter concludes by summarising the routines described and demonstrating that there are limits to patient centred care and service integration, and some differences with ART and HIV care.

3.1 A grounded and thick description of care

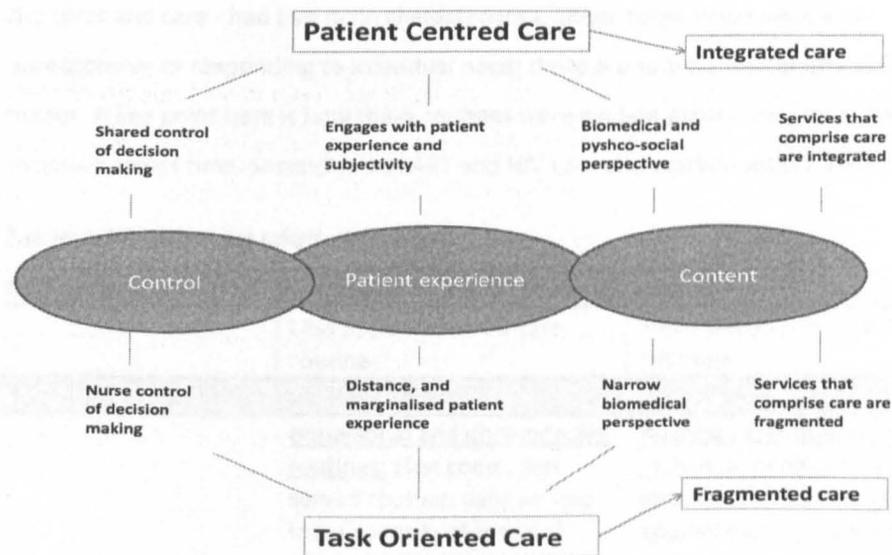
The clinics involved a number of people – nurses, patients, other clinic staff – in continuous and simultaneous activity as they went about their work, or received care. My goal was to understand the routines in this activity and to conclude whether care is patient centred and integrated or not. As discussed in chapter 1 I use the idea of routines – repeated patterns of action – to understand activity within the broader practice of care. Identifying routines rather than imposing a preconceived framework was challenging, and continually evolved throughout the analysis (As discussed in section 2.3). This analytical struggle points to the complexity that characterises care processes in South African PHC, and arguably any healthcare or social setting. Using this concept of a routine is challenging as care can involve two actions (a nurse instructs a patient, who then does X) or it can involve a sequence and combination of actions (a nurse instructs a patient to do X, which leads to action Y by the patient and then Z by the nurse). This quality of routines as existing at a range of levels and overlapping and nesting with other routines led me to iterate between different conceptualisations of care, reordering my analysis and fitting phenomena together in different ways. The dynamism and complexity of the clinic was difficult to conceptualise; or put another way, my difficulty in conceptualising what I was seeing made me understand care as complex and dynamic.

A challenge was how to use nurses' general accounts of care in understanding specific routines. Nurses used a general discourse of care that I was familiar with: care being integrated, or relationships with patients being good, even therapeutic. Challenging the use of these for understanding care is not to assume a difference between what people say and what they do, even if I do accept the accounts were generated for a particular purpose of a research interview. Instead, the analytical challenge is that these general discourses can in turn relate to a wide variety of phenomena: the idea of 'comprehensive care' can be operationalised in a number of different ways. As a result, how nurses often spoke about their care didn't fit my analytical purpose of making a thick description of care, and so I had to use these accounts, but critically, and combine data carefully.

My approach to this, and what is the basis for the account of care that follows, is to accept the complexity I have just described, and that routines exist at a range of levels and

overlap. An outcome of this recognition is that another analysis could identify different routines. However, I justify my analysis as valid – while accepting others as equally valid – for how the specific routines I identify give insight in to the qualities of patient centredness and integration of care (the framework discussed in chapter 1 is reproduced below as figure 3.2, as a reminder of the dimensions of how I explore patient centredness and integration). Following this, my approach is to present a series of routines that I argue reflect significant patterns in action within the clinic, and their significance comes from giving insight in to the question of whether care is patient centred and integrated.

Figure 3.2 A framework to describe the organization and delivery of care



3.2 The patient centredness of care

My analysis of the patient centredness of care focuses on two dimensions: how care is scheduled and how care is conducted within consultations. The focus of activity around a consultation as significant already has a clear basis in the ideas of patient centred care I have discussed so far. During the analysis it also became clear that the activity outside the consultations was significant, mainly because this is what patients spend the majority of their time doing in a clinic (often waiting for several hours for a consultation of a few minutes) but also because both nurses and patients reported it as a chief problem and focus of complaint. As a result I also focus on these routines around scheduling care, as well as consultations, exploring the routines for managing patients' arrival and movement

through the clinic. I reflect on the challenges of analysing scheduling care and considering it within a framework of patient centredness in the course of the analysis. Through the rest of this section I first discuss routines around scheduling care and then consultations. Within each section I discuss routines as they correspond to being more or less patient centred, exploring this interpretation alongside the description.

3.2.1 Scheduling care

The routines involved in scheduling care – how and when patients arrive and move through the clinic and care - had two main characteristics, either being impersonal and unresponsive or responding to individual need; these are summarised briefly in figure 3.3 below. A key point here is how these routines were evident across the clinics, with variation across time. Secondly, that ART and HIV care also worked within these routines.

Figure 3.3 Routines for scheduling care

Dimension of care	Care routines and their characteristics	
	Less patient centred care routine	More patient centred care routines
1 Scheduling care	<u>Impersonal and unresponsive routines</u> : First come, first served routine; daily service focus routine; absence of triage	<u>Routines that respond to individual need</u> : prioritising emergencies and triage; informal appointments; prioritising patient care over administration
ART and HIV care	Same routines	Same routines

3.2.1.1 Routines that are impersonal and unresponsive

I was anticipating clinics being busy in the morning and having a morning focus to the workload owing to conversations with my supervisor and related work (Lewin, 2004, Shelton, 2001). In all four clinics this morning focus was borne out, to varying degrees. All clinics with the exception of Joyful clinic (the 24 hour clinic) had opening hours from 7:30am to 4pm. Clinics were often full, if not very crowded, from soon after opening in the morning. Most extreme was 'baby day' in Aangekom clinic. Baby day was a focus for mothers and children, with the day starting with all parts of the clinic waiting area and adjoining corridors largely full of people. One of my first days of fieldwork was on 'baby

day', during which I had to spend most of the day sitting on the floor outside the clinic (along with many other patients) owing to the lack of any space inside. When I asked Sister Botala to describe the day, she simply exclaimed 'wow'; at the end of a Friday afternoon Nurse Tefo said he would rest all weekend so he was ready for baby day the following Tuesday. Both comments were likely tinged with humour, but still highlight how baby day was a spectacle. A pattern of clinics being busy in the morning was repeated in other clinics, although the chaos of Aangekom's baby day fell at the extreme end. Ba Banyane clinic served a small community, and although busier in the morning, there were normally spare seats in the waiting area.

The afternoons were often quieter than the mornings. Across the clinics there were afternoons when they were empty of patients. Nurses might be doing admin, chatting in the break room, and on two occasions I saw nurses dozing in their consultation rooms. In Aangekom clinic, I would occasionally find Sister Marais reading a book in her room; in Dula Clinic I saw Sister Sehlwela seemingly sleeping at her table. Afternoons however could also be busy. There could be patients in the clinic until the clinic closed at 4pm. Indeed, it was possible that patients would not be seen. Nurses were virtually unanimous that all patients would be seen. However, this did not correspond to several patients' accounts in Aangekom, Ba Banyane and Christen clinic of being sent home without receiving care. I also observed patients being told to leave the clinic in the hour up to the clinic closing at 4pm in Aangekom and Ba Banyane clinic. This is not to accept patients' accounts uncritically, as I highlight below, patients were at times likely repeating broader discourses around care rather than reporting their own experience. There were exceptions to nurses' insistence all patients were seen, although expressed obliquely. Sister Nomkhula in Dula clinic smiled when I asked her if all the patients would be seen that day, and just said that she would leave at 4pm as she wasn't paid overtime. Sister Fula in Dula also referred to turning 'patients back' in passing.

First come, first served

A pattern of morning focussed work can be largely seen as a result of 'first come, first served' approaches to work (Lewin, 2004), with patients attended to in the order in which they arrive. This was an aspect of care I was anticipating before arrival, and although only

two nurses actually used the phrase – Sister Fourier, Aangekom and Sister Mamdala, Dula – it was evident across the clinics as a broad principle in that there were no formal systems for making an appointment for a specific time and that patients were expected to arrive and then queue. These same routines were also visible for ART and HIV care. The ART areas in Christen and Dula clinics were normally very busy first thing in the morning, with a first come, first served system operating. Patients would often arrive as the clinic was opening, or at least early. Both nurses and patients reported patients arriving early, with 4am, 5am and 6am quoted to me by different nurses, for clinics that opened at 7:30am, although from my observations patients would arrive through the morning. This focus in the mornings is encouraged by nurses, with nurses across the clinics reportedly telling patients to come early. Sister Nomkhula said she ‘teaches’ patients, and Sister Habore from Ba Banyane said she discourages patients from coming in the afternoon. Such encouragement can take extreme forms with nurses shouting at patients if they arrived in the afternoon, or were suspected of just wanting a doctor’s note to justify an undeserved sick day (reported by Sister Seporo, Christen and Sister Moloa Aangekom). A substantial number of patients may arrive as the clinic opened or soon after, but patients would still arrive through the day and right up until the clinic closed in the afternoon across all four clinics. Christen clinic had a slight variation on this routine through having distinct morning and afternoon sessions, with a rigidly observed lunch break. Patients would queue in the morning, and then again in the afternoon. The other clinics would instead keep working, with nurses often telling me how they would take their lunch at 2pm or later, or even not at all.

Non-assessment of patients

There were occasions, particularly in Ba Banyane, where there was an absence of any process for prioritising patients who were understood as needing more urgent care. Sister Habore said that patients talk amongst themselves to clarify the order of who would be seen. At its extreme, this system also involved, in effect, patient-led triage, with discussion amongst patients on whether some patients should be given priority within the queue (this was also reported to me in Esita clinic). In Ba Banyane, Esther the cleaner would also facilitate this process, with her talking to the patients and some patients moving up the queue. A patient interview illustrates this: he had TB and was given priority in the queue, although he said some patients wouldn’t be aware of this and would complain when he walked to the front of the queue. He described how other patients would explain the

situation to those complaining. He suggested that the nurses don't take responsibility for ensuring ill people are seen, adding that the patients are involved in this process. Two patients in Aangekom also complained about nurses sending patients away regardless of how seriously ill they were. These accounts were relatively isolated, with no clear picture of whether this also happened in Christen and Dula clinics.

Service timetable

Overlapping with the routine of a morning focus to work was a daily variation in workload relating to specific services being scheduled for particular days. As I described in chapter 1, care can be understood as made up of particular services, a phenomena across health care globally, indicating that care is oriented around sets of tasks defined by a disease focus. Nurses would report to me the clinic timetables. As above, 'baby day' in Aangekom – Tuesday and Thursday – was a focus for work. Sister Marais also said they did 'chronics' on Monday and Wednesday. In Ba Banyane I observed particular days reserved for diabetes care and antenatal care. Sister Habore said that the day the doctor visits the clinic was the busiest day. In Christen clinic Monday and Tuesday was chronics day, with Wednesdays 'antenatal clinic'. The nurses would also notionally close the clinic on Friday afternoons to all patients except for emergencies to allow the nurses to do administrative work. There wasn't variation across days for all services and nurses; Sister Fourier in Aangekom was a TB nurse and said that her days were similar. All four clinics also responded to 'minor ailments' or 'curatives' every day. Other session health workers like physiotherapists and dentists were also focussed on a particular day. Friday, the last working day of the week for the clinics, was often quieter also. The provision of ART and HIV care did normally happen on everyday of the week in Christen and Dula, except for Fridays which in Dula the nurses tried to keep as a day for prioritising administration or for organising the drug readiness classes.

Nurses across the clinics reported that patients were technically allowed to come on any day and be attended to. However, patient care was still focussed on this timetable. Patients would then know which day to come on, or, according to nurses be told to come on an appropriate day next time, with nurses saying they 'booked' patients, i.e. told them which

particular day to come. There were tensions with this however, with some patients reporting being sent away and told to come on the correct day.

Assessing patient centredness

An overall characteristic of these routines is that they are impersonal and unresponsive, with a principal outcome of a congested clinic and so long waiting times for patients. Long waits were a feature of care I anticipated prior to fieldwork, reflecting existing accounts of care (Coetzee et al., 2011, Wouters et al., 2008). From nurses' accounts, patients' accounts and my own observations, it is clear that long waits are a common part of care in the four clinics, and are shaped by patients arriving in the morning. It should also be noted that some patients reported very short waits and even very quick visits, as did some nurses. A critical distance from claims for long waits is important. A patient in Aangekom clinic for example said that people would die while waiting, a report not mentioned by anyone else in the clinic, staff or patient, suggesting the influence of broader discourses as during the fieldwork there were national media stories about patients dying in clinics after being left to wait. However, the clinic manager in Fontein clinic did tell me about a patient dying in the waiting room, although not apparently from neglect, indicating that this patient's account can't be completely dismissed. A morning focus and long waiting times also add to the strains already ill patients face: having to get up early, potentially go for long periods without eating, the discomfort of actually sitting in the clinic for a long time and the danger of cross-infection when considering the prevalence of immuno-compromised HIV+ patients alongside patients with TB or other communicable disease. This is in addition to a sense of uncertainty (Campbell et al.) and aggravation (Fonn et al., 1998) felt by patients caused by waiting. These long waits are particularly disadvantageous to those who are working (Cornell et al., 2011) through favouring the unemployed and physically well (Jacobs et al., 2008), who are more able to cope with the long waits. An overall effect of this is to create challenges for adherence and accessing ART in other low income settings (Hardon et al., 2007, Chileshe and Bond, 2010).

These impersonal and unresponsive routines I interpret as indicating less patient centred characteristics. The routines lead nurses to have to neglect the individual patient's experience and their concerns and frustrations; this is clearly evident in how waiting time

was a source of frustration for patients that nurses were unable to respond to. Overlapping with this is how these routines indicate a lack of control for patients. That patients are waiting indicates a position of being disempowered within the clinic, evidenced in how their complaints are not able to be responded to. Finally, these routines also relate to ways in which the content of care is limited. The clinic timetable, although informal and often ignored, relates to an overall separation of care in to distinct services, implying a disease focus to care, a point I return to in discussing consultations and the extent of service integration later. A result of this timetable however is that it risks people having to return to the clinic on several days. An important consideration across this assessment of the routines is that just because these routines are not in patients' interests, does not mean they necessarily serve nurses' interests either. Nurses' exhaustion after a busy morning and delayed breaks can be understood as hindering their work satisfaction, for example.

As I have already stated, categorising routines as less patient centred is problematic. Raising issues of long waits can potentially seem absurd in a context where there is concern over the availability of staff and affordability and supply of essential drugs. My focus on scheduling care can be dismissed as the concerns of someone who is used to worrying about supposedly secondary aspects of care: this is in some respects valid, as I have relatively little personal experience of having to access care, certainly in comparison to the repeated interactions required in taking ART, and so issues of convenience have perhaps been more important to me. Further to a critique of my position in generating the data, a focus for analysis on scheduling care could be critiqued on the grounds that attending to this is arguably not feasible and/or these routines are also seen in high income settings. The logic of scarce resources in any health system – whether in South Africa or the UK – determines some limit to the extent to which an individual's needs can be met. An assumption that current routines are the only viable response is however an assumption I question later in my discussion. Here it is sufficient to develop my analysis on the basis that to understand a routine as less patient centred is still important based on 1) its pivotal role in the experience of healthcare as told to me by nurses and patients and on my own observations and experiences of the clinic, and 2) that problematising apparently mundane, everyday and taken for granted practices is part of the core purpose of sociological analysis. I do discuss in chapter 7 how my analysis can lead to considerations of alternatives.

3.2.1.2 Routines that adapt to individual need

Alongside these routines were those where nurses were able to schedule care linked to individual patient needs. The distinction between these routines, and which leads me to interpret these actions as more patient centred, are how the specific circumstances of the individual patient were responded to.

Triage and assessment of patient need

An obvious feature of adaptation to individual patients were processes of triage, which many nurses described as starting the day, with those most severely ill being seen first. It was never clear how this process worked, in that I never saw a highly ordered approach to it, suggesting an informal system of recognising clearly desperate patients while waiting and/or patients reporting to nurses directly. A dimension of this triage and responsiveness is how nurses would change their work schedule in an emergency. For example, I saw nurses in Aangekom using their own cars to take patients to hospital. That nurses should adapt their care schedule in response to severe illness is to perhaps state an obvious process within a healthcare setting. However, a context of other reports from South African health care of women in labour being left unattended (Jewkes et al., 1998) suggests prioritisation of emergencies is worth remarking on. Another incident from my data supports this as well. One afternoon in Christen clinic I walked in to the waiting room to see a man lying on the floor, seemingly unconscious, following from what I gathered was a fit. Sister Thabo was stood behind the nearby reception desk, looking on impassively and making no indication of attending to the patient. There are a number of factors behind this, not least that perhaps clinically the man was presumably not in any danger (I assume the fit had passed and so he was in no danger of hurting himself), however, a greater degree of attention to the patient could have been anticipated. My focus on exploring what underlies these sorts of actions comes in the next chapter; here my focus lies in problematising the everyday and mundane processes of the clinic, and identifying how an emergency response and triage fits within that.

Informal appointments

There were other adaptations for individuals. Nurses were willing to allow people who worked to arrive late in the clinic, and to be seen first in the morning to allow them to get

to work. Although there was no formal way to make appointments for specific times, some nurses did informally do this, and respond to patient requests. Sister Nomkhula, Dula clinic, referred to patients who travelled a long way phoning her and asking for their ART to be ready, she referred to the same thing for HIV+ health workers who would travel to the clinic from elsewhere. A sister in Esita clinic referred to arranging specific times for the police to visit with prisoners and Sister Seporo in Christen clinic mentioned making specific appointments if it was to follow up on previous appointments.

Assessing patient centredness

These routines were peripheral across the clinics, including for ART and HIV care. I interpret them as offering more patient centred care, on the basis of how patients' interests and needs have influence over the routines, indicating how nurses are able to respond to the patient's experience of illness and care, and also demonstrating an increased level of influence and control over care routines for patients. This assessment of more patient centred care reveals a particular issue within conceptualisations of patient centred care and the reference point of the interests of an individual patient. There is the potential that care routines that address a particular patient could, in the context of scarce resources, be to the detriment of other patients. For example, giving a particular patient an appointment for a time could mean other patients waiting longer. This dimension of equity is an additional consideration I return to in chapter 7.

3.2.2 Consultations

Consultations can be seen as the culmination of the care process, being the focus for nurses and patients addressing particular health issues. As I explained in chapter 2, I chose not to directly observe consultations, seeing this as a disruption of clinical practice that was unwarranted. This account of consultations focuses on the accounts of nurses and to a lesser extent of patients. I also explore the routines I identify with reference to other aspects of my data, in particular around what I could observe of the conduct of consultations from public areas of the clinic. As with the themes discussed so far, there is variability, but prominent outcomes of these routines are of consultation scope being limited and then more comprehensive. ART and HIV care again follow similar routines, but

within the more comprehensive consultations there are also slight differences. These are summarised in figure 3.4 below.

Figure 3.4 The routines within consultations

Dimension of care	Care routines and their characteristics	
	Less patient centred care routines	More patient centred care routines
Consultations		
PHC generally	<u>Limited consultations:</u> A narrow range of issues covered in consultations; poor communication with difficulty in sharing information and being understood	<u>Comprehensive consultations:</u> A broad range of issues addressed; good communication that is open although directed by nurses
ART and HIV care	The same	The same, 'but different'

3.2.2.1 Routines that limit consultations

Limited consultations can be seen as less patient centred for how they can involve nurses exploring a limited range of issues, even if they consider that more may be necessary. This can be compounded by poor communication between nurses and patients that can involve either tension or conflict, with an ultimate outcome of a lack of effective sharing of information.

Limiting the range of issues covered

The range of topics and issues covered in consultations was often limited. Nurses spoke about how they were not able to address all of a patient's needs and having to shorten consultations, usually with reference to the number of patients waiting and the pressure on time and resources. Nurses said they might 'postpone' issues for another time (Nurse Tefo) or only address 'one thing' (Sister Sediba). Sister Habore explained how she would like to counsel more, but the numbers of patients prevented this. This overall pattern of nurses not addressing issues was related to a regretful discourse from nurses of how they knew they couldn't provide quality care (Sister Habore), do patients 'justice' (Sister Mamdala), do everything they wanted (Sisters Setempe and Kgaba) or ended up not listening to patients

as they were focussed on other things (Sister Fula). Patients also complained about nurses not asking questions or how they feel.

A limited range of issues being covered in consultations was also evident with accounts that indicated an excessive routinisation of consultations, in that nurses repeated particular clinical steps without reference to patients' specific needs and so focussing on completing tasks. This came through in isolated circumstances. Sister Marais in Aangekom clinic said that consultations lasted between 5 and 7 minutes, adding that the patients knew to talk quickly. Sister Pretorius in Ba Banyane referred to how in the past she had worked like a 'wors machine', wors being a South African name for sausage, indicating a mechanised approach to care. An extreme example of this mechanised approach was when I observed Sister Kgaba provide diabetes care. The care took place in one large room, with all patients sat along one side on a row of chairs. The patients then moved along and sat by the desk in the middle of the same room where blood pressure was taken, minimal communication was involved and then patients left. The notion of 'fast laning' or 'lining' care also has implications for consultations. This implies a process for prioritising care, but also indicates that a full examination isn't given. Sister Habore, from Ba Banyane clinic said she will 'fast lane' family planning patients for them to leave, with a nurse in Esita clinic suggesting this 'fast line' means to just give treatment, without any in-depth examination of the patient. Other nurses referred to it as a process for dealing with those who need immediate attention, but then another added it was also for those patients – listing psychiatric, TB and geriatric patients – who could just come in and collect their treatment, in order that they didn't have to wait too long. Nurses' general references to working 'quickly' and 'fast' also suggest that consultations are in some ways being shortened.

ART and HIV care was also at times routinised, involved poor communication and was rushed. These consultations in both Christen and Dula clinics were sometimes just a couple of minutes long, with patients entering the room and leaving very soon after without the door even closing. An example of how talk with nurses could be stripped from the consultation was in Christen clinic, where Sister Seporo was testing a series of teenage boys for HIV, prior to their being involved in an initiation ceremony (which involves circumcision). The boys were all counselled as a group, and then I saw them go in to Sister

Seporo's room, one by one, with the door occasionally left open, and leaving very shortly after (and the boys would then leave the clinic). Although an 'exotic' example, this highlights how health care processes, where counselling is seen as central to ensure consent and behaviour change, can become highly routinised and in turn involve minimal opportunity for nurses and patients to talk.

Poor quality communication

Communication between nurses and patients was also often of poor quality, in terms of nurses and patients not being able to understand each other and share information effectively. Nurses would often describe various tensions and problems in consultations. It was common for nurses to refer to 'fighting' with patients. Nurses and patients across clinics described nurses shouting at patients, and nurses also reported patients shouting at nurses. Nurse shouting was linked by many nurses to a strong sense of frustration that patients wouldn't follow their advice or adhere to the medication or treatment plans they provided. Nurses reported that patients often wanted a prescription, i.e. medication, rather than to be counselled. Some patients reported, which was also recognised by some nurses, that patients feared nurses, linked by some to understandings of nurses as mean and 'nasty'. An issue across all clinics was the difference in the first languages of nurses and patients. South Africa has eleven official languages and with a highly mobile population many languages could be spoken in the clinics. Linguistic differences did overlap with race, with white nurses having Afrikaans or English as a first language whereas the majority of patients principally speak Sotho, and occasionally Afrikaans. However, many black nurses also did not speak Sotho. Some nurses described how they would ask other staff like clerks or receptionists to translate for them, but that this was an occasional response, rather than a permanent solution. Communication around ART and HIV care also featured some of these same issues, with complaints from nurses of fights with patients.

The effect of consultations being limited is further supported by my other observations from around the clinics. An obvious characteristic was of how privacy was often limited by consultation room doors being left open, and also by nurses frequently interrupting other consultations by walking in and out without knocking. There were also instances across the clinics of there being groups of patients, and at times several nurses, in a particular

consultation room. In the Christen and Dula clinic this was notable when nursing assistants did 'observations': measuring blood pressure, weight or testing urine before patients were seen by a professional nurse (Aangekom and Ba Banyane clinics did not have nursing assistants and so this grouping of patients was not so clear). I came to see this as the consultation boundary being frequently very porous leading to the privacy of consultations being undermined.

Assessing patient centredness

These routines combine to lead to limited consultations, both in the number of issues addressed and in the nature of communication through which these issues are addressed. This suggests limits to the content of care, and that care can have a narrow biomedical focus. The nature of the communication described points to tensions and distance in the relationships between nurses and patients, and the absence of any form of therapeutic alliance between nurses and patients. It is important to recognise that a brief consultation may be appropriate in some circumstances, for just a minor query that is immediately resolved. However, in a context of multiple morbidities and high HIV prevalence, any consultation is an opportunity to integrate care and explore related issues, and so these limits on the range of issues addressed and manner of communication can be seen to limit care.

3.2.2.2 Routines that lead to comprehensive consultations

Comprehensive consultations can be seen as more patient centred, for addressing a broader range of issues, including psychosocial elements of care, and involving nurse-patient communication that allows an exploration of the patients' situation and an effective exchange of information.

A range of issues addressed

In contrast with nurses saying the number of issues covered in consultations was limited, was a theme – from the same nurses – of responding to the specific needs of the patient, and of describing their care in ways that indicated they engaged with the psychosocial dimensions of care as well as the narrow biomedical dimension. An initial indicator of this

was how most nurses responded to a question about the length of consultations by saying that it depended on the patient. Nurses then described a range of ways in which they addressed various issues: nurses referred to seeing patients 'as a whole' (Sister Andrews), addressing a mother's needs as well as a child's when doing child care (Sister Botala), and of addressing everything a patient raised in a consultation, and so helping in 'totality' (Sister Fourier) and working 'from head to toe' (Sister Seporo). There were also references to care being comprehensive, integrated and holistic. Various nurses referred to addressing patients' social needs and concerns within consultations, or treating a patient 'socially, religiously, psychologically' (Sister Terene) and involving social workers in care (Sister Habore, Sister Seporo). Sister Pretorius described an example of a 'thorough' consultation, saying how she might do things like show a mother how to wash and bathe her baby by actually heating water and doing it in the consultation, and how to give medications to the baby correctly. Some patients accounts corresponded to this: with a patient in Ba Banyane describing the nurses as very helpful, and how they were helping him claim a welfare grant. I explore and discuss service integration in section 3.3 below, particularly these claims to 'comprehensive' care. A critical stance is needed in accepting these positive accounts of care. However, from public areas of the clinic I often observed long consultations of twenty minutes or more, suggesting nurses were often providing in-depth care and allowing time to address a range of issues.

Effective communication

The communication between nurses and patients in consultations could also be more effective than that described above, with nurses describing both patients and themselves as open, and so able to share information. Across the clinics nurses described interaction with patients in ways that suggested supportive and open communication. Nurses said they would try 'reaching out' to patients, trying to 'guide' and 'probe' in conversation in a consultation. Nurses described how they would respond to patients and allow patients to talk, asking open questions and having dialogue with them, and exploring the patient's situation and their responses. Nurses also reported adjusting their style of speech, to use 'lay language' and terms that the patients themselves used for illness, for example Sister Habore described using terms like 'the belt', as patients used it to describe herpes zoster. In a similar vein, Nurse Pretorius said she might draw pictures to aid explanation. Body language was also cited by a couple of nurses, saying how they would adjust seats so they

were sat adjacent rather than opposite patients, or they would sit back, and focus on the patients, in order to support communication; however, all consultation rooms in Christen clinic were set up with patients and nurses facing each other across a table. Whilst communication was often directly described as open, and much of it corresponded to this idea of nurses and patients talking freely, it could also involve nurses directing communication, with nurses usually describing consultations in terms of them asking all the questions and 'motivating' patients to follow certain courses of action.

ART and HIV care: the same, but different

My initial impressions were that there was little, if any difference in how ART and HIV care was provided. In Christen and Dula clinics where ART was available, the nurses providing ART (Sister Vermaak, Christen and then Sisters Mamdala, Nomkhula and Sehlwela, Dula) spoke about their work and seemed to follow similar routines as the other nurses. Similarly, the aspects of HIV care in other clinics – VCT, PMTCT – seemed to follow the other clinic routines. My early questions in interviews included exploring whether there was any differences between HIV care and ART and other services. For some nurses it was just the same; several emphasised that HIV and ART care showed no difference at all (Sister Vermaak and all the ART nurses in Dula). Nurses referenced HIV care as being the same or similar to other PHC services in a range of ways. Comparisons of ART or HIV to other 'chronic' conditions – in this context, diabetes, and hypertension - were common (Sister Williams, Aangekom; Sister Ngata, Christen; Sister Nomkhula, Dula; and nurses in Esita clinic). Other nurses simply remarked that there were no differences, or that it was the same as other services (Sister Marais and Kwena, Aangekom; nurses in Esita, Geheim and Joyful clinics).

Some of these same nurses would then however go on to say that there were differences. Sister Andrews for example said that HIV care was the same but that sometimes it needs more care; Nurse Tefo said that 'they differ' and that they give HIV+ patients more attention, but then immediately added that they give '100% attention' to other patients as well. Similarly, Sister Botala described the difficulties of care for HIV+ patients, before clarifying that there were other considerations for all patients. Nurses in Geheim clinic said it was not different, 'as long as you take your treatment', implying that there are

differences, while another nurse said there was no difference in HIV care immediately after describing how she counselled patients on ART more.

Other nurses were more forthright in stating differences. Sister Fula described more willingness to engage with social problems; Sister Fourier said ART needed quality care, and that you can't do a 'fast lane' approach as it was a 'delicate service'; Sister Nomkhula said ART patients are more demanding, Sister Seporo also said that they differ, based on a recognition of stigma and the need to be discrete and sensitive in exploring the issue. Nurses in Esita and Ithata said there was more effort in ART and in understanding the patient. The clinic manager in Fontein clinic gave a vivid account of the differences. She said how services like ANC and chronics were 'donkey work', in that they weren't challenging. She contrasted this with PLHIV, where the illness is different for every patient and that as a nurse you have to leave your point of view on one side, and then rely on your knowledge and rapport with the patient.

Analysis of these accounts suggests that although there is differences in ART ad HIV care that suggest can be more patient centred, it does not indicate a fundamental distinction. Firstly, some of these same nurses that readily identified differences also described care, or I observed it, in ways that could be considered less patient centred. Secondly, the difficulty some nurses had in describing any differences suggest it is not a significant variation from other care. Analysis of the differences identified by nurses alongside the accounts of PHC generally point towards a greater emphasis and energy rather than a fundamentally different approach to care. The attention to patients, sensitivity to stigma and patients situation is consistent with how nurses described other comprehensive consultations. This similarity in principle but difference in effort is clear with a nurse in Esita clinic commenting that ART should be treated like a chronic condition, but care for chronic conditions should put more effort in like is done for ART. Rather than trying to entirely explain away any tension in nurses' accounts, the paradoxical concept of HIV care being the same, but different seems useful, through summarising how although there are differences, they are hard to clearly delineate and can be seen as involving a more intense application of widely held principles.

Assessing patient centredness

The processes of responding to individual patients and a focus on communication and counselling by nurses demonstrates a commitment to engaging with the needs of individual patients, recognising and valuing their experience and taking efforts to explore it. The efforts to address a range of issues in consultations also indicate a more psychosocial perspective on care is possible alongside addressing biomedical aspects of care, with nurses taking efforts to explore broader circumstances and determinants of health.

3.3 The integration of services

The analysis of the scheduling of care and consultations in understanding the patient centredness of care has highlighted how care is understood as made up of separate services. In this section I explore this further to understand how these services were arranged within the clinic. Following my conceptualisation of patient centred care in chapter 1 I see service integration as giving insight in to the content of care. In this section I describe the routine for service integration across the clinics of nurses being allocated specific services to work on, with varying ad hoc integration of services building on that allocation. ART and HIV care is largely the same, although with slight variation on the overall patterns of allocation. These are summarised in figure 3.5 below. The overall outcome of this, I argue, is to represent a limited form of integration with the effect of limiting the content of care.

Figure 3.5 Routines for service integration

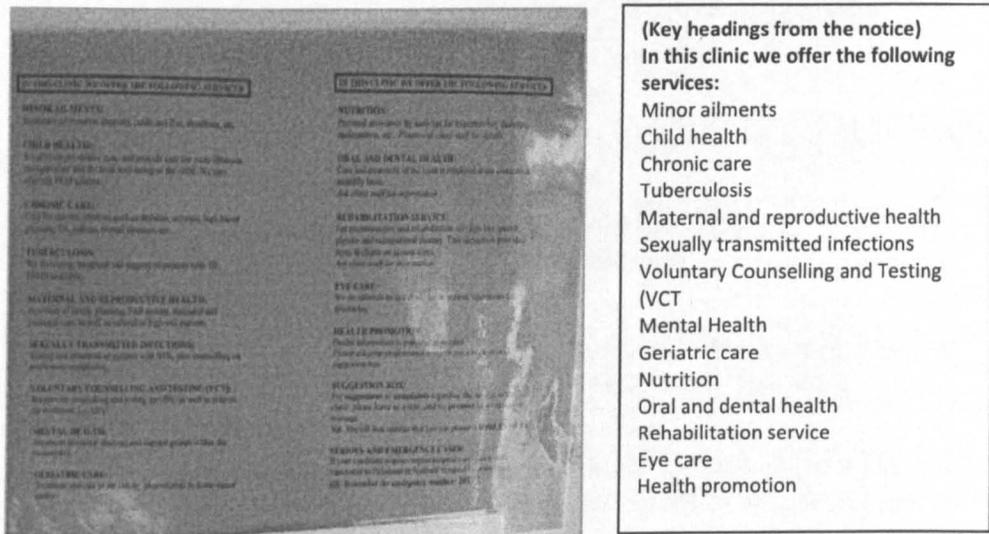
Dimension of care	Care routines and their characteristics
Service integration	
PHC generally	<u>Limited integration</u> : Service allocation (and so separation), with varying ad hoc integration
ART and HIV care	<u>Limited integration</u> : Service allocation (and so separation), with varying ad hoc integration (with distinct forms of provider integration around ART)

3.3.1 Routine of service allocation with ad hoc integration

A routine that leads to limited integration was evident across the four clinics. This focuses on how nurses are allocated a particular service to work on, with ad hoc integration linked to this. An understanding of care as made up of distinct services was clear across nurses'

accounts. The clinic timetables I discussed above are one indication of this, with days of the week focussed around particular services. These services can be seen as sets of clinical tasks focussed around a particular disease or area of concern. These separate services were also displayed on the walls in the clinic, as in Ba Banyane clinic as shown in figure 3.6.

Figure 3.6 Poster detailing the services offered in the clinic



In interviews and in passing conversation around the clinics, nurses would usually associate themselves with one particular service, and sometimes a few, as summarised in figure 3.7 below. These accounts initially led me to assume a high degree of separation of services and of nurses focussing on one particular service when providing care to patients.

Figure 3.7 Summary of how nurses described their work

Clinic	Nurse	Services they identified with
Aangekom	Sister Terene – clinic	'everything'
	Sister Marais (Staff nurse)	Family planning', 'dressings', 'VCCT', 'chronic
	Sister Botala	'general nursing care'; 'babies, child health'
	Nurse Tefo	'Curatives', 'EPI', 'family planning'
	Sister Fourier	'mainly TB' ANC, babies, sick people
	Sister Kopo	'mostly 'Sick children'
	Sister Metso	Never clear
	Sister Molao	Never clear, although mainly appeared to work
	Sister Kwena	ART nurse
	Sister Andrews	'Antenatal' programme
Ba Banyane	Sister Habore - clinic manager	Sees 'all' patients
	Sister Peo	'TB', 'pregnant women', 'general, everything'
	Sister Pretorius	'primary health care', 'everything'
Christen	Sister Seporo - clinic	'Comprehensive nursing'
	Sister Vermaak	I suggested she focussed on HIV care and ART, but she resisted my attempt at categorising like that.
	Sister Kgaolo	Sister Seporo said she did TB
	Sister Thabo	Sister Seporo said she did IMCI
Dula	Sister Fula – clinic manager	'all rounder'
	Sister Mamdala	'ARV'
	Sister Nomkhula	ART
	Sister Sehlwela	'ART'
	Sister Sediba	Sister Fula said she did 'chronic and antenatal'
	Sister Setempe	'minor ailments'
	Sister Kgaba	'chronic and pregnant women'
	Sister Setala	Sister Fula said she did 'minor ailment'
	Sister Lejwe	Sister Fula said she did 'ARV'

This understanding was however complicated by what I initially perceived as tensions within my data. Alongside these very specific descriptions of the services they worked on, nurses also used a discourse of how they would provide integrated care. A recurring theme was of care being 'comprehensive' (Sisters Terene, Fourier, Mamdala, Setempe, clinic manager from Esita clinic) and equivalent notions of doing 'everything' (Sisters Botala, Fourier), seeing patients 'as a whole' (Sister Andrews, Nurse Tefo), doing a 'continuity' (i.e. seeing a patient for all their needs, Sister Seporo) and having a 'supermarket approach'

(referred to by nurses in Dula and Joyful clinics). There was also an idea of holistic care (Sister Terene, Sister Fula, Sister Mamdala). Further tension in understanding service provision lay in how nurses could also be opposed to health system management pressure for further integration of services. I was left with the question of how was it possible for nurses to tell me in one instant that they focussed on a particular service, and then shortly after tell me they did everything.

One interpretation of these accounts is of nurses presenting a positive discourse of what they considered good care to be: comprehensive care that addressed patients' needs. Although this has analytical value, to accept it entirely would be to completely disregard nurses' claims as having any link with their work in the clinic. As I explored and analysed my data I approached this tension as stemming from different interpretations of the key terms that I and the nurses were using. For example, I was, implicitly, assuming that providing integrated care meant addressing everything within one room. However, integration as a term is multi-dimensional with a range of definitions (Atun et al., 2010). An illustration of the potential for different understandings came about when I asked Nurse Tefo about it; he responded by querying what I meant by integration. Notions like a supermarket approach are also contested; it can refer to facilities providing all services at one particular clinic (Fonn et al., 1998), whereas in other contexts it has been cited as a client seeing one provider for everything (Lush et al., 1999). Following this, there was a need to approach conceptualisations of comprehensive and integrated care from nurses' own perspectives.

My interpretation of these accounts is that they indicate a specific emic understanding of integrated care: while nurses can work on any service, their work is formally organised around specific service allocations – the services they identified with – and they can then potentially address a patient's other needs through ad hoc approaches to integrating other services in the context of that specific consultation. As in the discussion above, in outlining the nature of comprehensive consultations, nurses can take efforts to integrate services within a particular consultation, or not. This integration is therefore ad hoc, and left to the individual nurse to decide on an ongoing basis. Any apparent tension in nurses' accounts is overcome through recognising the emphasis on the potential to address all of a patient's needs, rather than it necessarily happening in every consultation.

The service allocation that a nurse has can also vary, with nurses perhaps primarily identifying with one service, but then also working on another service on a specific day of the week, or being able to cover staff shortages elsewhere in the clinic. Nurses would often tell me how they had gone over to 'help' on another service when they had finished their patients, or when a colleague was away. Sister Fourier described to me one day how she had seen TB patients until 2pm, and then started to work on 'minor ailments'. There were tensions in this however. Both Sister Fourier and Sister Fula, both clinic managers at the time, complained of nurses not being willing to help on other services and instead focussing on their own area of work.

ART and HIV care

ART and HIV care followed similar routines, with all nurses reporting some level of involvement in aspects of HIV care, whether counselling or health education linked to encouraging patients to test for HIV; nurses across all four clinics reported this. A factor within the process of service allocation was how some nurses in Christen clinic who were trained to provide ART chose not to provide it. Sisters Seporo and Thabo were both trained to provide ART, and yet only Sister Vermaak actually provided it. Dula clinic had three nurses who focussed on ART – Sisters Mamdala, Nomkhula and Sehlwela, later joined by Sister Lejwe. They tried to 'rotate' the nurses around the different services, in an effort to overcome the divisions that were emerging, but this failed, with the three sisters rapidly returning to provide ART again. These two clinics contrasted with Esita and Geheim clinics where all nurses were trained and provided ART, as a result of the choices of the nurses in those clinics. I go on to explore this in chapter 4, but here it is important to note a specific pattern of nurses either not being able or willing to work on ART.

Reflections on service allocation and the content of care

I presented service integration in chapter 1 as giving insight in to the content of care, within the overall framework of patient centred care. The routine identified here of nurses being allocated specific services, with nurses own ad hoc efforts to integrate services can be seen as limited integration. The first impact of this on the content of care is to potentially limit consultations. As already indicated in the discussion under consultations, if nurses are notionally focussed on a specific service it can narrow care to focus on just a few issues,

and close off discussion of other areas of need. Dividing care according to specific services conforms to a biomedical view of care, and in so doing acts to categorise patients according to a disease rather than their own experience of illness. This framing of a consultation around a particular service focus doesn't necessarily limit care – as nurses' ad hoc efforts to integrate services show – but it does lead to consultations being framed in a particular way, and so arguably increasing the likelihood of it. A process of nurses having a specific service allocation can however potentially support care, as specialisation can be linked to supporting quality care (Dudley and Garner, 2011); I explore this issue and how it features in nurses' accounts in chapter 4 and return to it in the discussion in chapter 7.

An additional outcome is that services are spatially separated within the clinics. In the case of TB this has a clinical logic, with patients with active TB posing a health risk to other patients, especially PLHIV. However, in the case of the separation of ART and HIV care and their allocation to particular nurses it risks areas of the clinic becoming associated with HIV and then leading to stigma that can undermine care (see also Uebel et al, forthcoming). In Christen and Dula clinics ART was focussed in particular areas of the clinic. In Christen clinic, Sister Vermaak provided ART from a single room at the far end of the clinic. Although she also provided other services, that part of the clinic was identified as the 'ART' part of the clinic. In Dula clinic many staff referred to the 'mainstream side', and then the 'ART side' of the clinic, with the 'ART side' being a self contained area. There were double doors leading outside, and patients would also often use this double door, rather than coming through the main reception. There was a corridor a few metres long linking it to the main reception area, allowing a clear view through: patients arriving for other services could clearly see in to the ART area. The stigmatising nature of this arrangement was identified by the nurses. Sister Fula reported patients talking about other patients going to the 'maroon chairs', a reference to the coloured chairs in the ART waiting area. The implications of this labelling were apparent when Sister Nomkhula said that patients are scared to come 'this side' and Sister Sehlwela described a story of a husband accompanying his wife to the clinic, and trying to pretend he wasn't there to be seen himself. The impact of a shift in spatial organisation of services was clear from the experience of Geheim clinic where a nurse reported how patients were more willing to come to the clinic when they abandoned ART being in one area of the clinic.

In summary, although initial interpretation of nurses' account can indicate a high level of separation between services, the precise routines point towards a limited form of integration, involving nurses being allocated to a particular service, that can vary, and then there being ad hoc integration from this basis.

3.5 Conclusions: the limits to patient centred, integrated care

This first stage of my analysis has provided a thick description of care routines across the four focus clinics, highlighting their key characteristics in relation to the patient centredness of care, and then the integration of services. On the basis of this description I make three conclusions about care.

The first conclusion is that care across all four clinics shows important elements of a patient centred, integrated approach, but this is also limited by many other aspects of care. Nurses are seeking to address broader psychosocial need and to orientate care towards patient needs. These efforts are also taking place within the context of routines that ultimately limit and frequently overwhelm these other efforts. Although this account highlights limitations to care it also differs from other accounts of care in South Africa that focussed on the task oriented nature of care, such as Lewin (2004) and Van der Walt & Swartz (2002) where strictly task oriented care was provided. A key distinction is how care in the four clinics largely focussed on private consultations in individual rooms, whereas other accounts of care have indicated care is more public and separated between a number of health workers.

A second conclusion is that ART and HIV care is 'the same, but different', with the potential to be more patient centred. This care is provided in similar routines to the rest of PHC, although with some nurses reporting a more intense application of widely held principles of care. This difference in care supports the conclusions of other studies that the introduction of ART and HIV care is motivating nurses to provide more patient centred care (Stein et al, 2007). The accounts from nurses of focussing effort and attention in these consultations suggests a higher level of motivation. I return to this issue of differences in care and the processes it indicates in chapter 6.

A third conclusion is that there is variation in practice across the clinics and nurses. All four clinics could be seen as having these different routines at different times. Nurses were also involved in these varying routines, being at times involved in both more and less patient centred care. Although my data hints at some nurses being more likely to provide more patient centred care, and the opposite, this is by no means clear, and I avoid making conclusions on those terms. Further data generation may have clarified this issue; however, it is still a useful conclusion to point to variation within the clinics, even if not focussing on particular nurses.

The thick description presented here gives a detailed insight in to care. In the following chapters I explore specific issues raised by this account of care. In chapter 4 that follows I develop a general analysis of the social processes involved in these routines, focusing on ideas of order, context and agency. In chapter 5 I focus in more depth on the agency involved in providing these routines. In chapter 6 I return to the specific issue of understanding the differences in ART and HIV care. Chapter 7 discusses these results together, including an effort to reconceptualise patient centred care for PHC based on the points raised through this chapter of how it neglects issues of scheduling care.

Chapter 4 - The social organisation of care

4 Introduction

In this chapter I explore the social processes and relationships involved in the care routines described in the previous chapter. The routines I identified indicate care frequently doesn't respond to patients', or even nurses', interests and needs. The basis for my analysis of these routines is that they involve specific forms of social organisation. In exploring this social organisation I also engage with a number of related questions: how are the limits to patient centred care understood? And so how to account for these routines? What underlies the differences with ART and HIV care? More theoretically, how to account for nurse agency within these routines?

Theoretical approach

My analysis draws on four key concepts: interaction, rules forming orders, context and relationship bound agency. I use these concepts to analyse the routines just described, on the basis that care routines involve nurses exercising agency in interaction, enacting orders of rules and roles, that in turn mediate context. These concepts, first discussed in chapter 1, can be summarised as:

- Care routines: the product of social action within the clinic, just described in chapter 3.
- Interaction: the process through which social agents – nurses, patients, clinic staff - produce care routines.
- Order of interaction: a set of roles and rules that structure interaction, through constraining and enabling social agents who enact these particular roles and rules.
- Context: the more fixed, macro-level structures of the social world, that provide resources and boundaries in which the local level orders of interaction are developed and enacted.
- Agency: the exercise of choice, based on the capacity to act (i.e. power) and this having meaning and intention for a social agent. It is through the exercise of agency – understood as bound up in particular relationships – that these orders and the influence of context are enacted.

I outline these concepts in more depth as I explore the layers in my analysis.

Nurses as the conductors of care

The focus of my argument is on nurses' agency to conduct care. Following my earlier discussion of Latimer's use of this concept (2000, see chapter 1), I argue that nurses are influential over care routines but are not entirely free to order them. This agency is visible in different ways in relation to the patient centredness of care and then service integration, and so I explore them separately.

I first of all discuss the care routines relating to the patient centredness of care, and establish how these are produced in interaction between nurses and patients. I explore how there are two orders in this interaction, corresponding to the routines that are less and then more patient centred: a controlling order and a collaborative order. These orders involve particular roles and rules about how nurses and patients should act. The controlling order involves nurses working to defend the broader interests of the clinic, and patients having narrow options for action. A collaborative order sees nurses seeking to guide the individual patient through the obstacles of the clinic and health system, with patients in more of a position to shape care. Nurses across the clinics all enact these two orders at different times, corresponding to the dynamism and variation across the clinics I discussed in chapter 3. I explore the role of context in this – looking at factors of resources shortages and understandings of nurses in particular – and show how these are influential in determining the order. However, the orders are not entirely determined by contextual factors, which I argue shows the role of nurses' agency in shaping the clinic routines. Nurses' agency is evident in how nurses choose between the two orders, and so enacting them. This choice is however constrained by contextual factors, and then also by the relationships with patients in which nurses' agency is bound up. I explore these relationships and how they have particular characteristics of power. I relate these forms of power to the meanings nurses' attach to their work, showing how a controlling order of care is linked to forms of compassion and then frustration and exhaustion, whilst collaborative care is also linked to concern for patients but also figures in nurses' accounts as the natural approach to care. The differences with ART and HIV care I explore as working through the same order and contextual influences, but involving specific meanings around stigma and the severity of HIV that motivate nurses to provide more intense care.

My exploration of service integration follows the same analytical approach, centred on nurses' limited capacity to conduct the care routines of services being separated and then allocated to individual nurses. I identify a cooperative order within interactions between nurses and the clinic managers, with nurses respecting clinic managers' decisions but themselves also having influence over decisions, and this influence is predominantly felt in nurses trying to maintain the status quo. I explore context and see it as highly influential over these processes of initially separating care and then allocating nurses to them. Although there is only one order of interaction across the four clinics, based on the similarity of routines, there is still evidence of how nurses are actively choosing these forms of care. I explore nurses' choices and limited power over each other, and how this highlights forms of autonomy and independence. I relate this to specific meanings nurses attach to maintaining a service allocation rather than integrating care, focusing on concerns for quality of care and relationships with patients, but also anxiety over the complexity of care. ART and HIV care again involve different meanings, with a greater concern for the complexity of care and the emotional demands of care also leading to a preference for separate services.

Through the chapter I develop this argument of nurses' conducting care by first discussing the routines relating to the patient centredness of care, and then secondly the routines of service integration. Within each section I first explore the nature of interaction, establish the rules and orders within it, then contextual influences before exploring the role of agency. The final section summarises these findings and the overall theoretical outcome of the chapter is a grounded, inductive theorisation of social action and agency within the clinics. Annex 4 has a summary of the coding structure used in developing these arguments, corresponding to the outline of my analysis discussed in section 2.3.

4.1 Orders, context and agency in patient centred care

An analytical focus on interaction stemmed initially from the variation and dynamism in the care routines in the clinics. This variation suggested care is being shaped and changed at the clinic level through the actions of local level actors. Nurses' accounts were rich with descriptions of how they made ongoing decisions about care and what they did in the clinic; these accounts can be interpreted as showing care is shaped by nurses, and not

structurally determined. The routines are nurses' work and my focus is on understanding nurses' role in clinic interactions, but a key dimension of this interaction is the role of patients. This active role was clear across routines, whether in patients adapting their arrival times at the clinic or shaping the content of consultations. The idea of patients as 'co-workers' in care (Allen and Pilnick, 2005, p689) and of playing an active role is a recurring theme in the sociology of health (Strauss et al., 1963, Roth, 1963, May, 2010), including in South African contexts (Lewin, 2004, Schneider et al., 2010) as well as broader analysis of service delivery and state-citizen relations (Lipsky, 1980, Barnes and Prior, 2009). I follow this and explore how patients can collaborate with, or resist and frustrate, nurses. As I will argue, it is clear patients are not passive objects of nurse power. The precise nature of care routines was constantly being negotiated or contested between nurses and patients, with patients responding to nurses, and nurses adapting and tailoring their work. In the next three sections I explore the three key dimensions of these interactions, the orders, context and nurses' agency.

4.1.1 The orders of interaction

The interactions between nurses and patients are not unstructured; there are patterns in this interaction, with rules of conduct bringing order (Dixon-Woods et al., 2006) and so acting to structure interaction. These rules are shared understandings (Strauss et al., 1963) that provide procedures for social interaction (Giddens, 1984) that outline a set of events and a set of roles (Strong, 2006a). A vivid example to illustrate this is from Christen clinic. I used the patients' toilet and by the sink were a row of plastic cups – looking like tall, thin wine glasses – I was thirsty and thought about having a drink, but hesitated: I didn't really know their intended use, and they were being kept in a toilet which didn't seem particularly hygienic; I decided to wait. Not long after this I was sat in the waiting room and saw a man walk through from the toilets with a urine sample in one of the beakers. Relief at a lucky escape was eventually accompanied by the realisation that the purpose of the cups was not written down, it was a shared understanding between nurses and patients, one that was relayed through interaction (either nurses telling patients to do this, or patients being told by others), with a set of events (use of the beakers to get a urine sample, in the toilet, and then returning to the consultation) and roles (patients can be put in an arguably undignified position where they are expected to urinate in a wine glass and walk through the clinic; nurses can ask them to do this).

Many of these rules are explicit, in that they are clearly formulated or codified (Giddens, 1984) and so are widely discussed. Much of my description in the last chapter outlines these explicit rules as they were how nurses' described the work they did, and as a consequence can be seen to be openly discussed. An example includes how nurses used clinic guidelines in consultations, whether the PALS PLUS guideline (See section 1.1.4 and appendix 1) or the IMCI forms, these are one set of rules, providing structure for a consultation and diagnosis. Sister Pretorius in Ba Banyane referred to the PALS PLUS as a 'tool' and 'like a bible', demonstrating through metaphor how it enabled and constrained her actions.

These explicit rules form just a part of an overall social order that also involves implicit rules around the roles that nurses and patients can adopt. These implicit rules are taken for granted to the extent that they don't need to be spoken about or explained. For example, nurses didn't speak about the fact that they expected patients to listen to them, or that it was acceptable to shout at a patient in a consultation; these are just established rules that reflect specific roles. In the rest of this section I show how there are two distinct orders in the clinics reflecting particular sets of rules, a controlling order linked to less patient centred routines, and a collaborative order linked to more patient centred routines. I discuss these in turn.

The controlling order in less patient centred care

The routines that I described as less patient centred included the routines for scheduling care that are impersonal and unresponsive – including the first come, first served system, the daily service timetables and the absence of triage – and the routines that limit consultations, including having a narrow range of issues covered, a high degree of routinisation and poor communication. These routines were at times referred to as having explicit rules. The first come, first served system, and the daily timetable for services were simply stated as such. The number of tasks to be done in a consultation was also subject to a specified minimum, of tasks of taking a patient's temperature and blood pressure. What was less clear were the norms by which nurses and patients were expected to behave and which allowed these interactions to happen and the routines to be produced. I discuss here

a role for nurses as guardians, and patients being confined to a role of having to respond to nurses. The essence of this order is of nurses controlling patients and the clinic.

Describing nurses as guardians of the clinic is a useful metaphor for how it implies a role in defending a position, involving authority and being on the front-line. This metaphor builds on similar comparisons made by Van der Walt and Swartz (2002) to nurses as 'combatants' in battling the public health emergency of TB and then Petersen and Swartz (2000) describing nurses as 'gatekeepers'. This role of guardian accounts for how nurses would seek to control patients. Sister Fourier explained her approach to managing the TB service in this way, saying how she was 'fairly friendly', but also threatened patients that if they didn't comply with weekly treatment they would have to come every day; compliance was also fostered through her claim to patients that she could test their urine at any time and tell by the colour of it whether they were taking their treatment. Many of the routines involve nurses trying to control and contain patients, in response to what are seen as excessive demands placed on the clinic, and in so doing protecting the broader interests of the clinic in terms of trying to balance and ensure all demands were responded to. An almost literal enactment of this role of guardians is how the nurses in Christen clinic would actually lock the front door at lunchtimes, and late in the afternoons to make sure no more patients came in to the clinic. The position of authority and control involved is also visible in how nurses can shout at patients, such as telling patients to come to the clinic early in the morning, or how nurses would stand in the waiting area and issue instructions to patients as a group. This role doesn't just involve open coercion, but also nurses trying to reason and soothe patients and at times apologising for the routines, but still from a position of ultimate control. As I raised in chapter 3, it is not that care is necessarily against a patient's interests, but that the individual interests and concerns of a patient aren't considered. The idea of a guardian also implies a role of being entrusted to protect and preserve, which is linked with how nurses role is to act in the interests of all patients and seek fairness, even if not an individual patient. This role could also involve nurses being domineering and rude. ART and HIV care also involved this combination of roles within a controlling order.

In tandem with nurses' role as guardians, is a role for patients of being consigned to only being able to respond to nurses' actions and wishes. The interests and needs of individual patients are largely subordinate, and that any action by them is within constraints set by nurses. As a result, patients are left to either respond to nurses instructions on where to go, or to nurses questions in a consultation, even if neither of these are forthcoming. For example, patients could come to the clinic at any time, in theory, but it was entirely within nurses' control as to whether they would then be seen or not. A reason patients don't come in the afternoon was suggested as because they knew the nurses were busy with their admin work, others that the patients wanted to be seen first within the first come, first served routine, whilst others that it was because the nurses would shout at them. As I go on to explore below, this care isn't necessarily coercive, with patients also reportedly perceiving that nurses were busy or stressed and so not raising issues. Patients' action however all reflect the underlying role of having to respond to nurses. The complaints from an ART patient in Christen also illustrate this, as she recounted how she had been sent away from the clinic and told to return for blood tests as results had been lost elsewhere, but was unable to get the nurse to act on her behalf and follow up her issue.

The collaborative order in more patient centred care

The routines that I described as more patient centred included the routines for scheduling care that allowed for flexibility around emergencies, informal appointments and then the prioritisation of patients over other tasks. In consultations these included addressing a broad range of issues, and good communication. I also reported on how ART and HIV care could involve an increased commitment to these more patient centred approaches. The explicit rules of these routines included nurses' accounts of how they would assess the patients in the waiting room and attend to emergencies, or that they try and explore particular dimensions of patients' vulnerability, or how certain rhetorical strategies in consultations were useful to get patients to discuss their health problems. In variation from the controlling order these rules involved a more collaborative form of rules and roles for nurses and patients to adopt, with nurses taking on a role as a patient guide, and patients having a role of being a focus for analysis and exploration.

The role for nurses as *guide* indicates nurses' efforts to be supportive, and relating to patients as needing support in accessing and overcoming the challenges and obstacles of the clinic and wider society in accessing care. Sister Seporo actually referred to an effort to 'guide' patients, as did Sisters Sediba and Setempe in Dula clinic. They were referring to specific processes in consultations of trying to talk to patients, but it also illustrates a broader trend in how nurses related to patients. This role involved providing an overall stewardship role, and so still implying a level of control, but also one involving being proactive in engaging with patients' circumstances and individual experience. This could be seen in how nurses used lay language in consultations, or recognised that patients found accessing care difficult and faced many social or environmental challenges in adhering to a treatment plan. A vivid example is how Sister Habore responded to a patient who visited one afternoon and spoke at length with her in the waiting area. Sister Habore was sat down and listened to the patient for fifteen minutes, which she later reported to me related to an issue of how apparently the patient had taken out a bank loan to cover gambling debts. Sister Habore referred to it as a 'social problem', and said she had arranged for a social worker to go and visit. Beyond the particular details of the situation, it demonstrates a willingness to engage with a patient's circumstances and support a solution.

Complimenting this role for nurses was how patients were in a position where nurses sought to understand their situation, rather than ignoring them. Patients have a valid position that is to be explored and understood. In contrast to being in a position of being expected to only respond to nurses, they instead presented a challenge or puzzle for nurses to try and understand and so allow nurses to help them, based on having individual circumstances that affected why they were in the clinic. Patients were seen by nurses as needing to be listened to, of needing questions to be asked, of having a legitimate point of view and correspondingly as having a legitimate claim on nurses' time.

Dynamic and shifting orders

This identification of orders within clinic routines points to key characteristics of the social organisation of care. Cutting across my identification of these orders are two points relating to this: first, that these orders summarise dynamic situations rather than discrete social forms; second, and further to that, that all four clinics and nurses across those clinics

were involved in providing care that corresponds to both orders, i.e. the same nurse could at one particular instance provide care in line with a controlling order, to later follow a collaborative approach. It is how clinics and nurses followed these orders at different times that led me to consider the precise role of context in shaping care routines.

4.1.2 The influence of context

Nurses' accounts were rich with references to events and influences on their work beyond the clinics themselves. These covered a range of issues, but principally focussed on the functioning of the broader health system and resources shortages. I conceptualise these phenomena outside the clinic as the contextual dimension of structure. As I set out in chapter 1, I consider context as the more fixed, macro-level dimensions of the social world. This level of structure I conceptualise as providing boundaries and resources through which the orders just discussed are enacted.

The argument I make in this section is that contextual factors of health systems policy, resource shortage, race and understandings of nursing are influential in producing the care routines, through how they shape the orders of interaction that nurses and patients adopt. However, they don't determine the care routines. I first of all show how the very existence of two orders of care demonstrates the limited influence of health systems policy over care routines. I then explore how the controlling order of care can be seen to emerge from specific contextual influences of resource shortages, race and understandings of nurses, and yet the collaborative order of care at times has these same contextual influences. It is in how these orders can occur under the same contextual influences that I see as highlighting a role for nurses' agency in care, which I then go on to explore in the next section, 4.1.3.

The limits to health system policy and management

Aspects of the two orders of care have clear contextual influences, with specific factors linked to actions in the clinics. Aspects of the health system like patient transport arriving at clinics at 6am, doctors only visiting for two hours in the morning, a need for referrals to

the local hospital to be made by a certain time or the early collection of blood samples for testing at central laboratories were a direct factor in fostering specific routines of morning focussed work that ignored individual patient need, and so fostering nurses acting in a controlling order. Vaccinations being provided in bulk volumes created pressure to group patients together to ensure nothing was wasted, and so influencing nurses to override individual concerns. Pressure to rush work can also be shaped by staffing shortages caused by staff going to training sessions and being out of the clinic. In this context, a controlling order of interaction can be seen as a practical or inevitable outcome.

The influence of health system factors over care routines wasn't uniform; instead they varied between clinics and nurses. An initial indicator of this is how health system policy and management guidance was implemented in varying ways across the clinics. For example, the use of PALSA PLUS, IMCI or EDL guidelines in consultations varied, with nurses' either not using them, or ignoring their advice. That clinical guidelines are not adhered to is widely seen (e.g. Horwood et al., 2009) and this can be seen as part of a process of how health workers implement and translate policy (Penn-Kekana et al., 2007, Lipsky, 1980, Walker and Gilson, 2004). This same process is clear across the clinic in a range of ways. One example is of how nurses had varying responses to the policy of patients' rights to care. Whilst many nurses referred to rights as a key principle and seemed supportive of them, some were critical, citing this as a factor in patients' unreasonable behaviour and behind patients making complaints. Policies that promoted patients' rights can therefore support and legitimise a collaborative order within care, providing a contextual influence for nurses seeking to engage with patients' individual circumstances, and yet it can also be linked to fostering conflict and creating relations more related to controlling forms of care (I return to consider issues of rights again in chapter 5). Health system policy and management at times therefore had clear and direct influence over care routines, through determining particular orders of interaction. It is also evident that other dimensions of policy and management can be translated in implementation and linked to both orders of interaction.

Resource and staff shortages and issues

Nurses across the clinics complained about staff and resource shortages. Staff shortages – whether through daily variations and absences, or long term challenges of recruitment – were cited across the clinics. There were also complaints of shortages of drugs, not just ART, but also TB drugs in Aangekom, and then of equipment like thermometers, but also phones and other equipment that meant nurses had to leave consultations. These staff and resource shortages create conditions where nurses and patients can't achieve their respective goals and were instrumental in creating conflict between nurses and patients. For example, patients could perceive nurses as withholding resources and nurses said how a lack of medical supplies would lead to them 'fighting' with patients. Nurses also 'pleaded' with patients in the waiting area when there were staff shortages, anticipating patient anger at the long waits that would result. Previous shortages of ART drugs owing to a province wide decision in 2008 to stop initiation of patients for three months - see section 1.3.1 – led to nurses being unable to give patients ART. This was a clear source of tension, anxiety and stress for the nurses (And which I reflect more on in chapter 6). In this situation nurses are not able to attend to an individual patient's needs, with nurses being required to adopt a role as clinic guardian in relation to patients, as nurses weren't able to overcome resource shortages. A controlling order of care can again emerge as a direct consequence of resource shortages.

Resource and staff shortages and issues were clear across the clinic, and were directly linked to challenges in providing care, and with care routines that are considered less patient centred. However, a collaborative order and so more patient centred care was still visible in the same conditions. Although resource shortages and a busy clinic can lead to rushed care in a consultation, this is not inevitable. Nurses described how they would choose to spend time with patients and how they would respond to the individual patients needs. Sister Botala described the dangers of rushing and how you could miss things. While nurses often felt a pressure to rush and so adopt a controlling order of interaction, this wasn't inevitable, with nurses seemingly choosing collaborative orders in the same conditions.

Race and language

Race didn't figure prominently in nurses' accounts of care, at least in terms of references to racial prejudice and the influence of apartheid. There were some accounts suggesting tensions that could foster a controlling order of care: Nurse Tefo said they expect 'special treatment' and Nurse Metso that they insulted her in Afrikaans when they thought she couldn't understand. Sister Marais complained about coloured patients not listening to her. Antagonism within consultations on the grounds of individual's prejudices – whether of patients or staff – could have shaped consultations. Overlapping with race is language, which was cited much more often as an issue, with nurses and patients often not sharing a first language (as in chapter 1, there are 11 official languages). Nurses cited this as a challenge, and would make efforts to involve other staff in consultations who could translate, but it is likely that language challenges make it difficult for nurses to adopt the role of guide in relation to patients, and lead to care being focussed on a more controlling order.

Understandings of nurses and nursing

Understandings of nurses and nursing also shaped interactions between nurses and patients. Several nurses reported patients seeing nurses as 'nasty', or that they don't treat them 'nicely'. These were grounded in broader understandings of nursing in South Africa, with Nurse Tefo citing this as a historical phenomena and Sister Botala referring to it as nationwide. That nurses treat patients as subordinates and behave in a controlling manner therefore has direct continuities with these understandings of nurses. Other analysis has suggested that nurses see themselves as apart from the 'lower orders' of society (Marks, 1994) and were correspondingly unpopular in their communities owing to a perceived role in supporting the hegemony of the apartheid state (ibid). The origins of South African nursing within colonial era English sisterhoods (ibid) which in turn link nursing to a distinctly moral character (Dingwall et al, 1988) can be seen to legitimise this role of a guardian within the clinic. While community and historical understandings of nurses may legitimise the role of a guardian and a controlling order of care, from the analysis above it is clear that a contrasting order and role of guide exists alongside it, showing that these understandings can be overcome.

The role of gender

An obvious aspect of context shaping the clinics is gender. In the four clinics I focussed on there was just one male nurse, Nurse Tefo in Aangekom. His presence drew attention to what can rapidly seem natural in the clinics, and across nursing, of it being a profession predominantly comprised of women. Gender didn't feature explicitly in nurses' accounts as a factor influencing their work, although there are other relevant themes. Most obviously, nurses referred to each other as 'sister', a legacy of the gendered history of nursing, and as I discuss in chapter 5 nurses have multiple identities, being mothers and wives as well as healthcare professionals, which are a point to problematise gender. There wasn't however any clear point in my data to understand whether gender affected nurses' enactment of particular roles of a guardian and guide. There is an obvious consideration that being a man I may be less sensitive to some dimensions of gender and their role in the clinics. This is difficult to deny. However, a sociological eye for the micro-operations of power and my familiarity with some areas of feminist theory can reasonably be seen as conditioning me to identify at least some elements of clinic level processes of gender inequity. The absence of a comparator, in terms of a high number of male nurses, also in effect hinders analysis. However, a potential hypothesis is that the existence and frequency of the role of a guide reflects particular understandings of nurses as women's work, and that the properties of this role – of valuing talking to people, and a sensitive and inquisitive position – reflecting understandings of what is appropriate for nursing, as a gendered profession. If critiques of medicine are accepted, then the role of a guide is potentially less likely to be taken on by doctors. I raise this here, and return to discuss related issues in chapter 5 in relation to how gender inequities can be seen in structuring the possibilities for nursing.

Context shapes, not determines care routines

Through this section I have explored how aspects of context shape care routines in terms of fostering particular orders of interaction. At times the existence of a controlling order seems like an inescapable response to contextual conditions: when there is only one nurse available and a clinic full of patients there is an inevitability to individual patients being neglected, as compared to a quiet afternoon when all the nurses were available and only a few patients. However, I have then also shown how context is not entirely determining as

shown in how the two orders are evident in similar contextual conditions, showing how context is mediated by these orders. It is these differences that highlight the role of agency in producing the care routines.

4.1.3 Nurses' agency: the conductors of care

A question that guided my analysis was trying to understand the role of nurses' agency in these routines. As a response to the literature reviewed in chapter 1 and my fieldwork I sought to understand the role of agency in apparently 'bad' care. I have already shown in 4.1.1 and 4.1.2 above how action was governed by specific orders of interaction and how these related to contextual factors. It was how the same contextual factors varied in influence that led me to focus on the role of agency within these routines. Agency, as I discussed in chapter 1, is about choice and so the capacity to act and the intention and meaning involved in that. In this final part of this section I explore nurses' capacity to choose and act within these structures of order and context, and the meanings attached to these actions.

My argument in this section is that nurses' agency over care routines can be understood as them being the conductors of care, following my discussion of Latimer (2000) in chapter 1. I argue that although nurses have influence over the care routines, they don't have complete control, as indicated through my discussion of orders and context that shape and limit nurses' choices. In establishing this form of agency, I explore three points. First, how nurses choices over care routines are constrained by the orders of interaction, and context, and yet, nurses do have some choice over what the order of interaction will be. Second, that these choices over the order of interaction happen within particular power relations with patients; the differing power relations of 'power over' and 'power with' patients is an additional layer of constraint and enablement on nurse action. Third, the choices nurses make have to be understood through the meanings attached to them. I explore nurses' meanings to show how their actions and choices are linked to a range of motivations, but with a key theme of how both the controlling and collaborative orders can be linked to compassion and concern for patients' interests.

Nurses capacity for choice over care

A restriction on nurses' agency over care routines is already indicated in my analysis of order and context. The existence of the orders of interaction logically imply how nurses' actions followed regular patterns, which can be understood as both constraint and enablement to follow certain courses of action, as evident in the orders, representing a level of constraint. These orders in turn represent the constraints of context, as set out above: certain orders of interaction are made more likely by contextual factors. A logical outcome of this is that nurses' choices over the nature of care routines are limited.

Nurses' choices are limited, but they do have some capacity to choose the order of interactions, and in the process mediate the influence of context over care routines. This choice over order is initially evident in nurses' descriptions of how they would respond to the patients in front of them, trying to adapt care to their needs and interests. This role of discretion and constant decision making was clear across nurses' accounts. The difference reported in ART and HIV care is an expression of nurses' capacity for choice; the variation around this underlining how it is individual nurses aiming to do this. There were also specific instances of nurses' accounts suggesting choice over the overall order of interaction, and they could adapt their work and deliberately take on the role of guardian or guide. Nurses often described a process of deciding whether to explore a patients' problem or situation in-depth. Nurse Tefo explained to me one day about how sometimes you had to be 'harsh' and 'rude' with patients to get a message across, implying a degree of choice over enacting the role of guardian. Similar efforts were apparent in nurses' choosing the role of guide. Sister Habore described her deliberate efforts to be 'open' with patients, knowing that an alternative approach wouldn't encourage patients. A nurse in Geheim clinic made a similar point, saying how in a good consultation you didn't have to be 'harsh'. Nurses' accounts of how they sacrificed quality are another illustration of how nurses were choosing an order of care, even if within specific constraints of context. These limited choices nurses are able to make show the exercise and expression of nurses' agency over care routines. This combination of orders and context constrain nurses, but nurses then exercise agency in choosing the orders demonstrates a process of structuration. Nurses

choices may be heavily prescribed, but by still making these choices they are recreating and embedding the rules, and influence of context.

Nurse choice and power relations with patients

Nurses' agency and their capacity to shape the order of interaction, and so mediate context, is embedded within relationships with patients. The roles I described of nurses as guardians and guides involve particular power relations. It is through these power relations that nurses enact the clinic routines by having influence over patients. As I demonstrate, this influence over patients is limited, and correspondingly, so is nurses' agency over care. In the next two sections I first of all discuss power relations in the controlling order, and then the collaborative order of care.

Nurses' role as guardians involves a specific power relation with patients, of what I described in chapter 1 as 'power over'. For an agent to have power over another agent demonstrates a form of power that sees nurses limiting the field of action of patients (see Göhler, 2009) with nurses able to subordinate and impose on patients. This is clear in how nurses would shout at patients, deny them access to the clinic or even like when Sister Botala said that patients will choose to breastfeed their child rather than bottle feed them as they believe it is what the nurses want. In providing TB treatment Nurse Fourier also makes clear to patients who come to the clinic once a week, that if they miss one treatment they will have to come to the clinic every day. This power of nurses over patients is also clear in the overall process of patients waiting for nurses across the routines, and how this leaves patients at the mercy of nurses schedule (Mulcahy et al., 2010) . This loss of control is especially clear in how patients would complain about waiting time and about nurses pace of work as it indicates their powerlessness to control it.

Nurses' power over patients can be complied with, but also resisted. This resistance can often be in the form of 'weapons of the weak'; the actions of powerless groups that fall short of open defiance, and instead relying on 'weapons' such as foot dragging, false compliance and feigned ignorance (Scott, 1985). Patients ignoring nurses' requests to come in the morning or on specific days can be seen as an example of this process of resistance

to nurses' power over them. Within consultations patients can withhold information or questions, out of fear of nurses or from also feeling pressure to make consultations short; or not wanting counselling. There is also more active resistance, with patients reportedly verbally fighting with nurses or loudly encouraging other patients to join them in writing complaints as I saw in Aangekom. As I stated at the start of this chapter, patients are not mere objects, but have some level of agency within the clinic. On this basis they can act to resist nurses' instructions or wishes, even if nurses are ultimately in control.

Nurses' role as a guide for patients was linked with more collaborative power relationships, what I described in chapter 1 as having power with patients. This form of power sees nurses as having power over, but then also using this to facilitate the power of others. In these expressions of power nurses can be seen to seek and respond to patients needs and wishes, with nurses deferring to patients choices in consultations, even if they didn't necessarily agree. Examples of this include Sister Peo accommodating patients visiting a sangoma, a traditional healer, and then trying to get patients to also use treatments from the clinic, Sister Andrews describing how she uses lay language with patients to ensure their understanding or Sister Habore listening respectfully to a woman who was drunk and behaving erratically, but who she allowed to speak and provided treatment to. This collaboration and power with does still however arise from nurses' occupying a position of power over patients. Any flexibility or deference shown by nurses is at their discretion and so functions as a 'gift' or 'charity', ultimately implying a power relation and superior position in that it can be withdrawn (Scott, 1985, Freire, 1993).

The relationships in ART and HIV care followed this same pattern, as they also followed the same orders of interaction. Nurses could exercise power over patients, as evidenced in how patients when waiting for care had the same lack of control, or in determining the nature of consultations. Power with was clear in instances like when Sister Fula advised two patients not to test for HIV together, but separately, but they went ahead and did this anyway, or with Sister Nomkhula reported how patients will ring ahead and ask her to get their treatment ready, and she will respond to that.

These power relations are the interactions through which nurses make choices about the care routines; their capacity to choose the order of care, and to mediate context, is ultimately reliant on the extent to which they can control or collaborate with patients to achieve particular courses of action. The limits on these power relations and how nurses can't determine patient action are a key dimension of this capacity to conduct care.

The meaning of care

Understanding nurses' agency fully relies on engaging with the meaning and intention of these actions and the roles of guide and guardian for nurses. I first of all discuss the meanings nurses attached to their actions around the controlling order of care and role of guardian, linking this to a form of compassion, and then also anxiety and frustration. The collaborative order of care I also link to compassion and in the case of ART and HIV care a particular sensitivity to the stigma attached to HIV and the perceived severity of the illness.

The routines that I described as less patient centred and involving the controlling order and role of guardian of social interaction were grounded in a form of compassion for patients. Nurses knowingly pressured and even coerced patients or neglected their interests, but based on beliefs and attitudes that suggest this is seen by nurses as necessary to achieve a good outcome for a patient, or that this is the best or fairest outcome possible considering the poor conditions. This combination of control and compassion is visible in how nurses justified morning focussed work, through it acting to ensure patients are seen, whilst recognising the inconvenience it posed to all patients. This controlling response – of telling all patients to come in the morning – can be understood when nurses statements about being concerned about an emergency happening in the afternoon meaning not all patients are seen are interpreted through an understanding of how nurses lack information on their workload, i.e. they do not know how many patients will arrive. The routines for scheduling care may lead to long waits or shortened consultations, but they are also seen as at least achieving basic goals of patients receiving care and so can be seen as favouring patients generally. Nurses' reported anguish around how they lacked the time and resources to provide quality care, and that this forced them to limit care in ensuring all patients are seen is another example of how nurses made sense of their actions that ultimately reflects a

concern for patients. The nurses knew they were rushing consultations, but felt the pressure of the other patients waiting outside.

This choice to limit care is evident in other literature. In a similar context, Evans and Ndirangu (2011) described nurses pressuring patients in to particular decisions based on the nurses' perception of benefits to the patients. Processes of care workers abandoning emotional labour to concentrate on providing technical care when short of time have also been reported (Fitzgerald, 2008). Without exploring the meaning behind these actions these actions could otherwise be interpreted as nurses' work being solely determined by contextual factors, i.e. resource shortages limiting options for action, or of nurses being mean or cruel. This argument instead suggests that care routines that are shaped by context and specific orders of interaction also involve active choice by nurses.

Overlapping with control motivated by compassion, were more isolated references to how actions like shouting at patients were shaped by frustration or exhaustion. Sister Seporo referred to occasionally getting angry as a result of feeling overworked, and Nurse Tefo gave an example of shouting at a patient if they were smoking outside the clinic when it was their turn to see a nurse. Sister Mamdala said how when she was tired she may end up not listening to patients, and repeating questions without realising it.

The role of a guide and more patient centred care was linked with nurses stating concerns for patients and of an orientation to patient need. The needs and concerns of a patient were referenced by nurses. However, across nurses' descriptions of more patient centred care was the sense of this care being the natural or normal work to be doing: nurses' didn't seek to give specific justifications for their work approach, as they would refer to workload and stress in explaining rushed care. The absence of specific discourses justifying these routines beyond a general orientation to caring for patients could reflect an orientation of my data generation and analysis towards understanding the problems in care. However, that nurses may see more patient centred care as the natural and inevitable work they should be doing would reflect the explicit discourses of comprehensive care, and also an underlying meaning of care being a process of attending to others needs.

The meaning of the difference for ART and HIV care

In suggesting that ART and HIV care had differences around a greater intensity of effort with patients and so a tendency to more patient centred care, this suggests there were specific meanings attached to HIV. Despite some accounts from nurses of ART and HIV care as 'the same' and 'normal', nurses also recognised stigma and the social challenges patients faced. Sister Seporo recognised the difficulty for patients in disclosing their HIV status to family, and Sister Andrews spoke of how a patient had feared rejection from her family. This perception of the increased difficulties PLHIV may face can then be seen as a basis for nurses' increased efforts to attend to patients needs. I return to the meanings nurses' attached to HIV, ART and HIV in section 4.2 below and in chapters 5 and 6 to suggest other meanings that could inform the differences in care; the recognition of stigma and patients circumstances seems to inform the increased motivation for nurses to provide better quality care.

Agency and patient centred care

In summary, through this first section of the chapter I have explored orders of interaction, context and then agency to show specific influences on the care routines. The overall implication of this analysis is that patient centred care is shaped by many factors, but nurses' agency has an important role. The health policy and resource poor context are influences over care, but nurses are still active within these constraints through their agency as conductors of care.

4.2 Order, context and agency in service organisation

In this second half of the chapter I use the same approach of order, context and agency to explore the interaction involved in producing the routines in service integration I described in chapter 3.3. I described an overall picture of limited integration, with a routine of services allocated to particular nurses, based on an underlying separation of these services. I then described how ART and HIV care followed a similar pattern, although with a slight variation in terms of the willingness of some nurses to provide ART. In this section I explore

the process of how these services are separated and then allocated. After outlining the modes of interaction I identify what I call a cooperative order within it, focussed on interactions between nurses and then with the clinic managers. I describe how within this cooperative order nurses take on a conservative role in trying to preserve current conditions, while clinic managers' role is limited to that of advocates. I then explore the contextual influences over this, showing how understandings of separate services result from health systems policy and associated discourses. I then also show how these contextual factors are mediated through interaction. This then brings me to the last stage of the analysis, where I explore nurses' agency and I argue that although this is limited in shaping service integration, owing to the influence of structures in the form of context and rules, nurses are still exercising agency in the provision of separate services. I again relate this to the idea of nurses as conductors of care, showing their influential, if limited role over the organisation of care.

In the course of developing the analysis presented here, I collaborated on a paper with colleagues from UCT who were conducting parallel studies with a focus on service integration, although with differences in design and intent: a STRETCH trial qualitative process evaluation and also a research diary from the STRETCH trial manager, Dr Kerry Uebel. Through informal conversations, it became apparent that these studies overlapped with my own study, and so we sought to combine the findings. The paper that is emerging from these findings is a synthesis of the various themes across the three studies, and is intended to inform health services management on the range of factors that can influence the integration of ART and HIV care in to PHC. This is distinct from my aim here to give in-depth insight to the underlying social processes. Despite the different purposes, the overlaps in the studies and the process of developing the paper have supported me in my ongoing interpretation and analysis of my data. I refer to the overlaps with the work in this collaboration – Uebel et al, in preparation - but then further develop these initial points with reference to my wider data and the specific clinic contexts I was working in. I also reference in this section an analysis of my findings related to this area, co-authored with colleagues from UCT, which developed these more specific points (see Guise et al., 2012).

4.2.1 The order of service organisation

The existence of clinic timetables for when services were provided, and the clearly understood allocation of services between nurses suggests a permanence and rigidity to the extent of service integration, despite the ad hoc way in which it varied as I described in chapter 3. Following the analytical approach outlined in section 4.1, I again sought to understand the role of interaction and the underlying order involved in this. In this section I outline a single cooperative order, reflecting the similarity of the routines across and within the clinics I described in chapter 3.

The cooperative order in service separation and allocation

The routines of services being allocated and the underlying separation of services relied on a cooperative order between nurses. Cooperative, as distinct from collaboration as described above, implies a more equal share and a joint enterprise between the nurses and clinic managers. I first of all discuss the explicit rules involved in this, and then the forms of interaction, before identifying nurses' conservative role and the clinic managers' role as advocates.

The explicit rules for what services nurses worked on are most clearly evident in the clinic timetables that nurses described; with nurses across the clinics referring me to how services were provided on particular days. Overlapping with this, was how the nurses would know which of their colleagues was working on which service. Neither the timetable or the service allocation were written down, as the nurses told me they weren't meant to organise their work in this way, and hence this wasn't a formal arrangement. Another form of rules was nurses' discourse of the need for comprehensive or integrated care. As I outlined in section 3.3, when trying to understand whether nurses were providing several services within one consultation, nurses in their general accounts would often insist they provided integrated or comprehensive care. I initially struggled to understand nurses' meanings for these terms, eventually understanding that a clinic providing integrated care meant the possibility it could happen, not that it necessarily did.

When nurses talked about the services they worked on, references to any interaction with others were minimal. Rather than regular and repeated interactions between nurses at which service allocation and organisation was discussed, or through regular formal meetings, a lot was taken for granted or assumed, and as a consequence hard to access and understand. However, there were a range of forms of interaction that shaped service separation and allocation. I reflect on each of these briefly, seeing a role for interactions with patients in consultations, then between nurses in the ongoing delivery of care, and finally between nurses and clinic managers with more focussed episodes of decision making.

Service allocation and separation is shaped through the interactions between nurses and patients within a consultation. Nurses' ongoing decisions about what to cover within a consultation – as in section 3.2.2 and 4.1.3 - are shaped by interaction with patients. It is within these consultations and forms of interaction that nurses make decisions about whether other services should be integrated within care. I also initially considered patients as influential over more formal decisions about service organisation. A particular episode in Christen clinic shaped this: Sister Vermaak suggested that they provided ART and HIV care separately from other services as that is what the patients preferred; they had tried to integrate care, but the patients had ignored them and continued to come and wait outside her consultation room. As the study progressed, the ideas of patient agency that I based on this evolved. As I outlined in section 4.1.3, patients have the capacity to resist and shape nurses work, but nurses ultimately have power over patients.

Interactions between nurses in the ongoing delivery of care are also influential. Nurses' service allocation was remade through nurses ongoing decisions about care, and how this was linked with referrals to colleagues; these referrals both shape an individual nurses' work and necessarily impacts on other nurses' work, through creating it. As I described in chapter 3, there was little sense of referrals being frequently made, but it was still an occasional point of interaction, with some nurses complaining about other nurses not attending to specific patients and instead referring them on. Another area in which service allocations were fashioned were in nurses' ongoing interactions about moving beyond their

primary focus, whether in helping on another service when their own work was completed, or through covering staff shortages.

The interactions between nurses and the clinic managers that shaped service allocation were notable for how they differed from the interactions between nurses and patients considered above, in that they were less regular and public, or at least as I was able to capture them in my data. Nurses described how when they first arrived at a clinic they were 'allocated' a service. Sometimes this was referred to as taking over the service from a previous nurse who was leaving, or a manager telling them, or it was left unclear. Rather than being frequently discussed in an ongoing way, as say routines for scheduling care were with patients, service allocation tended to focus on specific episodes and events. Evidence for this comes from reports in Ba Banyane and Dula clinic where specific meetings had been held to discuss service allocation. There was a common theme of how accounts of these interactions rarely reported compulsion or control, with nurses presenting processes of consensus between nurses and their managers. Across the clinics, nurses didn't seem to complain when allocated a service by their manager. Nurses and clinic managers also indicated there were overt processes of reaching consensus: Sister Habore said 'we arrange' the services, as did Sister Nomkhula; a nurse in Joyful said that 'we have decided' the service allocation for the week. However, the suggestion of consensus by Sisters Habore and Pretorius in Ba Banyane clinic amidst their conflict over this suggests that the appearance of consensus may serve additional purposes. Whilst Sister Pretorius was being accused by Sister Habore of going against her wishes and a group decision, Sister Pretorius presented her focus on children in the mornings as resulting from a decision by Sister Habore: it was clear that there was importance for both in having the other seen to be involved in the decisions, that is, it appears desirable for them to be seen to be in agreement.

As well as establishing the particular services to which nurses would be allocated, there was also interaction around the underlying separation of services that forms the basis for nurses having individual allocations. Integration of services was a prominent, and at times heated, debate amongst nurses. In Angekom clinic there was general agreement amongst the nurses I spoke to about the broad structure of service organisation, involving a

resistance towards health system management ideas for more integrated care. Christen clinic was the same as Aangekom, being similarly united against higher level calls for integration. Dula clinic presented a more complex picture, with nurses across the clinic expressing in interviews varying opinions on how services should be organised; some favouring separate services, others stating the need for more integrated care.

Across these interactions I identify a role for nurses of being conservative; by this I mean that they tended to seek to preserve existing conditions, through being respectful of the hierarchy with clinic managers, and yet also seeking to maintain both their own service allocation, and the underlying model of separate services. Nurses were deferential and respectful of the clinic managers. Nurses seemed to accept this authority. Within this authority nurses also had a high level of independence and autonomy, as evidenced in how they could make ongoing decisions about service integration through decisions in consultations and through referrals. Sister Fula's complaints about nurses not wanting to help on other services and how nurses had become divided illustrates the potential control nurses had over their work. This independence is also demonstrated in how nurses were almost uniformly defensive about the possibility for greater integration, with nurses being assertive in seeking to retain the status quo. Although nurses may sometimes have little control over the service initially allocated to them, they can then exert influence in maintaining that service and also preserving the underlying model of separate services that leads to specific allocations.

The clinic managers' role can be summarised as that of an advocate; they had certain points of influence, but were often reliant on nurses' agreement. Rather than being controlling, the position of the manager was within a relatively flat structure, with little overt hierarchy, and with little sense of nurse managers being able to issue orders and directly control the other professional nurses. For example, Sister Fula sought to change nurses' service allocation through trying to rotate the nurses around the different services. While she was able to initiate this, these ambitions failed for a number of reasons (which I return to below). Sister Fula also complained about nurses not seeing patients, and referring them; suggesting that this was a problem she was aware of and would like to change, but also that she had limited influence over this. This limited influence is also

evident in how Sister Habore couldn't insist on Sister Pretorius doing as she wanted her to do in Ba Banyane clinic. The role and influence of clinic managers in relation to the other nurses was therefore influential, but limited to advocating for a particular position.

The cooperative order in the context of ART and HIV care

ART and HIV care and how they were organised were part of the same processes of interaction around which separation and allocation were shaped, and so had the same forms of interaction. There were two distinct points however. Although Sister Vermaak was allocated the role of ART nurse by her manager, in Dula clinic a distinction was how there had been specific recruitment for these posts, with Sister Nomkhula saying she had applied for the specific job. This reduced focus of the role of the clinic manager highlights the influence of context, which I discuss further below. Secondly, in Esita and Geheim clinics nurses there had reportedly sought further integration by seeking a greater role in ART, rather than it being allocated to specific nurses. The overall process by which this came about still however featured nurses and managers having limited control over each other with this further integration achieved in Esita clinic by the manager leading a process of consensus, whilst in Geheim clinic there was resistance from the ART nurses to the other nurses taking on this role, but this was eventually overcome.

4.2.2 The influence of context

The care routine of service allocation and separation also had contextual influences, that were mediated by this cooperative order of interaction. Following my earlier analysis of how context shapes action, but doesn't determine it, I again explore here how the routines of service separation and allocation link to specific features of the clinic context. As I explore this, I show how the separation of services and their allocation to specific nurses is structured by a general discursive separation of care as well as specific health system policy. However, the way in which pressures for service integration in health policy were overcome in the four focus clinics demonstrates how the cooperative order is a particular response to context.

The discursive creation of services

A first point of context to consider is how a discourse of separate services manifests across the South African health system, and across much delivery of care globally. That PHC is understood by nurses as made up of discrete services represents a particular discursive construction of these services and PHC. This process is part of the social construction of knowledge about disease (Nettleton, 1995) and reflects particular biomedical understandings of health: that TB, care for chronic conditions and HIV care are understood as distinct with reference to identification of a particular disease causing agent, or set of symptoms. These constructions, and this discourse, are evident throughout the South African health system: as I referred to in section 1.1, PHC is presented as a package of services, and this is in turn evident in how PHC is managed and implemented, whether through the particular notices that are sent to the clinics or in how priorities are identified. The understanding of care as separate services at a clinic level can therefore be seen as part of a broader discourse that creates and legitimises it.

Health system policy

There are a range of specific health system processes that express this discursive separation, whether through ongoing training courses for nurses, policy statements, or administrative and reporting requirements. The administration and reporting on services was cited by nurses as one reason for having a particular nurse allocated to that service (see also Uebel et al, in preparation). TB in particular, was cited by nurses across clinics as having particular administrative demands that required a nurse to focus on it. A particular feature within this was of clinic managers being asked to work on TB to ensure quality, as reported by Sister Fourier.

The administrative separation of services was reflected in a number of other clinic level processes, notably through distinct filing systems for separate services (see also Uebel et al, in preparation). From my time observing clinics from the reception areas I became familiar with these separate systems: patients would often be filed according to a particular disease, sometimes in distinct filing cabinets, and occasionally in different areas of the clinic. In Aangekom minor ailments or general patients were kept behind the main reception, while the files for chronics patients were kept in a separate room. In Christen

clinic the ART patients' files were kept separately, with the rest in reception. When talking to Sister Marais in her room one afternoon a patients file had been left out on her table, with 'DM +HPT' written on it. When I asked she clarified that this referred to diabetes mellitus and hypertension.

A vertical ART and HIV care programme

ART and HIV care were also constructed in this same way as a distinct area of care. There were distinct systems and processes (see also Uebel et al, in preparation). An important point is that my questions and the focus of my study are also within this discourse. The questions I asked about how ART and HIV care were provided were a potential influence on how nurses framed their response. However, nurses' spontaneous and broader discussions suggest any role of my questions was limited. The broader position of ART, HIV care and HIV within South African society and politics also supports the idea of understandings of this service as distinct. A particular expression of how ART and HIV care was a distinct service was how aspects of it were organised 'vertically' within the health care system. This vertical nature was clear in a number of ways: the separate administration and patient filing systems (in Dula this was entirely separate with all files and records kept separately), the separate recruitment of nurses in Dula clinic, and then also the role of outside non-governmental organisations (NGO) within the clinics. In Dula clinic Sister Lejwe, who began work on ART during the fieldwork, was from an NGO called 'right to care'; Nurse Tefo told me about some training on ART he had gone to supported by the Elisabeth Glaser Foundation, an American organisation; whilst a group called 'ICAP' visited Ba Banyane clinic and in a brief conversation they said that they were funded by PEPFAR – the US President's Emergency Plan For AIDS Relief. This specific attention, not typical for other services, would reinforce the sense of a separate service.

A particular element of this separate nature of ART and HIV care was of how some nurses weren't allowed to provide ART and HIV care as they hadn't yet been trained on it. This reflects the relative novelty of the response to HIV within the South African health system, in that training on ART and HIV care hadn't been a standard part of nurse training and practice until recently. For example, Sister Pretorius in Ba Banyane clinic hadn't yet had

training. A role of providing ART was reliant on nurses having access to certain forms of training, hence structuring the possibilities for nurses to take on this role.

Mediating context

Discursive and policy processes were influential in producing care routines, but weren't determining. Despite the pressures for separate services as described above, there were also health system influences focussing on more integrated services. Nurses across the clinics reported how the health system management wanted more integrated services and yet this idea was resisted across most of the clinics, being seen as an imposition and not feasible, for reasons which I explore in depth in the next section. There were tensions and inconsistencies across these accounts indicating that the influence of context was not stable. Sister Habore raised the small size of the clinic as limiting integration, whilst a nurse in Ithata clinic said the opposite (see also Uebel et al, in preparation). Sister Fourier and Nurse Tefo both said integrated services wouldn't work, but then Nurse Tefo also acknowledged other clinics worked differently, referring to how it was 'convenient for them'. The limited influence of context is especially clear in how different patterns of service organisation emerged in Esita and Geheim clinics. Although service integration was resisted in Christen and Dula, it wasn't in these two clinics (even if there was an initial struggle in Geheim clinic). This supports the idea that context isn't entirely determining a model of separate services, but that this particular order of integration was just one response to contextual pressures.

Pressure for separation, that can be overcome

From this discussion I have suggested that the separation of services, and then their allocation to individual nurses is highly structured by a range of health system pressures, whether the widespread understanding of care as being provided in these separate services, or the range of administrative pressures that lead to it. These structures are not entirely determining however, which is evident both in how other health system policies fostering integration are resisted, and how other modes of organising services are evident in other clinics. It is this resistance and difference that suggests a role for nurses' agency in service integration.

4.2.3 The agency in service focus

The pressure for separate services is high, and the clinic cooperative order I have suggested is influential in maintaining this. I argue here that within this order and context, nurses' agency is still evident, with the idea of nurses' as conducting care again useful. I first explore nurses' choice over care, and then how these choices are shaped in the context of the power relationships with other nurses and the clinic managers. I then go on to explore the meanings associated with these choices. Across the discussion I also focus on ART and HIV care and the specific nature of agency and meaning associated with that.

Capacity for choice

A nurse's choice over their allocated service and the underlying model of care was frequently very limited. This highlights the characteristics of the context and order described above: the discursive separation of services is entrenched, and the clinic order limits nurses' capacity to change a service allocation. For example, with Nurse Fourier in Aangekom asked by the health system management to focus on TB and then her colleagues all referring to her, her capacity to choose to do a different service, or to integrate all care is very limited. In the case of ART and HIV care, nurses are limited in their capacity to do this by a requirement that they have had the requisite training. However, there is still choice. The existence of only the cooperative order, as described above, obscures the choices made, in comparison to how in patient centredness nurses could clearly choose between a collaborative and competitive order. In addition, nurses may not have had significant choice over their service allocation. However, the presence of this choice is evident in how other clinics had varying forms of service integration and so correspondingly, nurses can still be seen as exercising agency in maintaining the current system. In summary, there is little choice to change the order, but nurses are still choosing to act in maintaining the current system, as is clear in the meaning of their actions that I explore below.

Power with nurses

The conservative and advocate roles I described above were focussed around nurses' having a degree of autonomy and independence. My data shows how clinic managers had some capacity to issue orders and instructions, but that processes of reaching consensus and negotiation were most common. As above, the more episodic nature of interactions between nurses, within my data at least, means that I have less insight in to these relationships, but there are still clear signs of how the power relations between nurses took on certain forms. Returning to the conceptualisation used in discussing relations with patients of 'power over' and 'power with', there are only isolated instances of nurses having power over each other, and this is exercised by the clinic managers, if at all. The main focus is on nurses having 'power with' each other, as evident in the capacity to achieve something relying on cooperation and consensus, even if this can at times involve conflict. This is distinct from the power relations with patients, where nurses did commonly have power over patients, and could force certain forms of action.

The meaning of service separation

I now turn to consider the meanings behind these actions. Although nurses' choices over care were limited, the existence of choice in supporting this one cooperative order is visible in the meanings of nurses' actions. It is through considering these that the intention behind the actions becomes clear. I explore a range of themes in nurses' accounts, to understand nurses' intentions in supporting separate services. I first focus on issues raised by nurses that appeal to issues of the quality of care and impacts on patients. Overlapping with these I explore reasons of nurses having a particular passion for services, and how concerns over workload highlight underlying efforts to control workload and also a lack of confidence. At the end of the discussion I turn to consider the meanings around ART and HIV care in particular, and specific issues of the prestige of ART and HIV care as well as its complexity.

A resistance to integration and a desire to maintain nurses' focus on specific services was expressed by some nurses through the need to preserve relationships with patients (Uebel et al., in preparation), relating to the influence of trust and the need to maintain continuity of care. Sister Seporo in Christen clinic referenced how their efforts to integrate services hadn't been successful, in terms of getting all nurses to provide ART. When I suggested that perhaps she didn't want to integrate services she agreed, referring to the importance of

relationships and quality. The nurse manager in Ithata clinic said that having a nurse doing one service allows patients to 'build rapport' with a nurse, allowing them to 'become open'. Knowing patients better is therefore seen to be linked to trust and continuity of care. Nurse Tefo in Aangekom said that if a nurse is doing the same service then follow up is more effective; he referred to 'building up' patient care, with the need to make referrals and be able to discuss the specific patient; he said patients aren't a 'sugar pot' for just anyone to use at any time. He also added how if patients are seeing different nurses over time, then they don't feel there is a relationship, impacting on trust and threatening patients perception that confidentiality is maintained. There was also a concern to maintain quality of care through having separate services. As Sister Seporo described above, a nurse having her own service allows a 'quality' service. Sister Fourier in Aangekom said how 'they' – presumably the Department of Health and external clinic management – want her to focus on TB to ensure this quality.

Service separation was also grounded in other meanings, beyond references to patients and quality care. Nurse 'passion' for a specific service is one factor supporting service separation (see Uebel et al, preparation). Sister Andrews said you had to be 'passionate' for antenatal care; a nurse in Joyful referred to a 'passion' for TB care as did Sister Fula who said nurses have favourite services and 'likes and dislikes'. For example, Sister Kgaba in Dula clinic said she didn't 'enjoy' working on 'psych' services. This preference for a service could represent other concerns, in addition to an appreciation and preference for any inherent features of a particular area of care. Some nurses referred to how having their own service serves to prevent conflict. Sister Fourier in Aangekom clinic described to me how further integration of services would cause 'conflict' amongst nurses; Nurse Tefo said the same, describing how if nurses were all expected to see all patients, there is an issue of each patient taking a different length of time. Sister Seporo and Sister Pretorius in Christen clinic both raised the issue with integrated services of nurses giving conflicting diagnoses if the same nurse saw a different patient over time (that a conflicting diagnosis could eventually lead to greater insight in to a patients' illness wasn't referred to). A preference for a service can therefore overlap with a concern of being monitored and a danger of being undermined. While a separate service can be framed through nurses seeking to avoid conflict, an overlapping notion is of working independently allowing nurses to take greater satisfaction from their work. Linking to the importance of the relationship with patients, as

raised above, in maintaining separate services, being able to follow a patient's progress is perhaps a source for this passion nurses cited.

Separate services were also maintained on a basis that integration would be hindered by the clinic workloads (See Uebel et al, in preparation). As I suggested above, this logic wasn't clear, and was contradicted by other accounts of how clinics were integrating services. This is not to suggest workload isn't an influence, but that concerns about workload perhaps reflect nurses' concerns to control and contain their workload, linked to issues of clinical confidence and complexity. Some nurses referred to maintaining separate services as making work 'simple' and 'streamlined'. This need to simplify and contain I see as indicating concern about the complexity of integrating services, and their capacity to cope. Nurses' themselves didn't cite the complexity of care directly. My sense for this complexity initially arose out of my own experience of trying to understand the breadth of care. When sat in Ba Banyane clinic and looking across the rows of files for each service that were kept in reception it seemed to symbolise the breadth of what I was trying to understand, and also my then inability to do this; it then occurred to me that these files represent nurses' own efforts to manage the range of work. This was supported by Sister Habore explaining how she felt happier about her work after her manager had visited and she was now clearer on what was expected of her. As an example she showed me the PMTCT folder, and how it contained everything that needed to be done around the clinic. The range of services I have already referred to through this chapter and the previous chapter is one demonstration of this complexity. Instances of Sister Habore trying to diagnose Leukaemia for a patient and then Sister Peo delivering a baby in the clinic are indications of the extreme dimensions that this complexity of care can take on, with PHC as the first line of care, and the point of referral on to hospital.

The meaning of ART and HIV care

In section 4.1.3 above I discussed how the recognition of stigma and the social conditions patients faced pointed to a wider issue of how HIV was still exceptional for nurses, despite the many indications of it being normalised. I build on that analysis here to show how although ART and HIV care were provided as separate services in much the same way as other services, there were also some crucial differences.

The same 'passion' was reported for ART and HIV care (See also Uebel et al, in preparation). Sister Nomkhula referred to a 'passion' for working with PLHIV, less effusive was Sister Mamdala who said she liked working with PLHIV, and seeing them get well, while Sister Vermaak demonstrated an enthusiasm for the service when she said she wanted to do ART until she retires. This passion was also overlaid with how nurses linked ART and HIV care to various forms and sources of prestige (See also Uebel et al, in preparation). As indicated, ART nurses sometimes defined themselves as distinct from the other nurses, with Sister Fula describing this as a problem in the clinic. A potential element in this prestige, and passion, was Sister Fula's remark that patients considered the nurses in the clinic better nurses because they provided ARVs; Sister Nomkhula in the same clinic said how the community 'honour' the nurses when they work in HIV. A passion to work in ART and HIV care could be shaped by the prestige associated with it. Access to computers is a possible symbol of this prestige and elevated position. I asked Sister Fula if ART nurses were seen as better nurses, and she said that ART nurses weren't seen as better, but that they had computer skills and this was something that other nurses sought. An example of this was Sister Habore in Ba Banyane referring to other clinics getting computers, in a seemingly plaintive way. Perhaps more prosaically, Nurse Tefo said a passion for a service was linked to money 'as well'; this is not to reduce nurses motivations to material concerns, but, to highlight these are potentially important.

The complexity of ART and HIV care also figured in my data (See also Uebel et al, in preparation). The challenge of nurses lacking confidence to practice ART and HIV care was clear in nurses' accounts. Several of the ART nurses expressed no doubts at all, but others did – notably Sister Vermaak, and also nurses in Esita, Fontein and Geheim clinics. This lack of confidence was expressed in terms that referred to the complexity of care, with Sister Vermaak talking about the challenges of diagnosing TB and how consultations with ARV patients take a longer time to consult with. A lack of confidence was also indicated in how many nurses cited the need for more training to allow them to provide ART and HIV care, and also how training had led them to be more confident.

A final consideration is how the additional clinics had greater integration, as compared to Christen and Dula clinics, and this was linked to the nurses in Esita and Geheim clinics wanting further integration. The nurse manager in Esita clinic reported that all nurses wanted to be involved, linked to how their families were also experiencing HIV. This familial and community oriented source of motivation has been reported by others in the Free State, with Dr Lara Fairall, the principal investigator in the STRETCH trial reporting, a lack of resistance from nurses to the introduction of PALS PLUS, on the basis of nurses wanting to help people in their communities (Fairall, 2007) with similar findings reported in Zimbabwe (Campbell et al., 2011c). This raises an important question, which I am unable to clearly answer, of why nurses in Christen and Dula clinic didn't also take on this response.

In summary, I have argued through this analysis of service integration how nurses have a limited agency to shape the processes of service separation and allocation. This further supports my argument of nurses' capacity to conduct care. Although contextual influences from health system policy and discourse limit action, and the cooperative order reflects nurses' limited influence over each other, there is still the exercise of agency in nurses providing individual services.

4.3 Conclusion: nurses' as the conductors of care

Through the chapter I have sought to explore the underlying social organisation of the care routines across the four focus clinics, and in particular identify the role of nurses' agency. In showing the role of particular clinic level structures of the orders of interaction, and then of contextual factors and how these relate to clinic level interactions, I have presented a detailed analysis of agency. The specific conclusions of the chapter are that nurses' agency within care routines is significant, if limited: they can conduct care, rather than control it. In the course of identifying this agency I have also shown how this is embedded in, and reliant on, particular power relationships, with patients and with other nurses. Within this broader analysis I have also shown how ART and HIV care are provided within the same orders of interaction.

In the following two chapters I further develop aspects of the analysis presented here. In chapter 5 that follows I elaborate on this conceptualisation of nurses' agency and give further insight in to it through exploring the identities within which this agency is embedded, this gives further insight in to the tensions and pressures that nurses must manage and the range of motivations involved in care. In chapter 6 I further develop this understanding of agency in the context of exploring processes of change within the clinics. I also return again to the detail of these findings in chapter 7 in section 3 where I explore the broader theoretical and policy implications of this analysis.

Chapter 5 - Nurses' agency and complex identity

5 Introduction

The previous chapter explored the role of nurses' agency to conduct care, and argued that although limited, this was a key dimension of the social organisation of care. In this chapter I explore this conclusion further, to contextualise nurses' agency and to give insight to the variation in how agency is exercised and, correspondingly, the variation in care.

My argument in this chapter focuses on understanding nurses' complex identities. I base this analysis on Cleaver's (2007) conceptualisation of social agents having complex social identities. It is through these complex identities that the range of motivations people have can be fully understood. As an example, Cleaver cites studies that describe how women access forest resources by drawing on identities as legal citizens, but also as 'daughters, wives and mothers' and members of certain castes (Cleaver, 2007, p233); she concludes that for these women 'exercising agency through public institutions may not always be the preferred option' (ibid). It is through understanding the dimensions of this complex identity that the range of motivations that shape action can be understood. In this chapter I develop this idea in relation to nurses, and show how different dimensions of nurses' identities can inform their exercise of agency. This then gives insight in to how and why nurses take on particular roles within the clinic; I understand the roles I described in chapter 4 as expressions of the broader identities I discuss here. A concept I use to explore the complexity of nurses identity is the idea of fragmented unity (Parker, 2000). Parker uses this in arguing that organisational cultures should be seen as fragmented unities, with members identifying as divided at some times, and then as a collective at others. I use this idea to show how nurses' identities involve them being, at different times, fragmented and unified with, respectively, patients, other nurses and then the broader health system management.

On the basis of this approach I argue that nurses have a complex social identity, beyond the initial label of professional nurse which I have applied through this study so far. The chapter has three main sections, in which I explore three perspectives on nurses' identity with respect to their relationships with patients, nurse colleagues and then the broader health system. I explore a fragmented unity with patients and argue that despite the distinct identity of a professional nurse and how that can lead to fragmentation, various other

aspects of nurses' lives point to other identities and experiences that are shared with patients: being members of the same community, being wives and mothers, and then also experiencing HIV. These shared identities are a source of tension to be managed in consultations. Nurses' relations with one another also involve distinct identities of clinic manager and ART nurse, and I raise the possibility of other forms of division on the grounds of race. I conclude this section by exploring the conflict between nurses in Ba Banyane clinic to show how negotiations over service integration are overlaid with these differences. The final section briefly considers how nurses' identity as an independent professional is in tension with how they perceive themselves as unsupported and neglected by the broader health system management. Exploring this complex identity gives insight in to the variation in care routines across the clinics through identifying a range of motivations and tensions that nurses need to manage in providing care. This analysis acts to demonstrate the challenges involved in the everyday accomplishment of clinic care.

5.1 Nurse identities: relations with patients

In trying to understand the relationships between nurses and patients the social distance between them was an early focus for my data collection, shaped by my foreshadowed problems around nurses' identity and how nurses may seek distance from patients (Jewkes et al, 1998). Based on this idea of distance an early hypothesis I explored was of nurses and patients occupying different lifeworlds (Thiede, 2005), a concept describing the existence of sets of shared assumptions and perceptions, with the implication that nurses and patients had differing assumptions and perceptions which undermined their communication and relationships. The data I have already discussed involving nurses shouting, getting angry and often having poor relationships with patients initially suggested nurses and patients occupied very different lifeworlds. As I explored this further I realised that although there were clear points of division, many nurses and patients shared a number of experiences, and references to friendships and close relationships forming were common. The idea of a fragmented unity is useful here in understanding the tension and paradox in how nurses share experiences with patients. I explore this by first outlining nurses' identity as healthcare professionals, and how this is the source of difference and fragmentation with patients, but then explore the shared identities with patients based on various points of shared experience. I finally consider how these contrasting, yet

overlapping identities create tension that nurses manage as they exercise agency in producing care routines.

Nurses as health professionals

Nurses as professional health care providers occupy a distinct identity in relation to patients. The qualifications and knowledge nurses hold is what ultimately defines the purpose of nurses' work and why patients are in a clinic: a patient is seeking nurses' knowledge and skills to gain treatment for illness, or nurses' power and control over access to other levels of care through onward referral. The role for nurses as either a guide or guardian acts to express this identity, and involves particular forms of power; all serving to highlight the differing identities nurses and patients hold. This basic distinction – or fragmentation - between nurses and patients was the foundation for further points of difference: how nurses can hold a different perspective on health, which can involve a narrowly biomedical view of the challenges and issues patients faced, and then also how a position as healthcare professional entailed a particular socioeconomic position distinct from patients.

Nurses can exacerbate the fragmentation with patients based on their training and position by expressing attitudes that interpret patients' issues through a narrow biomedical lens. Nurses' training in biomedicine gives them a privileged position in relation to patients, in that it is the reason why the patient is there. This position was acknowledged in some ways by some nurses, who made efforts to overcome any barrier this may pose, generally through adopting the role of guide, but also through specific actions in relation to their biomedical expertise by using lay language – for example Sister Habore referring to herpes zoster by the local name of 'the belt' – or by taking efforts to accommodate patients use of traditional medicine alongside the treatments they provided. Nurses could also however not respect patients' knowledge or position. Some nurses' accounts implied that patients were erratic or unreasonable for not responding to a biomedical logic: Sister Kopo called a patient 'ignorant' for not using family planning, while Sister Kgaba expressed surprise to me one day in that 'even educated' people get HIV, both these comments suggesting a narrowly biomedical view of health issues. Although a position of biomedical expertise is a

point of difference from patients, specific responses from nurses can see this lead to further fragmentation.

The position of a trained healthcare professional involves a specific socioeconomic status of being a waged professional which indicated another form of difference from patients. As professional nurses, the nurses I spoke with were relatively well paid, and nurses pay had significantly increased prior to the fieldwork starting (an impression I had during a fieldwork site visit in February 2008 was of nurse pay and conditions being a source of grievance for nurses, this had however changed by the time the fieldwork started in February 2009, with no critical comments from nurses about their pay, and some nurses going so far as to say they were happy with it). This socioeconomic position distinguishes nurses from many patients, which was clear in the reports from nurses of the severe poverty that many patients experienced and how they lacked food and money, as well as other evidence of high unemployment and deprivation in South Africa (see chapter 1). This difference in socioeconomic status was reinforced through various symbols: nurses often drove expensive cars that would be lined up outside the clinics; wore mobile phones or jewellery, or were unworried by conspicuous displays of money like when nurses paid back money they owed to each other in front of patients.

Nurses and patients shared experience

Despite the position of a professional nurse implying a distinct identity in relation to patients I explore here how an assumption of this one identity is unhelpful. A focus for my argument here is to consider how categorising nurses solely as nurses is problematic, in terms of understanding the range of experiences they have, and consequently what informs their work. The people I spoke to on the grounds that they worked as a nurse in the four PHC clinics also had a number of identities, including community members, wives or mothers, and experiencing HIV. These identities can be seen as involving forms of unity with patients in the clinic in terms of demonstrating shared experiences and background.

Some nurses lived in, or near, the same geographic locales as the patients. Sister Fula had been born and grown up near the clinic in which she worked. Other nurses referred to

community work and volunteering, such as work through their local church. After discussing this, Sister Andrews said she was on duty '24 hours a day'. Living in the same or similar communities does not however mean that nurses experienced the same poverty as some of the patients. However, although nurses were relatively wealthy, there were still signs of how access to money and resources was a concern and nurses were involved in a range of ways to manage money. In Aangekom, the nurses were involved in a rotating savings club, where all paid money in and then received it back on their birthdays. In Christen Sister Pono had an informal lottery scheme she ran to make money, whilst in Dula clinic one nurse tried to sell me tupperware. This is not to suggest that nurses experienced poverty like some of their patients, but that they are sharing the same resource poor context and experiencing it in comparable ways.

Nurses also had identities, centring on their gender, whether as wives or mothers. The tasks relating to their home lives that nurses did during the working day were a reminder that they are mothers, and wives as well as nurses. Nurses would often go shopping at lunchtime, or I would see them looking at catalogues for various household goods. As wives, mothers or girlfriends nurses could also experience the same gender inequities and allocation of roles that can typify South African society (and many others). Sister Kgaolo said to me how she worked all week, and then all weekend as well with reference to cooking and cleaning. Other references crept in to nurses' discourse: a nursing assistant in Dula clinic complained about how in her relationships with men she was seen as someone's property. This experience of gender norms is also clear in how nursing in South Africa is one of the key job opportunities available for women, which Sister Botala hinted at when she said that she had gone in to nursing as it was one of the few jobs available to someone of her 'social background'; she presumably meant race but her gender would likely have figured in this too. The gender norms that can shape nurses' lives therefore reveal further dimensions of this complex identity and also point to shared experiences with patients in terms of experiencing specific roles in the family or in society.

Nurses not only lived and worked in similar contexts, but experienced the same health challenges. The way nurses talked about other nurses' experience of living with HIV highlights how nurses not only live with HIV but also the stigma and social isolation that can

accompany it. As I discussed in chapter 2, I was unable to explore directly the experiences of nurses living with HIV; that I was unable to do this through my approach of reaching out to key contacts and civil society organisations gives some insight to the extent of HIV related stigma that nurses face, in that very few nurses are openly living with HIV in South Africa (or at least not with a high profile). Some nurses said how they did know HIV positive nurses, but that they were reluctant to discuss their status openly. A HIV positive nurse would drive for several hours to visit Dula clinic, to avoid those closer to their homes. Nurses' reports of nurses gossiping about other's HIV status give further demonstration of this stigma. Sister Fula's conversation with me when she imagined her child being in a clinic somewhere having a HIV test when she had just tested a young couple also highlight that HIV impacts on other areas of nurses' lives. Ultimately, nurses are sharing and experiencing the same challenges of dealing with HIV as the patients they work with.

Managing shared experience

The challenge this complex identity raises for nurses is of having to manage the tensions and contradictions this differing and shared experiences with patients lead to. That consultations with patients can vary results in part from this complex array of influences and motivations that nurses have to manage. Sister Seporo told me of the stress of telling a friend they were HIV positive, a stress borne not just of the diagnosis but also their shared identity as community members. Sister Botala said how in a previous clinic that had been in a small community the patients had complained that she was too strict. The challenge of managing relations with patients was also evident in Sister Habore saying that she can't be too friendly with patients or they won't respect her. These last two accounts reflect similar processes as in the argument of Jewkes et al (1998) that nurses' abuse of patients can be understood by their efforts to assert a middle class identity; in this instance, nurses are not necessarily seeking a middle class identity, but are seeking to manage a distance from patients. Nurses' shared experiences of living with HIV or in communities and with families affected by HIV also gives some further insight in to ART and HIV care being 'the same, but different'. Nurses' recognition of stigma and the difficulties facing patients living with HIV are grounded in these broader experiences. When providing care nurses are therefore combining consideration of both the biomedical and professional discourses of HIV and ART and also local and community discourses.

The existence of this shared experience also gives insight in to the patient activity, resistance and power that I discussed in chapter 4 and the complexity of agency. This fragmented unity and shared experience can be seen to lead patients to have two modes of relating to nurses, through nurses' professional position and through shared community ties. A useful idea in understanding this is of how people can be both citizens and subjects (Nyamnjoh, 2002, citing Mamdani, 1996). In this context, patients have claims over nurses from the shared identities through community ties, as well as the state centred ties of rights holder in relation to a service provider. Context for this is the rights patients hold formally in South Africa, as citizens and also in specific policy measures. The 'patients' rights charter' was adopted by the department of health in 1999 to support the achievement of the right to health, and is intended to provide a set of service standards (Van Rensburg and Pelsler, 2004, p119). The rights included in this focus on having access to care, to information and to the choice of provider (ibid). Batho pele – 'people first' in Sesotho – originated in efforts to transform public service delivery, with the ultimate aim of putting people's needs first and to be responsive to these needs (ibid.). They are intended as a set of principles to guide the delivery of all government services, not just health care, and focus on areas such as ensuring openness and transparency, being courteous, increasing access and setting standards to be adhered to (Government, 2007).

Nurses described a lot of their work and how patients were rights holders. Nurses' accounts often indicate a level of acceptance of patients' rights: nurses' referred to patients' right to come to the clinic at any time, to choose a nurse, to be treated; this discourse was supported by notices and posters around the clinic that listed the rights patients had. A minority of nurses complained about these rights and batho pele principles, seeing them as a basis for patients to make unreasonable complaints and of saying how nurses didn't have rights and weren't empowered. This discourse is echoed in other studies of nurses and health workers in South Africa, where nurses have complained of patients being empowered but not themselves (Walker and Gilson, 2004) or complaints that patients don't keep to their responsibilities as set out in the patients' rights charter (London et al 2006 Erasmus and Gilson, 2008). Alongside this formal relationship determined by rights, are some reports from nurses of how patients also used community ties: Sister Fula said how her family complained about patient interruptions at the weekend with people

knowing where she lived and coming and asking for help. Sister Marais said patients come to her house to complain about the clinic, while Sister Nomkhula said the patients will also phone her for advice. This patient action perhaps hints at desperation and dire need, but also that patients have these more community oriented and focussed relationships that they can draw on. Together, this gives further insight in to the complexity that nurses manage and how their complex identities can lead to patients making a range of claims on them in the process of care.

In this first section I have outlined dimensions of nurses' identity and shown how this can be seen as leading to a fragmented unity between nurses and patients. Recognition of this complexity of nurses' identity gives insight in to the challenges and tensions that nurses have to manage when providing care.

5.2 Nurse identities: relations with other nurses

Marks (1994) described nursing in South Africa as a divided sisterhood, on the grounds of class and race divisions within the profession. I explore the same idea of divisions in contemporary South African nursing using the concept of fragmented unity, although focus less on class and race. Continuing the argument of the chapter I explore the theme of nurses' complex social identity and show that beyond the shared identity of professional nurse, there are also points of fragmentation focussing on the position of clinic manager and then ART nurses, as well as exploring the role of race.

Divided sisterhood

Nurses have a common identity by virtue of the shared role and experience of working as nurses in the clinics. A unity based on this common role was visible in a range of ways. Across interviews nurses would report that there was good teamwork; I critically explore this below, but the process of nurses seeking to present a positive view of teamwork in the clinic demonstrates the importance that an appearance of unity with other nurses had for them. Specific forms of solidarity were evident in reports from Sister Marais and Sister Botala of how they would defend colleagues if a patient were to complain. Sister Marais

said that if the other nurses were working slowly and patients were complaining she would make an excuse, of perhaps there being a meeting, but then she said that she knew that wasn't the reason but that she 'must cover', meaning to cover for colleagues and represent them in a positive light. Sister Botala's account differed, her defence of colleagues didn't seem to consider that the nurse could be in the wrong, instead she said she would explain to the patient what had happened, and then linked nurses being nasty to people being due to the patients being difficult to work with. A unity between nurses wasn't confined to the nurses within the clinic; sometimes nurses I didn't recognise would visit and the nurses would be very friendly. I also saw Sister Fula looking stressed one day, and when I asked her about it she said she was stressed and that she and the other nurses were all going to a memorial service for another nurse that had died.

There were limits to this unity however. In chapter 4 I have already outlined the issue of some nurses not being apparently willing to help others, and how the allocation of separate services served a need for nurses to have a discrete area of work. A theme within nurses' accounts was of the importance of working hard and how this could be monitored. An initial form this took was of nurses effectively boasting to me about how many patients they had seen that day, or that they had delayed or missed their lunch and breaks (as reported in section 3.2 above). An outcome of this focus on working hard was how nurses would monitor each other's work. Sister Mamdala told me one day about the good teamwork, and as part of this she explained how nurses would tell each other about a particular kind of problem they might be facing so the others would know why they were working slowly. The implication of this need to account for slow working is that nurses are monitoring each others work pace, and correspondingly that there isn't total trust in one another (Lewin, 2004). There was also open questioning of some nurses work. Sister Marais said she was pleased another nurse had left the clinic because she was lazy. She also told me one day of how Sister Andrews had told her she was taking her lunch late and then not coming back to the clinic, which Sister Marais had apparently questioned. She also complained on more general terms about the other nurses taking long breaks. Sister Marais's complaints and tension with the other nurses can perhaps be explained by her position as a staff nurse and so had less training and responsibility than others; there is therefore a potential for either a real or perceived hierarchy which she was trying to

overcome. Sister Pretorius also complained about the other nurses work rate and taking of breaks, an issue I return to below.

This potential for division within a unity amongst nurses can take a range of dimensions, involving a number of specific identities. Here I explore three: the position of clinic managers, ART nurses and then racial identity. I then explore the conflict in Ba Banyane clinic in depth to show how these various identities can combine.

The clinic managers are also professional nurses, but had different responsibilities within the clinic which illustrates a level of fragmentation. I have already developed my analysis around the distinct role of advocates for clinic managers, which expresses a distinction in identity. Further illustrations of this, are how Sister Habore saw herself as a 'leader' and as setting an example to the other nurses, which she linked to the need for her to be honest and respectful so that the other nurses respected her. Positioning herself as a leader, perhaps the natural function of a manager, is nonetheless to illustrate how she sees herself as separate and with a responsibility to the other nurses and so indicating an unequal relationship. On another occasion, Sister Fula was listing out the nurses and staff in the clinic and their responsibilities within the clinic, she added that with so many people it was 'too much' and 'not easy' for her 'to handle' all these people. I got some insight in to the toll of this responsibility and her role in relation to nurses when I asked her what she felt about my research towards the end of the fieldwork; Sister Fula replied that it was good to talk, and helped her for a couple of weeks. She may have been trying to support me in justifying my presence in the clinics, but that she saw an interview as some kind of outlet for stress suggests she is not able to share problems and stress with the other nurses. A possible dimension of why clinic managers can't share their stress is suggested by the account from the clinic manager in Esita clinic. She described how some of the nurses were giving her 'grief', she said that some of the nurses were 'misusing alcohol' and also faking illness so as to not use holiday time. The existence of these possible issues highlights the role of the clinic manager to investigate and possibly discipline and intervene with other nurses. In summary, the distinct responsibilities of clinic managers was one form of identity that caused fragmentation within the clinic.

The position of ART nurses was another axis of division and cause of tension amongst the nurses. In chapter 4 I suggested how working on ART could be linked to particular forms of prestige, relating to their role in certain activities like use of computers and position in the community; on the basis of this, there is a sense that working in ART is a distinct and desirable identity. A potential factor in this distinct identity is that ART nurses may view themselves as having greater capacity, in terms of clinical skills or the capacity for emotional labour. Sister Nomkhula reported the fear of other nurses in the clinic at the thought of working on ART, linked to a fear of themselves getting infected with HIV. She didn't say that she had experienced this, acting in some ways to distance herself from other nurses. A distance from other nurses was more clear in how she said the other nurses wouldn't cope with working on ART, as the patients were very demanding. That she herself could cope was therefore implied. Linking back to the earlier reference of how some ART nurses were recruited through a separate process, the fact that she had applied for the post specifically may also give insight in to a sense of greater competence. A sense of greater competence was certainly not clear in my data, and any tensions between ART nurses and other nurses were only clearly expressed in the form of concerns over an unwillingness to see certain patients. Sister Vermaak in Christen clinic, who worked on ART, and how she spoke about her work also cautions against seeing a great division amongst the nurses in terms of perceptions of their own competence. She was ready to talk about her lack of confidence in certain areas and didn't clearly refer to forms of division with other nurses related to her role working in ART. However, in some instances the specific identity of working on ART was the cause for some distance amongst nurses.

Reflecting on Sister Vermaak's position within Christen clinic gives some insight to how unity within a clinic can be hard to achieve or maintain. Sister Vermaak, as mentioned above, is white and Afrikaans speaking, which could be interpreted as distinguishing her from the other nurses; however, there was never any clear sign of fragmentation between the nurses on this basis. Sister Vermaak's experience of work gives other insight however. In an interview she explained how the nurses at the clinic don't have time to talk to each other; she cited how Sister Kgaolo's mother was ill so she had gone to her room to see her, but she suggested this required a specific effort to go and see a colleague and otherwise they are too busy working. On another occasion I saw Sister Vermaak and Sister Kgaolo in the corridor commenting that this was the first time they had seen each other that day,

and it was almost the end of the day. This is not to suggest division and fragmentation between nurses necessarily, but to highlight the difficulty nurses can face in maintaining unity when there is apparently such fleeting contact. Any unity may be further challenged by Sister Vermaak's consultation room being at the far end of the clinic, and that she also would drive home for her lunch, rather than stay in the clinic as the other nurses tended to do. Sister Vermaak's identity as Afrikaans was perhaps a factor in a tendency to be separate from the rest of the nurses, but certainly not clear, and what is most clear from her experience in Christen clinic is the challenge of maintaining unity in a context of nurses working separately and in isolation.

Conflict in Ba Banyane clinic

I turn now to focus on the conflict in Ba Banyane clinic which I have already cited in previous chapters, drawing in points from the discussion above to illustrate how they could combine. I referred to the conflict in Ba Banyane clinic in chapters 3 and 4, as it initially showed itself to me as tension over service integration. There were additional dimensions to this, with Sister Habore relating the conflict to an original issue of Sister Pretorius taking days off work as study leave, which Sister Habore had contested, suggesting that she was lying and hadn't actually been at college. Sister Habore on another occasion told me that she thought Sister Pretorius was trying to undermine her; this then links back to her comments on needing to be seen as a leader and respected, and in the process highlighting her identity as clinic manager. Sister Pretorius spoke about the conflict and didn't directly relate the service allocation issue to it, but hinted at racism against her and favouritism towards the other nurses in the clinic in how they had been appointed. Sister Pretorius also complained to me about Sister Peo taking long breaks, and arriving at work late. In summary, what was initially expressed as an issue about service integration also involved, from nurses' different perspectives, issues relating to identities around race and the role of a manager, as well as a fragmentation based around concerns nurses aren't working hard. It is in these contexts of multiple points of fragmentation amongst nurses based on their complex identities that negotiations around service integration can take place.

Managing tension in teamwork

This section has illustrated the range of motivations and tensions that can be involved in nurses' relations with each other, resulting from nurses' varying identities in the clinic. As I reported in chapter 4.2 these relations and interactions between nurses were less visible in my data and so this discussion is necessarily brief. However, in highlighting the different identities of nurses it gives further insight in to the challenges for nurses in negotiating their work with each other, in particular around service integration.

5.3 Nurse identities and their position in the health system

In this final section I consider nurses identity as a professional nurse in relation to the links and pressures with the broader health system. The idea of a fragmented unity is less clear, principally because my data is focussed on nurses' views of general health system management and processes, rather than individuals. However, a point I still explore here is how the identity of a professional nurse involves at varying times being subordinated by various health system processes and pressures. The recognition of these tensions demonstrates additional motivations and pressures shaping nurses work and activity in the clinics.

Unsupportive management

Many nurses raised problems with the management outside the clinic, relating to an overall theme of feeling unsupported, and at times burdened and neglected. Sister Habore said she felt 'alone' in facing her problems, and spoke about how she felt the clinic was 'neglected', describing the process of her and the other nurses writing a letter to their superiors to request the clinic be painted. Sister Fourier, in response to a question about how she felt about her work, at first said she enjoyed it, and then immediately said that 'it gets too much' when new rules are introduced without telling them. She then gave an example of a new register that had 'been dumped' at the clinic, and she had had to work out what to do with it (Sister Habore made a similar complaint about another set of forms), she then said how her and sisters in other clinics would work together to solve these kinds of issues, suggesting nurses are finding the support they need from peers, rather than from the broader health system management. A specific example of a lack of support for Sister

Fourier is in the failure of the Dept of Health to replace a broken bulb in a machine for killing TB bacteria that was in her consultation room.

Sisters Botala and Kopo in Aangekom raised similar points about management not responding to complaints from nurses. Sister Pretorius in Ba Banyane was very strident in her criticism of clinic management, accusing them of 'corruption', 'abuse' and 'intimidation', in suggesting procedures for recruiting her and Sister Peo hadn't been correct. During an interview she started to cry as she talked about other nurses not working properly, and how their supervisors were aware of it and did nothing. Sister Pretorius, along with Sister Fourier, likened nurses to 'donkeys', with work being continually given to them. The comparison is certainly unflattering, but draws attention to a sense amongst some nurses that they are expected to do a lot of work with little reward. In Dula clinic Sister Sediba and Sister Kgaba complained that their managers were very interested in the mistakes they made, but didn't give them support, this then led on to a lengthy complaint about nurses difficulties in taking sick leave, and how they were expected to fill out extensive forms, and so nurses would come to work even when they were ill.

A lack of support also sat alongside being controlled by health system management in ways which nurses found distressing or alienating. One example of this is nurses being rotated around clinics without any influence on these decisions. Sister Kopo and Sister Moloa reported this. It wasn't clear if this happened in other clinics in exactly the same way, but Sisters Sediba, Setempe and Kgaba complained about being taken out of the clinics to work in mobile clinics for occasional days and in Christen, Sister Seporo spoke about nurses having to go and cover in other clinics. This rotation demonstrates how nurses are at times a resource to be allocated around the health system, and not agents with voice and influence.

An example of how this control combines with neglect and lack of support was the Dept of Health trying to stop clinics praying within clinic time. I had seen a notice sent to clinics left in Aangekom clinic and raised this with both Sister Fula and Nurse Tefo and both were aggrieved by it. It wasn't clear whether they actually resisted it, but they were certainly

contesting it by raising it on such terms in an interview. That the Department of Health would advise clinics to ensure prayer was finished before clinic opening hours started at 7:30am was certainly interpreted by Nurses Fula and Tefo as clumsy and lacking compassion, and ignorant of what they felt was the symbolic importance of allowing people to pray together.

Accounts of unsupportive management were not universal however. Sister Terene talked generally about the management and didn't criticise at all. Sister Andrews also apparently sought to present any inaction by their management as understandable on the grounds that challenges may not be reported up to them. Sister Marais gave a unique account, describing how she was friends with the clinic supervisor, having previously worked together. She said that the other nurses didn't like her for it, based on her general willingness to accuse others of laziness and report to the supervisor. Sister Habore, despite at times complaining, as above, was also very positive at the start of the second period of fieldwork, following complaints in previous visits. When I first visited the clinic at the start of this second phase she said she had 'more hope', which seemed to be due to support from her manager as they were having regular meetings, and also receiving particular paperwork that provided guidance. In a later car journey home from the clinic I referred to her manager being a good manager, and Sister Habore agreed and made reference to her manager comparing her in age to her daughter, suggesting both familiarity and how each was accepting a certain position within the relationship.

This discussion of the characteristics of the health system management of nurses demonstrates how nurses work with what they frequently perceive as limited support. Despite the identity of a professional nurse, which implies a level of independence and respect, nurses often perceive their position as subordinate and neglected.

5.4 Conclusion: nurses' complex identity

My purpose in this chapter has been to explore how nurses' agency to conduct care and produce the routines described in previous chapters is embedded in a complex social identity. The significance of this analysis is to illustrate the challenges and tensions involved

in nurses' exercise of agency to produce care routines. The existence of a fragmented unity with patients and other nurses has revealed varying possible dimensions of nurses' identity; whether as community members, wives and mothers, living with HIV, clinic managers or as ART nurses. Overlaid with this is the tension in the identity of being an independent professional in the context of health system management that can be controlling and unsupportive, and so undermining nurses' independence.

The analysis in this chapter has further developed and grounded my conceptualisation of nurses' agency from chapter 4, demonstrating the additional challenges involved in nurses' conducting care. In the next chapter I return to issues raised by my analysis in chapters 3 and 4 around the nature of ART and HIV care in particular, to further explore nurses' agency and how it is shaped by specific contextual factors.

Chapter 6 - Exploring the response to ART and HIV care

6 Introduction

In this chapter I return to the differences identified in ART and HIV care in earlier chapters and further explore why there has been this particular response. The basis for my analysis is that the differences in ART and HIV care I reported indicate only a small change in nursing care since its introduction; a question then arises of why wasn't there more fundamental change considering the scale and apparent significance of the rollout of ART and HIV care? In chapter 3 I described ART and HIV care as 'the same, but different'. This indicates how some nurses are approaching ART and HIV care with a greater intensity of effort – and so care is more patient centred – even if this is based on the same widely held principles. I concluded then that this supports the hypothesis of Stein et al (2007) that ART and HIV care is supporting a shift towards more patient centred approaches to care. In chapter 4 I linked the differences in care to specific meanings attached to HIV, focussing in particular on stigma and nurses own experiences of HIV. Overall, my account of difference suggests a slight, incremental change towards more patient centred nursing care in response to ART and HIV care. This response is however arguably modest in comparison to what could have been anticipated. Stein et al (2007) proposed that motivation based on hope spurred by ART finally being available led nurses to provide more patient centred care. This hypothesised role for nurses' motivation is reasonable considering how ART and HIV care - from some perspectives – is a health system intervention of enormous significance, owing to the scale of the intervention but also how it is transforming HIV from a 'death sentence' to a manageable condition. That nurses are motivated to provide high quality care for ART is evident in my earlier analysis. However, not all nurses appear to be strongly motivated, and although ART and HIV care has specific meanings, it isn't clearly seen as of enormous significance, as nurses statements of it being 'the same' and 'normal' could suggest. One focus for understanding the nature of change is therefore to explore this motivation and meaning in more depth. For example, why aren't nurses more motivated? Why aren't nurses seeking to fundamentally alter their practice? These questions are problematic, both because they relate to a counterfactual that doesn't exist (a radical change in care) and because some may even doubt that these are reasonable questions (i.e. reject the idea that ART could motivate nurses to fundamentally change their practice). However, trying to understand what could be shaping this motivation and how that could link to the small changes seen reveals, I argue, key issues about the health system context.

I explore this question of meaning and nurses' motivation on the basis of the theoretical approach used in chapters 4 and 5. In chapter 4 I explored how care routines were produced through nurses' agency and how it was shaped by orders of interaction and context; chapter 5 further built on this and elaborated this concept of agency in relation to nurses' complex social identity. The analysis in chapter 4 already, to an extent, answers the question of why only small changes have been seen: because nurses' agency over care is constrained by orders of interaction and context. In this chapter I add to that analysis by focussing on particular aspects of agency and context and specifically how context and agency relate with respect to nurses' motivation. My approach is to relate the motivation reported by Stein et al (2007) and also Campbell et al (Campbell et al., 2011c) to work by Bernays et al (2007) on hope and uncertainty. I consider how nurses' motivation could be linked with hope and how hope is shaped by uncertainty in the South African health system.

The argument I develop through the chapter is that the slight change to more patient centred care following the introduction of ART and HIV care needs to be understood within the context of constant change that surrounds the introduction of ART and HIV care. There are two dimensions to this. First, in a context of constant change the introduction of ART and HIV care forms part of a long series of reforms, and within that, there is an existing trajectory of change towards more patient centred, integrated care. In this context, an appearance of small changes in response to ART and HIV is a function of how these reforms are relative to broader reforms and their effects; in addition, that ART and HIV care figures in nurses' accounts as just one change of significance suggests a reason as to why nurses' motivation to change their practice may not be as high as could be anticipated. The second issue I explore is how this context of constant change suggests the structural context is characterised by uncertainty. In discussing nurses' discourses of the future around ART and HIV care I show how this context of uncertainty can be linked to limits on nurses' motivation and agency to provide high quality care. I also remark on how despite these limitations nurses show a high capacity to manage and adapt to this uncertain context, again demonstrating how nurses' actions are not determined entirely by the structural context.

6.1 A trajectory of change to patient centred, integrated care

In this section I explore nurses' accounts of change to demonstrate both the range of recent reforms and constant change in the health system, and how a trajectory of more patient centred, integrated care can be identified within this. Nurses identified – spontaneously or in response to my direct questions – a number of changes linked to the introduction of ART and HIV care. Nurses also referenced a wide range of reforms and changes across the health system, not just in relation to ART and HIV care. This discourse was very varied, reflecting the range of reforms and changes nurses cited; and correspondingly many of the themes below are made up of isolated accounts. In this section I outline themes in nurses' discourse and show how the changes linked to the introduction of ART and HIV care have overlaps with the effects of other reforms. I then summarise how these overlaps demonstrate the particular significance of ART and HIV care in relation to other reforms: that it can be seen as relatively normal, and correspondingly not as a significant motivation for nurses to adopt fundamentally new approaches to care.

Drawing conclusions about changes in care based on these accounts must be done cautiously. These accounts reflect nurses own efforts to interpret the world and so are constructed, and these constructions may be shaped by nurses' knowledge of my institutional links with the STRETCH trial and my study being presented as exploring the impacts of ART. A knowledge of my position could potentially have shaped nurses' responses to questions about change. Although changes reported by nurses may overstate or create a link with the introduction of ART and HIV care there is little sense of nurses repeating a standard discourse when reporting changes: as is clear from the responses, they were varied and nurses were not agreed on any particular processes of change. This supports the notion of nurse reflexivity on their practice, and correspondingly, the validity of any claims to changes in care.

In this first section I introduce three areas in which the changes in care brought by the introduction of ART and HIV care and then broader reforms to PHC, overlap. These areas are an increased scope of practice, responding to the individual patient and a rising workload.

Increased scope of practice

A theme across nurses' accounts was of an increasing scope of practice; relating this back to chapters 3 and 4, this can be related to increased integration and the ability to address a patient's needs more holistically. This change was evident in how nurses referenced the introduction of PHC and shifts in nurses' role to taking on work from doctors. In talking about changes following the introduction of ART and HIV care nurses talked in a similar way about how this was leading them to take on new areas of work.

Nurses reported changes that related to the reforms to orientate the South African health system towards a PHC focussed strategy (see Chapter 1). Nurses referred to changes in terms of additional services being offered within clinics: Sister Andrews (Aangekom clinic) said how when she had started with 'community health' the clinics didn't provide antenatal care or ARVs; Sister Habore said clinics had previously just provided immunisations and TB care, whereas now minor ailments came to the clinic rather than the hospital. The nurse manager from Geheim clinic linked the change to more services with more patients coming to the clinic. Sister Terene also linked the introduction of PHC to more holistic and comprehensive practice, saying how since then they had been trying to integrate HIV, STIs and TB care. Nurses' accounts also referred to other changes in their role in addition to increased service provision, focusing on comparisons to medical practice and a general shift to an expanded role and advanced practice. One aspect of change was a shift to a 'nurse driven' approach, where nurses were no longer dependent on doctors, as noted by the nurse manager in Esita clinic. Another nurse in Esita suggested that nurses previously had been 'under' doctors, but are now 'inter-dependent', where 'he' is a medical 'specialist, and she herself is a 'nurse specialist'. A third nurse from Esita clinic remarked how she had noticed how PHC was 'nurse driven' and they weren't reliant on doctors, in contrast with her previous work in hospital based care. Nurse Tefo from Aangekom saw this changing role in nursing as part of an inevitable process of nurses taking on roles from doctors, saying how he had believed in 'nurses improving' to reach a 'standard' of doctors. He linked this to the need to see nurses as 'medical professionals', and to move away from the focus on nurses being there to wash the patient. The natural progression and suggestion of inevitability that Nurse Tefo hints at was also voiced by Sister Vermaak from Christen clinic who said they always used to know what doctors would write, and now they can do it themselves. A particular element of this advanced role is nurses being able to prescribe

drugs, which was cited by Sister Kwena, Aangekom and the nurse manager in Esita as notable changes in the clinic. However, the nurse manager from Ithuta presented a conflicting picture, describing how professional nurses weren't willing to be left alone on a unit, whereas she had done that early in her career, suggesting that nurses are now less independent in practice, despite the more formal independence nurses have gained as evidenced in other accounts.

This theme of an increased scope of practice was also clear in how ART was also linked to advancing nurses' practice, in terms of increasing their technical competence and areas of responsibility. Sister Kwena's comment above relates to this: she spoke about ART giving nurses more 'power'. The ability to prescribe and do what had previously been done by doctors was related to nurses learning and becoming 'more clever'; she added that nurses now know things doctors don't. Later on she returned to this relationship with medicine, adding that the nurses are engaging with new diseases through the patients and with the process of referrals to doctors they are learning about them. The nurse manager in Geheim clinic also said this factor of being able to prescribe ART was a big change. A nurse in Esita clinic said that ART was giving nurses more 'confidence' to 'deal' with patients, as previously all they could do was 'counselling and bactrim' (bactrim is an antibiotic), 'confidence' in this context of what nurses can do apparently referring to the ability to actually intervene clinically. Here it is both specific medications that nurses are able to administer and a relationship to their broader practice that is shifting. A nurse from Joyful clinic linked the 'era of HIV' to increased integration of services. She said previously there had been different programmes, but now everything has to be done holistically.

Responding to individual patients

Nurses' accounts also had a common theme of how attention to the interests and needs of an individual patient had increased.

In previous chapters I have raised how nurses referred to patients' rights and the batho pele principles. I tended to discuss them as overlapping and asked several nurses whether they had changed nursing. The nurse manager from Ithuta suggested that nurses now

know when they have done something wrong to patients, with notions of rights therefore acting as a benchmark for nurse conduct. Another nurse from Esita said batho pele and rights had made a big difference, but didn't elaborate on the point. Sister Kwena from Angekomb also said nursing had changed, as nurses treat patients with respect, and if they don't patients know how to complain, suggesting that the change isn't in nurses' behaviour itself but in how patients can respond to this. As evidenced, this wasn't a wide ranging aspect of nurses' accounts, but it did figure and supports how patients' rights have become embedded within clinic discourse.

An increased orientation to the needs and interests of individual patients was evident in relation to ART and HIV care. Sister Seporo said attitudes and how they 'deal' with patients were having to change since ART was introduced; with nurses having to 'follow up' owing to the greater 'vulnerability' of the patients. The clinic manager in Fontein clinic said how ART had led to a change in 'nurses' brains': she described how for other conditions tests and 'gadgets' had resulted in nurses losing the 'feel' for patients, whereas now nurses were actually investigating patients and so ART is giving the 'feel back'. She included in this a comparison to antenatal care and chronics services, which she saw as 'donkey work', whereas with HIV the illness is different for every patient, she noted. The introduction of ART and HIV care was linked to changes in control of care. Sister Kwena, Aangekomb, said how nurses were 'learning and becoming 'more clever'', and contrasted the care provided by private doctors with that of nurses, where patients would learn about the care they were involved in. This equates to ideas of a partnership approach and of nurses seeking to ensure patients are informed, even if Sister Kwena didn't hint at issues of empowerment. Sister Habore in Ba Banyane linked the introduction of the PALSA PLUS guideline to shifts in communication with patients, describing how now she sought to 'guide' and 'advise the client' rather than issue instructions. These comments could however be shaped by nurses knowledge of how I was indirectly linked to the STRETCH trial team that was associated with PALSA PLUS.

Rising workload

Nurses' workload was a focus for discussion through my time in the clinics. Existing research has already explored the impacts of the PHC reforms and removal of user fees

cited above, finding that clinic use has risen (Walker and Gilson, 2004). A rise in workload since the introduction of free care was noted by a nurse from Esita clinic and by pharmacy staff in Dula clinic. In some of the clinics the workload reportedly increased during my fieldwork. Staff in Aangekom, Christen and Dula referred to rises in workload linked to context specific factors. It wasn't clear if this was supported by clinic records, or whether this was due to staff shortages (which Nurse Tefo in Aangekom suggested). In Aangekom clinic several staff referred to increased numbers of patients owing to a local 'squatter camp'.

References to increasing workload following the introduction of ART were also made by nurses from Christen, Dula, Geheim and Joyful clinic. Increases in workload are potentially offset by new staff: Dula, Esita and Geheim clinics all reported gaining additional nurses for the ART programme, and then there were also lay counsellors and additional data clerks. However, there were still reports of negative impacts on care. Sister Setempe and Sister Kgaba in Dula clinic linked the increased workload because of ART to leading them to working quicker, whereas before they had more time with patients.

A trajectory of change

A theme across these accounts from nurses is that the clinics have been involved in a series of reforms; in the next section I explore the significance of this constant change in the clinics. Across these reforms another theme emerges of how there is potentially an overall trajectory of change towards more patient centred, integrated care. The overlapping effects of these reforms in terms of an increased scope of practice and of increased attention to individual patients suggest the existence of this trajectory. The references to rising workloads also highlight the mutual threat to patient centred care arising from these reforms. Overall, ART and HIV care can be seen as producing similar effects as other reforms. The suggestion of a slight change to more patient centred care in response to the introduction of ART and HIV care can therefore be seen as reflecting the nature of the broader health system, in that there are other changes that overlap with, and obscure, any changes that could be linked to the introduction of ART and HIV care.

A point to consider within this trajectory is that the 'ART approach' of empowering and rights based care that I referenced in chapter 1 isn't relayed to the clinics as part of a coherent strategy or call for change in care. This discourse isn't formally promoted at the clinic level – or at least it was never visible to me, or voiced by nurses in those terms. When I did occasionally raise terms like patient centred and empowering care with nurses they seemed to engage with them as terms they recognised, but didn't seem to necessarily connect them to ART and HIV care. This is perhaps not surprising, but it is worth highlighting that policy and analytical discourses of care are distinct from those that are used in delivery of care. Indeed, calls for more patient centred care linked to specific interventions have been seen in other areas of South African PHC like TB care (Dick et al., 2004) highlighting that there is no single, specific impetus for change linked to ART and HIV care.

The existence of these overlapping effects also provides insight in to nurses' accounts, demonstrating the significance of other reforms to nurses, and, consequently, that ART and HIV Care are not the only recent reforms of significance. This was clear in Nurse Tefo's response to my suggestion that the introduction of ART might change care. He was annoyed and incredulous at this suggestion. He spoke at length about how nurses constantly adapt and do new things. Indeed, ART and HIV care are arguably figuring in nurses accounts as just one of a number of recent reforms. It is this lack of significance in relation to other reforms that can be interpreted as a limiting factor on nurses' motivation to fundamentally change their practice. For Stein et al (2007) nurses' motivation to change their practice was linked to the hope of ART finally being available after long delays (see references above to government policy around the denial of the links between HIV and AIDS). In that context ART took on enormous significance; whereas the accounts from nurses in this study suggest less significance with ART at times considered alongside other reforms, and so potentially less motivation to fundamentally change their practice.

Accounts of change that focussed only on ART and HIV care suggest a normalisation of it, which correspondingly could impact on motivation. The introduction of ART and HIV care was linked to changed perceptions of ART, HIV care and HIV. Some nurses were reportedly

more willing to engage patients in VCT. Sister Seporo said that people want to know their status and are now willing to come to the clinic because of ART, suggesting ART is also changing patient perceptions of HIV care and giving different meaning to long-standing services. Sister Seporo from Christen clinic described how there had been an attitude shift, to now seeing HIV as 'ordinary'. A nurse from Geheim said how the community was 'used' to ARVs, whilst another from Ithuta also referred to stigma going down and patients being willing to come to the clinic (although my question was framed in the context of ART she actually referred to VCT). Sister Fula said ART had been a 'big change', leading on to talk about how they used to be afraid of HIV. In Zimbabwe, a similar context, it has been noted how ART has become a normal part of nursing even within the short time since ART was introduced (Campbell et al., 2011c). This same process could be evident in the clinics studied here, with ART and HIV care becoming increasingly seen as normal and also normalising perceptions of HIV. Following this, when ART and HIV care was first introduced there may have been high levels of motivation (as in Stein et al's study) but this may have dissipated as perceptions of ART and HIV care changed.

The suggestion of ART and HIV care becoming normalised must be done cautiously, as indicated by specific reports of stigma from nurses, as well as the experiences of NLHIV I highlighted in the previous chapter. The introduction of ART in Dula clinic initially led to more stigma, with patients questioning why that clinic had been chosen, with an apparent logic that this reflected that the nurses themselves were HIV positive. But since 2005, when ART was introduced to the clinic, this stigma towards the clinic and nurses linked to ART availability had been replaced by a willingness to use the clinic owing to confidence in the nurses and their experience in relation to HIV. Other accounts also indicate there is no inevitable link between ART availability and a reduction in stigma. A nurse from Geheim clinic suggested patients only started coming to the clinic in large numbers after they changed from a separate ART area within the clinic. In other contexts in South Africa stigma has reportedly changed rather than reduced, with the suggestion there hasn't been complete normalisation, even if interpretations of HIV have shifted significantly (Colvin, 2011).

There were also distinct accounts of change linked to ART and HIV care. I raise these briefly here to both further support the idea of care as different, and as having specific meanings, and to raise the idea that ART and HIV care can potentially be seen as extending the trajectory of change towards more patient centred, integrated care, and not just overlapping with other reforms. A first element of unique changes was the responses from three nurses of how ART was impacting on patient health. Sister Nomkhula in Dula clinic said how 'very sick patients' are 'back on their feet'; a nurse from Geheim described a conversation from a recent funeral, where someone had commented that they were now burying less people; and complementing this, she said how they are now 'saving more lives'. This discourse is perhaps however notable for its relatively minor role in nurses accounts of care, and doesn't clearly fit with the 'recovery narratives' reported elsewhere (Campbell et al., 2011c). This perhaps results from the more mature ART programme in South Africa, resulting in fewer patients presenting at clinics with advanced AIDS.

In this section I have explored nurses' accounts and identified a range of reforms alongside ART and HIV care. I have suggested that these reforms can be seen as having common effects and consequently that there is a trajectory of change towards more patient centred, integrated care which ART and HIV care forms a part of. This trajectory may account for the introduction of ART and HIV care having a relatively slight response, and provide insight in to why nurses may not consider ART and HIV care of considerable significance. In the next section I go on to explore the effects of the constant change indicated by the range of reforms included here.

6.2 Constant change and uncertainty

In this second section of the chapter I explore the implications of constant change in the clinics and what this reveals about the South African health system. I conceptualise this constant change as contextual uncertainty – building on the analysis in chapter 4 – and relate it to nurses' agency to develop a hypothesis of why there has only been a slight change in care.

My analysis that conceptualises the health system as uncertain builds on theory of how hope attached to HIV and ART can shape agency. Stein et al (2007) hypothesised that nurses were motivated to provide more patient centred care because the availability of ART inspired hope for the future. This relates to broader theory on the role of hope. Hope is a central discourse around the global scale-up of ART and its availability (Bernays et al., 2007) and is here understood as 'a positive expectation of the future' (Bernays et al., 2007, p55). Agency is a key dimension of hope, with hope involving a belief and motivation to try and achieve goals (Westburg and Guindon, 2004). Bernays et al (2007) conceptualise hope as shaping behaviour, and in turn being shaped by the broader risk environment. They suggest that 'certain environmental conditions can puncture or limit hope, leading to a lack of investment in the future' (ibid, p56). In particular, fragile delivery systems can create an environment of 'pervasive uncertainty' that is 'absorbed as anxiety' by PLHIV (Bernays et al., 2007, p59, see also , Bernays and Rhodes, 2009) and so affecting treatment decisions. Hope has predominantly been discussed as figuring in patients' experiences of HIV (Bernays et al., 2007, Westburg and Guindon, 2004) and in nursing around how nurses can support hope in those experiencing ill health (Tutton et al., 2011). My approach in this analysis is to develop this conceptualisation of hope and uncertainty focussed on patients' responses from Bernays et al, and build on Stein et al's initial work relating hope to nurses' motivations. I do this by showing how a structural context of uncertainty can be interpreted as shaping nurses' agency, mediated by hope and other meanings.

My argument explores how the contextual uncertainty linked with the introduction of the ART and HIV care programme undermines nurses' agency to provide more patient centred care, and so gives insight in to the small changes seen in care. I first of all build on the analysis from section 1 of the chapter and show how there is a pattern of ongoing, but unpredictable change and reform around the ART and HIV care programme that I characterise as uncertainty. I then relate this to nurses' agency, showing how nurses do report some hope, but that nurses' discourse around the future prospects of ART and HIV care focus on challenges of resources and workload. I use these ideas of motivation and hope to then suggest how this contextual uncertainty can be understood to limit the potential for a significant shift in care following the introduction of ART and HIV care. I also note how, despite the challenges, nurses' play a key role in managing and adapting to this uncertain context.

6.2.1 Uncertainty in the ART and HIV care programme

Characterising the ART and HIV programme in the South African health system as contextual uncertainty responds to key accounts and aspects of my data. The political context of AIDS denialism by Thabo Mbeki and his government and how that led to delays in adopting and implementing ART is an initial factor. Additional factors since then add to this characteristic of uncertainty. A moratorium in the Free State province on starting patients on ART in 2008, just prior to the fieldwork starting (also raised in section 1.3.1 above), also illustrates this potential for unpredictable change. The moratorium led to a three month period when clinics were told not to initiate more patients on ART, as a result of provincial budget shortfalls. This is an illustration of a fragile delivery system within South Africa and of the potential for periodic crises. Although the Department of Health has since been praised, with new leadership in place, challenges still remain. Shortages of ART drugs are not currently a problem in the Free State – although supply challenges were reported, as I discuss below - but have been recently reported elsewhere in South Africa (TAC, 2012, Mhlana, 2012), with ART provision in South Africa described as ‘tenuous’ by some (Gilbert and Walker, 2009).

Uncertainty is also evident in the operational management of the ART and HIV care programme, beyond the broad scale political crises mentioned above. The ART scale-up in the Free State was initially implemented cautiously and gradually, with an effort to phase in the programme across the province to avoid disruption and to develop experience (Van Rensburg, 2006). Despite, or alongside, this caution, the management of the programme can still be seen as involving a rapid stream of decisions and initiatives, with many announced through the course of the fieldwork. In the course of the fieldwork the role of nurses in ART initiation and prescription was still being debated (the STRETCH programme was a trial, to inform decisions regarding scale-up of this role), and this was eventually announced as national policy. An HIV testing campaign was also implemented, conducted in March and April 2010. This was an initiative of the new Health Minister, and consumed nurses’ time in the clinics. There were also announcements about changes in treatment guidelines: on World AIDS Day, 1st December 2009, President Zuma announced a shift in guidelines regarding when patients would be initiated on ART, as well as on treatment for

pregnant women. Such announcements and initiatives were all part of a fast evolving policy and delivery context.

I discuss in the next section nurses reactions to this context, but here I outline how this emergent and changing nature of the ART and HIV care programme management impacted at the clinic level. What was clearest across nurses' accounts was of an absence of information about future plans, with nurses often having little understanding of how the ART and HIV care programme would affect them. The experience of Aangekom clinic illustrates this. In the course of the fieldwork it gradually became engaged in the ART programme, after having originally been included in my study for not delivering ART. I first heard that Aangekom Clinic would be distributing ART in March 2009. Sister Terene, the nurse manager at the time, described how she was going to meetings to discuss this, although she also said she didn't know when it would start. The clinic then received an extra 'park home' (a portakabin or ready built structure) in November 2009 to create additional space for this. When I visited the clinic shortly after this had arrived, neither a nurse I spoke to, a counsellor nor the clinic cleaner had any information about when it would start. As my data generation was finishing in April and May 2010 they still hadn't started distributing ART. Nurse Fourier, by now the nurse manager, had shortly before this said to me that 1st April 2010 would be when they would start, but this deadline passed. Ba Banyane clinic had a similarly ad hoc timetable to its role in the ART programme. In the final weeks of the fieldwork I was in the clinic when Sister Habore received a phone call from her manager telling her she would be going to Johannesburg for some training in two weeks time to allow her to initiate ART; she hadn't expected this and was initially anxious as she had an exam coming up and thought this might make it difficult. Other complaints from Sister Pretorius about programme instructions not being passed on to them compound the overall nature of clinics often functioning in an information vacuum with no clear idea of the future role for themselves and their clinics.

This environment of changes in policy and unclear direction for the clinics, as well as problems with drug supply which I explore further below, I see as revealing key aspects of the clinic context of uncertainty. Bernays et al (2007) in analysis of HIV treatment experiences in Serbia relate treatment interruptions to a sense of uncertainty that PLHIV

experience as anxiety. Bernays et al (2007) conceptualise challenges of treatment supply as producing specific risk environments that then moderate hope, and so behaviour. I build on this idea of risk environment and uncertainty and relate it to my conceptual framework in chapter 4, and so suggest that the clinic context has a key characteristic of uncertainty. In the rest of this section I explore how this could relate to nurses' agency.

6.2.2 Nurses' agency in a context of uncertainty

My focus here is on understanding how the uncertainty that characterises the policy context was taken on by nurses at the clinic level and this then potentially shapes care, and gives insight to the slight change following the introduction of ART and HIV care. I explore this by first outlining how nurses' accounts do indicate some level of hope, but that this is alongside a discourse of concerns about resources and workload. These concerns can be interpreted as one factor limiting nurses' motivation to provide more patient centred care. I then also explore how nurses are actually managing this uncertainty, reflecting on how nurses day to day efforts to adapt to the contextual uncertainty and the relative absence of accounts of despair, stress and burnout illustrate a capacity to manage and work within this uncertainty.

Discourses of hope and resource shortages

Direct references to the idea of hope didn't figure in nurses' accounts. Instead, there are a range of themes which I argue relate to the existence or otherwise of hope around ART and HIV care. Nurses' accounts included positive expectations and attitudes towards providing HIV care. Nurses described excitement, relief at it arriving, that they were 'pleased' and that it was a 'blessing'. An extension of this optimism was a sense of the inevitability for nurses taking on the increased role in ART delivery, and unquestioning of their capacity to do it. Nurse initiation of ART was described as part of the 'normal order', 'how it should be' and, that it 'had to come'. Nurse Tefo said he was 'excited' because ART was 'something new'.

Alongside positive and hopeful accounts, nurses were also concerned about resource shortages and workload, which shows how nurses are responding to the uncertain health system context. In Aangekom clinic where ART was being introduced as my fieldwork ended almost all the nurses expressed concerns for more staff and the workload. Sister Habore complained about how with initiating ART nurses were expected to do more work but did not get paid like doctors. In Christen, Sister Vermaak said the work was getting too much, whilst in Dula clinic several nurses also complained about ART increasing their workload. Nurses' concerns were largely expressed in terms of how to manage the organisational challenge, rather than as despair or panic. For example, Sister Pretorius in Ba Banyane said there were challenges, and illustrated this with how she needed to improvise a rack for drying blood samples on (for PMTCT). Overall, there was a common discourse of resource issues and challenges, that was perhaps at times framed as urgent and important, but not generally in terms of crisis or desperation.

There were, however, instances in which the uncertain environment clearly led to despair for the nurses. The ART moratorium was raised by Sister Fula, who referred to that period as 'the worst', and described how patients were denied 'that life' they had seen others live, of regaining their health; Sister Sehlwela similarly described that period as 'painful', with patients distraught in consultations and threatening suicide. This particular sense of stress related to these specific events wasn't directly voiced by others, although Sister Terene and a student nurse in Aangekom clinic raised drug shortages as a concern.

The balance of hope and concerns about resources within nurses' discourses, reported in a similar context by Campbell et al(2011c) , I interpret as a factor in limiting nurses' motivation to provide high quality care, and as leading to the slight change in care seen. I see the contextual uncertainty, following Bernays et al (2007), as puncturing nurses' hope. This can also be seen in nurses' complaints of feeling unsupported, abused and unmanaged in chapter 5. An interpretation of change undermining health workers is supported by literature in other settings. Hunter (1979), in discussing the Scottish National Health Service, suggests that uncertainty may lead to people favouring stability and order, rather than change. Further, that 'initiative fatigue' can result from constant change (Huczynski and Buchanan, 2007, p591) and that change in itself can be a cause of burnout (ibid, p595).

In a context of uncertain policy and administration that impacts on the clinics through an absence of clear direction and information about future plans, nurses are often mindful of the challenges of workload, staffing, drugs and the reality of providing ART and HIV care. Although individual nurses are motivated to provide high quality care, this discourse of concern for the future could explain why some nurses may lack motivation and other nurses do not seek more fundamental change, with uncertainty limiting agency to seek change.

Managing uncertainty

A final point I consider here is that despite the potential limitations on nurses' agency, nurses still display a capacity to manage and adapt to contextual uncertainty. Sister Vermaak described to me how she managed the risk of problems in the supply of ART by putting aside certain drugs, in Esita clinic the nurses there also responded themselves when there were interruptions to the drug supply by going and getting more drugs from a central depot. Sister Fula and Sister Kwana said how they were learning as ART was introduced, indicating a readiness to adapt.

A further dimension of this capacity to manage uncertainty is how despite the uncertainty there is a relative absence of accounts of stress, despair and burnout. Reports of stress and burnout were evident, with the clinic manager in Fontein clinic taking time off work because of this and Sister Fula reporting stress, and how nurses would hide their stress. Several nurses also complained about the lack of counselling and 'debriefing' from the Department of Health. However, nurses' accounts generally focussed on their happiness and satisfaction with their work. This relative absence of accounts of stress and despair is noteworthy considering the past reports of burnout and fatigue in South Africa and elsewhere (Engelbrecht et al., 2008). That nurses are able to maintain a level of hope, when another possibility for dealing with this uncertainty would be despair or burnout, points to nurses' capacity for managing uncertainty in this context.

6.3 Conclusion: coping with constant change

In this chapter I have argued that the small change in care following the introduction of ART and HIV care needs to be understood within the context of constant change in the clinics. I first argued that the range of reforms that nurses' report can be seen as forming an overall trajectory of change towards more patient centred, integrated care. This existing trajectory of change then gives insight in to why the introduction of ART and HIV care may lack significance for nurses and may obscure the effects of its introduction. I then went on to discuss the impacts of this range of reforms in terms of how this illustrates a process of constant change and contextual uncertainty in the clinics. Nurses concerns over resource shortages and workload in relation to ART and HIV care need to be interpreted through this lens of contextual uncertainty, which in turn can be potentially undermine their motivation to provide high quality care.

The analysis in this chapter adds to my theoretical approach used in chapters 4 and 5 in trying to explore and understand nurses' agency and how that is influenced by broader structures. In the discussion that follows I further develop these links and explore their implications.

Section 3 – Research implications

In this final section of the thesis I discuss the analysis presented in the last four chapters, and explore a series of implications that arise from this.

Chapter 7 - Discussion and conclusions

7 Introduction

This study set out to understand the organisation and delivery of PHC nursing in the context of ART and HIV care, in the Free State province of South Africa. This aim involved two objectives: first, to describe care, and address the question of whether care is patient centred and integrated; secondly, to explain these care routines through analysis of the social processes and relationships underpinning them. In this chapter I return to this overall aim and objectives. The focus of the chapter is to summarise my findings around the organisation and delivery of PHC and ART and HIV care in the study clinics, and then demonstrate how this can support theoretical development of this field and also health services management and policy.

I first of all summarise the study findings related to this aim and the objectives. In the second section I discuss these findings in relation to specific areas of theoretical literature and policy issues to demonstrate their significance; this dual discussion reflects the study focus of seeking to inform health service debates and policy through developing social theory in relation to PHC and nursing in LMICs. In the third section I critically reflect on the study and explore its strengths and limitations to provide general lessons to inform future enquiry.

7.1 Study findings

The principal finding of my study is that both PHC in general, and ART and HIV care specifically, are being provided through patient centred, integrated routines, yet this is also limited by other care routines that don't respond to patients' needs and interests. Nurses' agency ,shaped and constrained by orders of interaction and by context, is an important factor in producing these routines. In the following paragraphs I summarise the findings in more detail in relation to the study objectives.

The first study objective was to describe the organisation and delivery of care in the context of ART and HIV care. In the clinics studied I found that there are limits to the patient centredness and integration of services in PHC nursing in the context of ART and

HIV care. Through exploring routines that were more and less patient centred, I described how although nurses are seeking at times to respond to patients needs and wishes and provide comprehensive care, dominant routines in the clinic ultimately limit these efforts. A key part of my approach in this argument was to explore both scheduling care and consultations, on the basis of the importance they both have for the experience of care. A second conclusion was that ART and HIV care is largely provided through the same routines as other clinic services. The idea of ART and HIV care being 'the same, but different' captures the slight differences in the scope of consultations, but highlights how these differences reflect an intensity of application of widely held nursing principles that care should address patients' needs and be comprehensive. I also discussed the usefulness of the concept of patient centred care. Although helpful in identifying key characteristics of care, it is also limited in a PHC setting, through its inability to engage with a key aspect of care: scheduling and managing processes outside the consultation.

The second study objective sought to explain these care routines through exploring the underlying social processes involved. I adopted two perspectives on this. In Chapter 4 I looked at the role of orders of interaction, context and agency in producing these routines. I found that nurses can exercise agency in adopting different roles in orders of interaction, that in turn mediate the influence of context. In relation to patient centredness, competitive and collaborative orders lead to nurse roles of guardian and guide that produce less and more patient centred care respectively. These orders are shaped by health policy, resource shortages and understandings of nurses, but the influence of these contextual factors is mediated by the different orders. The variation in orders is linked to nurses exercising agency, which I characterise as being able to conduct care: the orders and context limit nurses' agency, but they still have influence. This exercise of agency is crucially reliant on the power relationships with patients, which further shape nurses' actions, and the meanings linked to nurses' behaviour. I argued that both the competitive and collaborative orders can ultimately be linked to a concern and compassion for patients' interests. The specific differences leading to more patient centred care for ART and HIV care I attributed to nurses attaching specific meaning and significance to this service, owing to the stigma attached to HIV and recognition of the challenges patients faced. Service integration can be understood with the same approach. A cooperative order between nurses and the clinic managers sees nurses adopting a conservative role and their

managers a role as advocates. This interaction is also shaped by health policy factors, but again these factors are not determining. Despite the constraining influence of the order and context nurses exercise agency in producing the routine of separate services. This is linked to a range of motivations, focussing on a concern for patients and the quality of care, but also concerns about workload and the complexity of care. In chapter 5 I elaborated on this concept of agency by exploring nurses' complex identity to give insight into the range of tensions and contradictions that nurses manage in exercising this agency.

A second perspective in chapter 6 sought to understand the introduction of ART and HIV care and how that has resulted in a slight but not fundamental change in care. I argued that this slight change reflects the overall context of constant change in the South African health system. This context is the basis for ART and HIV care being just one of many recent interventions, that I suggest form part of an existing trajectory towards more patient centred, integrated care. I also suggested that this context of constant change can be conceptualised as contextual uncertainty which, in turn, undermines nurses' agency to provide more patient centred care.

7.2 Implications

In this section I discuss the findings outlined above in relation to existing literature to outline the implications of my study. In this discussion I explore how the study contributes to theory and to current health services debates and policy development.

7.2.1 Theory development

This section discusses how my study findings can be the basis for theory that can be used in study and research in other settings. I first of all discuss how conceptualisations of patient centred care could be further developed to relation to PHC. I then evaluate my framework of order, context and agency to explore how it can contribute to further understanding of PHC.

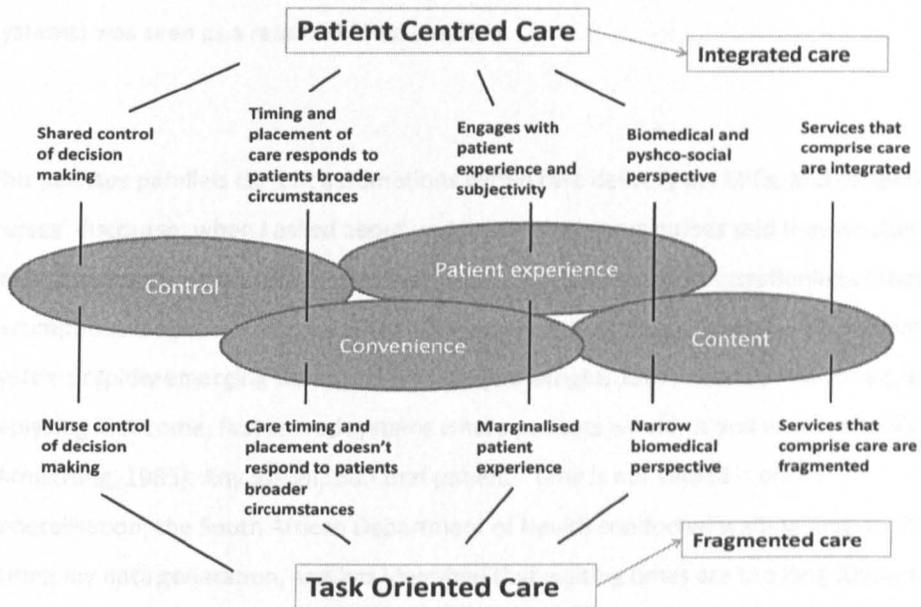
Reconceptualising patient centred care

My study suggests that current conceptualisations of patient centred care don't pay sufficient attention to aspects of care beyond the consultation that are crucial to a full understanding of PHC, in particular around scheduling care. Existing conceptualisations of patient centred care are oriented towards understanding consultations, with their emphasis on the range of health issues explored, and how decisions around care content are made (Mead and Bower, 2000, Lewin et al., 2009, Bensing, 2000). A conceptual focus on consultations neglects broader aspects of care, such as the scheduling of care which I discussed in chapters 3 and 4 and which I argued are a core aspect of the experience of PHC. Patient centred care as it is conceptualised in nursing has engaged with the 'care environment' and the need for supportive organisational systems (McCormack and McCance, 2006). This can include having systems that support shared decision making and having appropriate staff available (ibid.). This provides a useful perspective from which a conceptualisation of patient centred care for PHC could be based. However, this framework originates in hospital based care (ibid) and so doesn't clearly engage with how care is scheduled, beyond general references to supportive organisational systems.

A framework that is useful for PHC in LMICs, and in high income settings also arguably, must engage with this dimension of scheduling care. As I discussed in chapter 3, the long waits resulting from a lack of attention to scheduling care undermine patients' capacity to access care, are disempowering and indicate a lack of control over care, and so undermining continuity of care and treatment adherence. With PHC needing to manage the repeated interactions with care that are demanded by ART and HIV care as well as other chronic diseases (Beaglehole et al., 2008) it is imperative that care be considered in a way that can effectively support these interactions. Strategy in support of PHC has already cited the need for 'people centred' care that is convenient for patients (WHO, 2008b), while strategies for supporting patient retention on ART have called for decentralisation and efforts to reduce the costs for patients caused by time from work and travel (Harries et al., 2010). A specific framework for patient centred PHC care would build on these existing themes, and could consider convenience alongside content, control and the patient experience. A representation of this is in figure 7.1 below, adapting the framework I introduced in chapter 1. Convenience provides a focus for how care is determined by more than the consultation, and how the timing and placement of care should seek to respond to

patients circumstances (placement being included here on the basis of these services being decentralised and available at the PHC level). This is not to necessarily suggest that care should somehow be tailored to respond to every individual's needs, but that care routines should consider a patient's circumstances and the demands that care places on their time and resources. Routines to more effectively schedule care would then fit within that.

Figure 7.1 A framework for describing care that addresses care convenience



A general neglect of issues of organisational functioning like scheduling care and patient waiting reveals important assumptions within global health policy and discourse. A perhaps common perspective is that in contexts where shortages of drugs, health workers and clinics are a problem, then a concern for waiting time is secondary. This is an assumption, often unspoken, which I question. As I have argued, the experience of waiting is pivotal for patients. An additional consideration, oriented to the demands of resource poor settings, is that efforts to schedule care – using appointment systems for example - could actually provide more efficient use of scarce resources, as well as ensure nurses are less exhausted by a busy morning and more able to work effectively through the day. That routines involving long waits aren't urgently questioned hints at assumptions that changing these routines would be difficult, or that more health workers are needed. An additional unspoken assumption is perhaps that the patients of PHC in LMIC settings are seen as not in need of systems for scheduling care, with the time of these patients seen as of having relatively little value. To illustrate these assumptions from another context: a report from a

UK study on appointment systems published in the 1960s prefaced the study with many issues around their introduction, but one of them was: 'would working-class patients welcome a change in their habits?' (Cardew, 1967, pvi). It would be unreasonable and crude to judge many years work by a team of dedicated professionals by a single remark, but that the question could be asked illustrates certain assumptions: that the interests of a 'working class' could be defined, and that these may be different to upper or middle class patients (who presumably don't need to be asked whether they would accept appointment systems) was seen as a reasonable assumption.

This perhaps parallels current assumptions within care delivery in LMICs, and certainly in nurses' discourse: when I asked about appointment systems nurses said they wouldn't work, as patients wouldn't keep to their times. Data that supports questioning of these assumptions is how systems for scheduling care in the UK then changed, with appointment systems rapidly emerging through the 1960s (Cartwright, 1967, cited by Armstrong, 1985) replacing first come, first served systems where patients would sit and wait for hours (Armstrong, 1985). Any assumption that patients' time is not valued is only a generalisation; the South African Department of Health conducted waiting time audits during my data generation, and has identified that waiting times are too long (Department of Health (SA), 2010) and also called for the need to minimise waiting time and have appointment systems (Department of Health (SA), 2000). However, these efforts are largely peripheral and secondary within current strategy, and certainly not within efforts to conceptualise care in a way that meets patients' needs.

Agency, orders and context in patient centred care and PHC

My theoretical framework of nurses' agency, orders of interaction and context develops theoretical literature around how patient centred nursing care is produced. In particular, this framework provides a way of recognising the key role of nurses' agency and how that interacts with other factors. Existing studies in the global health literature have identified nurses' discretionary power (Erasmus and Gilson, 2008) and highlighted their role in shaping and adapting clinic functioning and care delivery in the face of macro-level policy pressures (Walker and Gilson, 2004, Rajaraman and Parker, 2008, Blaauw et al., 2006). A recognition of nurses' agency in turn is informed by broader work exploring service

provider agency (Lipsky, 1980). Research that informed this study by Stein et al (2007), Evans and Ndirangu (2009) and Campbell et al (2011c) has also drawn attention to nurses motivation to provide high quality care and the compassion shown for patients in delivering ART and HIV care. My study has developed these two areas of literature – around nurses’ agency and nurses’ motivation and compassionate role in producing high quality care – and positioned them within a broader theoretical framework that allows both a detailed understanding of the precise role of nurses’ agency as well as the structural factors constraining and enabling this. My recognition of contextual factors and their role in shaping care routines is not necessarily novel, as a key theme in global health policy is around issues of financial resource shortages (Taskforce, 2009a). However, my approach has sought to show how these contextual structures are not determining, and so still allow a role for nurses’ agency. My incorporation of Strong’s ideas of orders of interaction also allows for more local forms of constraint on nurses, while still allowing for the exercise of nurses’ agency in how these orders are realised. In summary, my approach has provided a way of understanding nurses’ agency and how that operates to produce patient centred care.

My conceptualisation of nurses agency as the capacity to conduct care (building on Latimer’s (2000) conceptualisation) also provides a more accurate and relevant insight in to power relations within nurse-led PHC. A focus on the conduct of care shifts analysis from less nuanced understandings of power. Analysis of doctors’ power and control informed the development of ideas of patient centred care (Mead and Bower, 2000). Understandings of doctors having power and control relates to the core idea of medical dominance that has informed much analysis in low and middle income settings (Sheikh and Porter, 2011). A theme of dominance and control in turn resonates with research in to South African nursing that has drawn attention to nurses’ control and abuse of patients (e.g. Jewkes et al., 1998). Understandings of medical dominance reflect a particular conceptualisation of power, namely one of power over – as I discussed in chapter 1 and again in chapter 4 - and do not clearly account for resistance to this power. I instead sought an understanding of power that is more nuanced (Nugus et al, 2010), considering ideas of power as control unsuitable to the context of nurse-led PHC (and indeed, perhaps any form of health care). My analysis of how nurses can conduct care incorporated understandings of ‘power with’ and ‘power over’ (Göhler, 2009, Chambers, 2005) and recognise the key role of patients as

active agents, and their power to resist (Scott, 1985). This approach therefore provides a nuanced understanding of power and how it is set in relationships.

My analysis has also sought to demonstrate the variation in nurses' agency as a way to engage with the dynamism and variation in clinic activity. Work cited above by Campbell and Evans and Ndirangu has outlined both nurses' compassion, but also the capacity to neglect patients' needs and interests. Conceptualisations of agency need to be able to engage with these often contradictory processes; as I have shown in my analysis, the same nurses could be both compassionate and then neglect patients' interests. I have allowed for this variation in both recognising different orders of interaction, and then exploring nurses' complex identity as a way of understanding the range of motivations nurses bring to their work (following Cleaver, 2007). Recognising this complex identity in which nurses' agency is embedded then allows for the paradoxes and contradictions that are involved in the everyday practice of care; analysis can then engage with nurses maintaining distance from patients that are also community members and friends, or in how different discourses of HIV can co-exist for nurses, with the biomedical and the professional and then local and community grounded meanings shaping their work in the clinics.

My approach to nurses' agency and how it is shaped by orders of interaction and context is the basis for a number of questions that relate to theory development, which would develop this understanding of PHC nursing and patient centred care further.

A first area for development would be further analysis of the specific contextual factors and social forms that act to constrain and enable nurses' agency in producing more patient centred care. An implication of my analysis so far is that patient centred care is being adopted at the clinic level through specific social forms and processes; a useful starting point for enquiry would therefore be to understand the precise factors that are shaping this. My study highlighted how contextual factors have influence, but are not determining. However, a focus was largely on understanding the constraining role of context, and relative neglect of how contextual factors also enable nurses to provide more patient centred care: for example, what health system policies support more patient centred care? In addition, I have suggested the role of a guide for nurses is important in producing patient

centred care; further analysis could explore the precise contexts in which this role is taken on, and, whether other roles similarly allow for patient centred care. A specific question would also be to understand how the contextual and order level factors lead to the differences (and so strengths) of ART and HIV care. I suggested the differences in this care involved specific meanings attached to HIV, reflecting stigma and nurses' broader community experience of HIV. A question then is whether specific contextual factors legitimise and support nurses' to act on these meanings; and correspondingly whether these factors could be fostered and supported in other areas of care. For example, is it that potentially more resources are available (if they are)? Is it the high profile political debates? Or do these actually undermine the delivery of ART and HIV care? Some nurses referenced the possibility of other services replicating HIV care, and so understanding the precise factors that support nurses' exercise of agency to produce this more patient centred care for ART and HIV care would usefully inform the development of PHC.

A second question would be to further explore the conceptualisation of health systems context as uncertain. In chapter 6 I explored how an uncertain health system context can limit nurses' agency to provide patient centred care, and yet I also showed how nurses are working to manage and adapt to this uncertainty. A hypothesis emerging from my analysis in chapter 6 is that nurses' agency to manage uncertainty provides a means by which uncertain health systems are sustained. A relationship is therefore not just that uncertain health systems impact on nurses' agency, but that a process of structuration leads nurses' agency to allow the processes that create uncertainty – e.g. constant policy reform – to continue. That health systems don't collapse as a result of ongoing structural change is a result in part of health workers agency to manage and adapt to these ongoing changes; this process therefore allows a process of ongoing change to continue. Exploring how uncertainty is managed and then allowed to continue would add to literature around the role of street level bureaucrats (Lipsky, 1980) in not only showing how health workers adapt and translate policy, but also how they allow the macro-level processes of policy change to continue. This could apply to other health settings like the UK National Health Service, that are also experiencing ongoing reforms, and yet don't appear to suffer serious catastrophe.

7.2.2 Health services policy

In this section I explore how my study findings can be used to inform policy for PHC and nursing in South Africa and similar settings. I show how the theoretical discussion above, and specific points developed in chapters 4, 5 and 6, can be used to develop potential interventions within clinics and the health system. I discuss efforts to foster more patient centred care, the integration of services and then effective ART and HIV care and ART.

These potential interventions are suggested cautiously. This caution follows the argument of Petticrew & Chalmers (2011) that one study is arguably the basis for further research rather than the basis for action. Others are more cautious on the utility of ethnographic findings in particular, suggesting that they are arguably more useful in qualifying policy judgements and modifying practice than directly judging efficiency and efficacy (Bloor, 2001). The suggestions for interventions I outline below are therefore made on the basis that further research should confirm the validity and generalisability of my original findings. Further grounds for caution is based on the analysis in chapter 6 of how the South African health system involves uncertainty and constant change. Interventions discussed below would risk becoming a further part of a problem of constant reform and so being undermined or ineffective. This caution in suggesting interventions is ultimately a recognition of the power of a researcher to make recommendations, which forms part of the global health and development discourse and a process of constructing problems, and assuming the power to act in the interests of others. It is difficult to step outside of this power relationship and discourse, except to accept that this study sits within it and so I make recommendations on the basis that broader reflection is necessary.

Supporting patient centred care in PHC

My study suggests that forms of patient centred care already exist and that there is already a trajectory of change towards more patient centred, integrated care in PHC clinics studied; correspondingly, this recognizes that current interventions and processes are having some impact and so should be continued. I consider this trajectory further below, but here it is worth recognizing the relative progress towards more patient centred care and how this has been potentially shaped by the introduction of ART and HIV care. Other elements of PHC reform also appear to have been important, including the expanded service provision

at the PHC level, the shifts in nurses' role to more independent practitioners and then the introduction of patient rights and batho pele principles. This is not to suggest precise causality, and more work is needed to understand the precise role – if any – of these broader changes I have reported. However, recognizing current progress and basing any future policy on this alongside the recognition of the dynamism of clinic contexts and how care is being shaped there is a basis for a specific policy approach: namely, that fundamental reforms are perhaps not needed, and that continued efforts to support nurses in providing the more patient centred care that many are already seeking may be an effective approach.

Any support provided to nurses needs to respond to how care is shaped at multiple levels. My study found that care routines were shaped by context, orders of interaction and nurses' agency, with an implication of this that interventions to foster more patient centred care should also consider these multiple levels of influence. In chapter 4 I argued that less patient centred care routines were determined by contextual factors of resource shortages, health systems policy and historical understandings of nurses; this is alongside particular understandings of nurses' role as a guardian and then nurses' agency in enacting that. Interventions to support more patient centred care should therefore seek action at all these levels. A multi-dimensional approach to responding to health services issues isn't necessarily novel. Responses to global health challenges and health systems challenges are often presented in terms of strategies that seek action at a range of levels. This call for broad ranging action to health system challenges is already reflected in existing policy statements from the South African government (Department of Health (SA), 2011a) and from global health stakeholders (WHO, 2007); even if not necessarily clearly translated in to action. As a consequence, any action in support of patient centred care should continue this multi-dimensional approach.

Following these principles, of recognizing existing progress and supporting this at multiple levels I consider here how interventions to support scheduling care could be addressed. As chapter 3 set out and I have discussed above, a key challenge within the clinics is in scheduling care and how care is focussed in the mornings, creating difficulties for nurses and patients. The routine of peaks in work and how this leads to unpredictable amounts of

work and the pressure to work fast could be replaced with routines that led to more predictable workloads. One suggestion has been the introduction of appointment systems (Church and Lewin, 2010, Bachmann and Barron, 1997), and these could take on a range of forms: allocating specific times in advance, allowing people to call/book appointments in advance, parallel systems of one nurse dealing with appointments while another nurse sees patients without appointments and emergencies. During the study I came across a few references to appointment systems: Ithata clinic actually introduced an appointment system immediately prior to my feedback visit, there are also other instances of this being introduced and having positive impacts (Ammari et al., 1991, Mahomed and Bachmann, 1998).

My analysis suggests specific considerations when trying to implement any new routine, such as for scheduling care. Contextual issues of workload and resource shortages are challenging: as well as creating the need for routines for scheduling care more effectively, they create a busy clinic environment in which a new routine would face considerable pressure. The orders of interaction would have to adapt to a new routine; that patients may have more control over the routines for scheduling care would disrupt established orders of interaction and power relations, potentially threatening nurses' privileged position within the clinics. Even if nurses accepted this, a process of establishing new rules of interaction and norms and understandings around a new routine would likely be disruptive and a lengthy process. A final consideration is to recognise the role of nurses' agency in allowing a new routine, and ensuring successful introduction. An initial point is that nurse reluctance to engage and adopt a new routine may reflect intransigence and efforts to maintain a particular position. However, as I have shown in discussing how nurses justified rushed and apparently poor care, there can be a clear logic for this too (a point I return to in the next section); correspondingly, the unanticipated challenges of adopting apparently beneficial systems may only become clear through engaging closely with nurses responses. In summary, the implications of my analysis are that new routines are potentially possible, but would be challenging to introduce and require a range of actions in support of them.

The possibilities for integrated PHC

My study found there were limits to service integration within the clinics, and that this reflected a range of factors. In considering these I question both the desirability and the possibility of further service integration.

Nurses' accounts of integration threatening the continuity of relationships with patients and quality of care suggest further integration may not be desirable. In my analysis I established other factors involved in this reluctance from nurses to integrate services, yet these accounts still do give valid insight in to gaps in the logic of integration. In a context where there are few formal systems for scheduling care, trying to establish full service integration where all nurses can see all patients for any health issue would complicate efforts to maintain the continuity of relationships between nurses and patients. Nurses reported patients 'choose' nurses in the clinics, but this tended to involve informal processes of patients manipulating the queue in the waiting area rather than a formal system. In this context, having services allocated to individual nurses does allow nurses and patients to develop relationships that can then support positive care outcomes (see also Uebel et al, in preparation) (a reverse is of course also true, bad relationships could also be continued). In addition, maintaining the allocation of nurses to a specific service can be linked to aspects of care having higher quality (see also Uebel et al, in preparation). The specialisation inherent in task oriented approaches has been justified for how it is a strategy to develop providers' skills (Church and Lewin, 2010; Van Der Walt and Swartz, 2002) and specialisation more generally has been linked to high quality care (Dudley and Garner, 2011). My insights from chapter 4 therefore offer reasons for not seeking further integration at the level of the consultation.

My analysis also suggests that further integration at the consultation level may not even be possible, even if desirable. In chapter 4 I suggested that nurses' passion for a service and concerns over workload reflect an underlying concern for the complexity of care. I also demonstrated in chapter 4 that PHC in a South African context, and potentially any context, can be complex. The range of services and the logic of PHC being the first line of care and point of referral within a health system means that patients can present at a PHC with a vast range of health issues. Other accounts of limited integration have called for training as

a solution (Mall et al., 2012). Nurses did reference the need for more training and this could potentially support a further level of integration. The absence of managerial support that I highlighted in chapter 5 could, if reversed, also mitigate nurses' low confidence around integrating services. However, an overall picture of complexity suggests that further integration may not be possible.

A conclusion from this discussion is to support more specialised forms of care. This is a conclusion reached with colleagues in Uebel et al on the grounds of supporting expertise and patient relationships (Uebel et al, in preparation) and which I raised in Guise et al (2012), on the basis that specialisation can be seen as allowing relationships to be maintained. An argument for specialised ART and HIV care is perhaps even more pertinent considering the concerns about complexity raised by nurses around that. Previous analysis has sought nuanced approaches to integration, seeing it as not necessarily about one provider addressing all issues in a consultation but ensuring a mechanism exists to coordinate care to ensure all services needed are provided (Mitchell et al., 2004). Building on this nuanced approach to integration, and a recognition of the potential for specialisation in Uebel et al, I suggest that a more coherent approach to integration in the context of South African PHC that my study supports would be to allow nurses to specialise, and then to focus attention on having effective referrals within clinics. Currently referrals within a clinic would likely involve patients waiting for a considerable period of time to see a second nurse, and potentially having to return to a clinic on a different day. This links back to the calls above for attention to better scheduling of care; if effective and equitable routines for referring patients across a clinic and scheduling care could be established then more specialised care could be introduced.

ART and HIV care and health systems strengthening

My study suggests that the role of ART and HIV care in supporting more patient centred care may rely on the catalytic role of other past interventions, giving a new perspective on approaches to health systems strengthening. My discussion in chapter 6 linked the introduction of ART and HIV care to more patient centred care. I also demonstrated that ART and HIV care are continuous with longer standing processes of reform. A hypothesis that emerges from this is that previous reforms may be providing a catalytic role or a

foundation for ART and HIV care to then support more patient centred care. For example, previous PHC reforms may have facilitated continued integration of HIV care, reforms to nurses' role may have better prepared them for responsibility to initiate ART and previous reforms to embed and respect patients' rights may have fostered a sensitivity and appreciation for the individual patient. The evidence of continuity between these reforms doesn't of course necessarily imply causal links. However, highlighting the potential relationship between past and ongoing reforms is an interesting area for enquiry. Existing debates focus on the potential for diagonal health systems strengthening (Ooms et al., 2008), that focuses on how ART and HIV care can be used to leverage broader benefits across a health system; this debate is itself a synthesis of the often heated debate on the role of vertical and horizontal approaches to delivering health care and how they can support or undermine a health system. My findings suggest that the success of a diagonal approach may rely on initial conditions in order to enable change. Exploring this role of other reforms in catalysing the role of ART and HIV care in strengthening health systems would be a useful focus for future research. An initial basis for this could be comparative research; with efforts to understand the sequencing and then potential links between different interventions. For example, countries without explicit legislation to support patients' rights could be explored as a focus for comparison with South Africa. The implication of this could then be that diagonal approaches to health systems strengthening may not succeed in some settings owing to the absence of initial conditions, and that a more broad based approach to health systems strengthening may be required.

Support for nurses living with HIV

My study supports the need for attention to nurses own experiences of HIV, including living with HIV, and how that impacts on their work. I have shown how nurses face pressures and strains in managing the different discourses of HIV, the biomedical and the community, in which they are situated. I have also demonstrated the particular challenges facing nurses living with HIV. Nurses own reports of the challenges of stigma facing colleagues, and then my methodological lesson from not being able to interview any nurses living with HIV suggest that nurses have a problematic position in relation to HIV, despite any claims from nurses of HIV and ART being normal. Understanding this issue more and responding to it is a priority for health policy for several overlapping reasons: firstly, for nurses own welfare, the understandings of HIV and stigma raised in chapter 4 and how these are changing

rather than diminishing could potentially act to limit nurses in accessing necessary HIV treatment, prevention and care; secondly, in the context of health worker shortages, the loss of nurses through illness or death linked to HIV undermines health system capacity to respond to HIV and other PHC issues (see chapter 1), and thirdly, the combination of experience of living with HIV and taking ART with the professional role of a nurse could be a valuable source of insight in to how to ensure health services in these contexts best meet the needs of patients. In accepting this as a priority for action and research in support of nurses, this study has also given insight in to how this research can be approached. The experience discussed in chapter 2 of not being able to interview nurses living with HIV suggests that either alternative approaches be considered, such as framing research as specifically focussing on nurses living with HIV rather than trying to nest the issue within a broader study, or that researchers with a different institutional background and/or social position and identity attempt the same approaches as I described above.

7.3 Critical reflections

In this final section I critically reflect on the overall conduct and contribution of the study and draw general lessons that can inform future research. Throughout the study I have sought to critically reflect on my methodology and the results of my analysis, and highlighted specific gaps and limitations in the process. My discussion in section 7.2 has also outlined specific theoretical and policy contributions and how they can be the basis for future policy and research. In this section I consider more general lessons from the study that can also inform future enquiry.

An initial lesson from my study is that research in busy clinic environments should allow for the lack of control of the researcher. In chapter 2 I reflected on the methods followed and how my initial plans for repeated interviews, and to even gain initial interviews, were often limited. This lack of control reflects a number of factors: firstly, the nature of nurses' work and how it can constantly vary; secondly, that I assumed a high level of engagement from nurses and their willingness to commit their work time to the study; and thirdly, a possible influence of my identity as white, male and a non-nurse, or at least how I responded to that identity within the clinics in trying not to be assertive and demanding. I was still able to gain insight in to a range of clinic processes that other methodologies – such as in-depth

interviews alone, or surveys – would not have. The data on scheduling care is one example. However, future research could allow more for the lack of control over data generation and how this can be optimised within busy PHC clinics. One approach could be to engage nurses and other health workers in ways that are more responsive to their often varying schedule; distributing voice or video recorders for health workers to use in their own time in response to general questions may be one approach. A second approach would be to extend my own efforts to ‘work’ within the clinics, and take on a more formal position. I found helping with administrative duties a way to present myself as willing to help, and of recognising the challenges nurses faced. Adopting a role in a more formal way may provide more avenues to engage with nurses, as distinct from the observer asking questions. This would however be challenging in terms of potentially undermining other staff and/or even threatening the viability of paid positions within a clinic. Research approaches that recognise and allow for a researcher’s lack of control would be one way of developing the methodology I used.

The challenges of implementing the study and developing relationships with the nurses would also support the idea for future research of working with local fieldworkers to assist in implementation. A local fieldworker who spoke Sotho and Afrikaans would support the development of stronger relationships with nurses, clinic staff and patients, overcoming any language differences which would support a more rapid acceptance of non-local researchers in the clinics. The linguistic and cultural grounding from being a member of the local community would also allow a fieldworker to support the process of accessing the meanings and interpretations of the people I was studying. A particular consideration would be to work with a current or former nurse who also spoke local languages, so allowing me further insight in to the cultural and profession specific meanings of the nurses and people in the clinics. This ‘insider-outsider’ research team (Thomas et al., 2000) would bring more perspectives to the research (ibid) and so ultimately potentially allow more in-depth insight in to the phenomena under question. Efforts to team with local fieldworkers would however raise financial and logistical considerations, which this study was not able to address, but with proper support could be overcome.

In-depth observational study in LMIC care settings is valuable, and should engage more with specific nursing research and theory. A primary strength of this study is the focus on nursing care in PHC settings in a LMIC setting; and in isolated, rural settings in particular. As my earlier discussions highlighted, this field is relatively neglected, despite these settings and cadres of health worker providing a majority of care. Although ethnographic methodologies are valued in health services research (Kielmann, 2012) and there are calls for greater support for them in addressing global health debates (Sridhar and Craig, 2011), they arguably occupy a peripheral status. My study has added to this literature, and with a particular approach. I approached this study of PHC nursing in a LMIC setting as a sociologist, with background in development studies and general social theory. My perspective was therefore one of bringing my insight from theory as it relates to LMIC settings. Although my conclusions are valid and add to the relevant field, a greater engagement with nursing focussed research is a clear opportunity. Future research could therefore seek to align literature as it relates to the specific contexts of care in LMICs and to the nursing profession.

A direction for future analysis would be to engage further with the network of relationships across the clinics, rather than the principal focus on nurses I took in this study. There are two ways in which this could be strengthened: 1) provide greater, or equal, attention on patients' perspectives, and then also 2) explore the clinic as forming a network of relations with dynamic interactions across them. I explore each of these in turn.

The focus of this study on exploring the idea of patient centred care would logically imply engaging with patient views of care; the limited extent to which I engaged with these perspectives in my study largely resulted from logistical constraints. However, more in-depth insight from this perspective would increase the validity of my findings around the impacts of care routines on patient care. The focus this study developed on patient agency and the relational nature of agency between nurses and patients is another reason to develop this focus. An equivalent approach to what I adopted with nurses would likely be appropriate, of in-depth semi-structured interviews. A constraining factor on the interviews I conducted with patients was holding them in the clinics; this created potential for nurses to interrupt interviews, and also meant patients were not necessarily being interviewed in

a site where they felt comfortable and empowered, with corresponding impacts on their willingness to talk at length about problems in the clinic. A solution would be to explore hosting interviews away from the clinic, which would also facilitate greater efforts to explore the links with the community, a point I raise below.

Future research could engage with more dimensions of this network of relations, for example, exploring relations between patients and other clinic staff, or clinic staff and nurses. A further step would be to look beyond binary relationships, and consider the broader dynamism of these interactions; for example, how clinic cleaners mediate between nurses and patients (as with Esther in Ba Banyane clinic, who played a pivotal role at times in scheduling care). Analysis of this network of relationships could also engage further with the specific community contexts of the clinics. My analysis sought to link clinic routines to broader social phenomena, including community focussed experiences of HIV. Greater efforts to understand the clinic-community links and the specific context and history of each clinic would have added depth to these areas of my analysis. This would have involved considerable challenges: although I was able and willing to move around township settings to get to clinics independently, by car and by foot, extensive research in these settings would have been logistically difficult and also vastly time-consuming. In addition, understandings of a clinic's community are not simple: that patients travel over 80km to get to Dula clinic highlight the challenge of putting a boundary around this focus for analysis. However, contextualising the specific routines of a clinic and the network of relationships there would provide richer analysis.

7.4 Conclusions

This study has provided detailed insight in to the organisation and delivery of PHC nursing, in the context of a global health priority to rapidly make ART and HIV care more widely available. The specific contributions of this study are to have shown how patient centred care is evident within South African PHC and ART and HIV care, even if this is limited. The study provides insight to processes of structure and agency and how they operate at a clinic level, thereby providing a theoretical approach for further clinic level research. These theoretical conclusions have then been the basis for considering policy level implications,

and how patient centred care can be supported through interventions to foster certain combinations of clinic orders, context and agency.

This study adds to a growing literature on PHC organisation and delivery by nurses in LMIC settings, in the context of the scale-up of ART and HIV care. The detailed insight it offers in to clinic level organisation and delivery of care, and the social processes involved in this, are an important basis for policy development and future research in this area.

Appendices

STRETCH

The STRETCH programme – Streamlining Tasks and Roles to Expand Treatment and Care for HIV – builds on the PALS PLUS programme. STRETCH is a complex health intervention decentralizing HIV care, including monitoring of stable clients and initiation of antiretroviral treatment in selected cases, to primary care nurse practitioners in the Free State province, South Africa. STRETCH combines educational outreach training to nurses with system-level changes including revising the professional roles of health workers, establishing multidisciplinary support teams for facilities and promoting integrated care for clients with HIV and TB.

The STRETCH trial includes an adapted version of the PALS PLUS guideline, with specific guidance on the nurse initiation of ART.

Information on both programmes is available from:

<http://www.knowledgetranslation.uct.ac.za>

Appendix 2 – Clinic information sheets

When initially visiting clinics to gain initial permission to try and observe and conduct interviews I would distribute general information on the study and myself, with an example below.

London School of Hygiene & Tropical Medicine
(University of London)

Keppel Street, London WC1E 7HT
Tel: 020 7636 8636 Fax: 020 7436 5389 Web site://www.lshtm.ac.uk



improving health worldwide

Research study: The impact of ART and task shifting on Nursing Care in the Free State

Thankyou for showing interest in this study.

The focus of the research:
The research is trying understand if the antiretroviral treatment (ART) for HIV programme is changing care within clinics. The introduction of ART has led to a change in the work of some nurses within the clinic. The study aims to understand if this is causing other changes in how nurses provide care. The study aims to talk to both nurses working on ART and those not.

I would like you to participate in the study. Your opinions on care in the clinic will allow a greater understanding of the care that is being provided.

I have already spent five months working in several clinics across the Free State; talking to nurses and patients and observing how the clinics work.

Reasons for doing the study in the Free State:
1 Support the ART programme and primary health care in the Free State – the study aims to increase our understanding of what needs to be done and identify any changes needed.
2 The STRETCH trial is the only large scale trial globally of nurses providing ART – the experience of clinics involved in the trial will have important lessons for elsewhere in Sub-Saharan Africa.

This is not an evaluation of your clinic or your work. The study will be used to learn general lessons about nursing care and the ART programme across the Free State. The study is being done for my PhD research.

What the research involves:
You do not have to participate in the study. It is entirely voluntary.

If you choose to be involved I would visit the clinic at a time convenient for you. I have spent several months in clinics across the Free State and know about the conditions in which nurses work and the demands on nurses time. Following this, I know that it can be difficult to find time for an interview in addition to your normal workload. As such, I am completely flexible in arranging a time and day for interviews.

If you were available for an interview it would last between thirty minutes and an hour. Interviews will take place in a private room within the clinic. During this interview a series of questions will explore your opinions on your work, how care is provided within the clinic and what may influence this.

The researcher will ensure that all data is kept private and confidential. This will ensure that anything you say cannot be linked to you in the future.

If you have any questions at all about the study please do not hesitate to contact me.

Thankyou

Andy – 073 291 4889, andy.guise@lshtm.ac.uk

Andy Guise, London School of Hygiene and Tropical Medicine, London, UK

Appendix 3 – Study ethics procedures and documents

The study was given ethical approval by the London School of Hygiene and Tropical Medicine (LSHTM), the University of Cape Town (UCT) and the University of the Free State (UFS). Initial ethical approval from all three institutions in 2009 was followed by further approval in 2010 for minor changes to the study to explore findings in additional clinics.

Ethical approval from LSHTM – February 2009

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE		
ETHICS COMMITTEE		
APPROVAL FORM		
Application number:	5447	
Name of Principal Investigator	Andy Guise	
Department	Public Health and Policy	
Head of Department	Professor Anne Mills	
Title:	An exploration of nurses' accounts of change in the organisation and delivery of nursing care in primary health care in the context of the introduction of ART and task shifting in Free State province South Africa	
This application is approved by the Committee.		
Chair of the Ethics Committee	<i>T. W. Meade</i>
Date	16 February 2009
Approval is dependent on local ethical approval having been received.		
Any subsequent changes to the application must be submitted to the Committee via an E2 amendment form.		

Ethical approval from LSHTM – April 2010

LONDON SCHOOL OF HYGIENE
& TROPICAL MEDICINE

ETHICS COMMITTEE



APPROVAL FORM

Application number: A151 5447

Name of Principal Investigator Andy Guise

Department Public Health and Policy

Head of Department Professor Anne Mills

Title: An exploration of nurses' accounts of change in the organisation and delivery of nursing care in primary health care in the context of the introduction of ART and task shifting in Free State province South Africa

Amendments to this application have been approved by the Ethics Committee.

Chair of the Committee *T. W. Meade*

Date 16 April 2010

Approval is dependent on local ethical approval having been received.

Any subsequent changes to the application must be re-submitted to the Committee.



UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Research Ethics Committee
Room E52-24 Grootte Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: lamccs.ernjedi@uct.ac.za

04 March 2009

REC REF: 460/2008

Mr Andy Guise
London School Of Hygiene & Tropical Medicine
Public Health & Policy
Keppel Street
London

Dear Mr Guise

PROJECT TITLE: AN EXPLORATION OF HOW NURSING PRACTICE IS CHANGING IN PRIMARY HEALTH CARE IN RESPONSE TO THE ART PROGRAMME AND TASK SHIFTING IN FREE STATE PROVINCE, SOUTH AFRICA.

Thank you for submitting your study to the Research Ethics Committee for review.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study including the following documentation:

Approval is granted for one year till the 15th March 2010.

Please send us an annual progress report if your research continues beyond the approval period. Alternatively, please send us a brief summary of your findings so that we can close the research file.

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

Please quote the REC. REF in all your correspondence.

ernjedi

Yours sincerely

M. Blockman

PROFESSOR M. BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulations Part 50, 56 and 312.

temjedi

Form FHS006: Protocol amendment

Instructions

<ul style="list-style-type: none"> Forms to be downloaded from the Administrative Forms web page at http://web.uct.ac.za/depts/sapweb/forms/forms.htm All changes to the approved protocol must be reviewed and approved by the Human Research Ethics Committee (HREC) before implementation. See: Preparing an Amendment - Pointers for Researchers on the Administrative Forms web page.
<p>Submit Amendment and supporting documentation to:</p> <p>Mrs Lamees Emjed, Research Ethics Committee E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory Telephone: 27 21 406 6336 Fax: 27 21 406 6411 Email: Ncw11ywb@uct.ac.za</p>

1. Protocol information

REC REF Number	460/2008		
Title	An exploration of change in the organisation and delivery of nursing care in primary health care, in the context of the ART programme and task shifting in Free State province, South Africa.		
Principal Investigator	Andy Guise		
1.1 Does this protocol receive US Federal funding?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No	
1.2 Is this a major or a minor amendment (see FHS006hp)?	<input type="checkbox"/> Major	<input checked="" type="checkbox"/> Minor	

2. Protocol status (tick ✓)

<input checked="" type="checkbox"/>	Open to enrolment
<input type="checkbox"/>	No participants have been enrolled
<input type="checkbox"/>	Closed to enrolment (tick ✓)
<input type="checkbox"/>	Research-related activities are ongoing
<input type="checkbox"/>	Research-related activities are complete, long-term follow-up only
<input type="checkbox"/>	Research-related activities are complete, data analysis only

3. Proposed changes will affect: (tick ✓ all the categories that apply)

	Protocol
<input checked="" type="checkbox"/>	Study objectives, design (including investigator's brochure, clinical advice, study length)
<input type="checkbox"/>	Study instruments, questionnaires, interview schedules
<input checked="" type="checkbox"/>	Sample size
<input type="checkbox"/>	Recruitment methods

<input type="checkbox"/>	Eligibility criteria (inclusion and exclusion criteria)
<input type="checkbox"/>	Drug/device (composition, amount, schedule, route of administration, combination with other drugs/therapies, safety information)
<input type="checkbox"/>	Data collection/analysis
<input type="checkbox"/>	Principal Investigator. (Please attach revised conflict of interest and PI disclosure statements. Refer: sections 7 and 8.4 in the New Protocol Application Form)
<input checked="" type="checkbox"/>	Consent form and information sheet
<input type="checkbox"/>	Recruitment materials (e.g. advertisements)
<input type="checkbox"/>	Administrative (e.g. change in sponsor's name, change in contact information)
<input type="checkbox"/>	Other. Please specify:

In your opinion, will there be any increase in risk, discomfort or inconvenience to participants? If yes, please provide a detailed justification/explanation.	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

3.1 What follow-up action do you propose for participants who are already enrolled in the study?

<input type="checkbox"/>	Inform current participants as soon as possible
<input type="checkbox"/>	Re-consent current participants with revised consent/assent forms (append)
<input checked="" type="checkbox"/>	No action required
<input type="checkbox"/>	Other. Please describe:

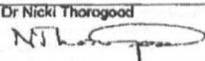
4. Detailed description of the change(s)

Please attach, for each amendment, a summary of all changes which clearly indicates:

- I. Old wording (e.g. underlined) and CHANGED FROM and CHANGED TO)
- II. New wording (e.g. italicized, bold, bracketed)
- III. Detailed rationale/justification/ explanation for each change

5. Documents for approval

Please itemise on the following page all amendments, with revised version numbers and dates, which need approval. This page will be detached, signed and returned to the PI as confirmation of approval. Please omit extra pages if necessary.

Signature of PI	Andy Guise	Date	15 / 3 / 2010
Signature of Supervisor (if PI is a student)	Dr Nicki Thorogood 	Date	15 / 3 / 2010

Amendment Form

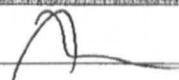
REC REF Number	480/2008
Title	An exploration of change in the organisation and delivery of nursing care in primary health care, in the context of the ART programme and task shifting in Free State province, South Africa.
Principal Investigator	Andy Guise

List of Proposed Amendments with Revised Version Numbers and Dates

Document: Updated protocol – Andy Guise - March 2010
 Amendment 1: see p8, amendment to clinic sample (also summarized in table form on p11).
 -The original protocol stated three clinics would be sampled for the study. This was increased to four before starting the fieldwork. This decision was based on discussions with staff in the Free State Dept of Health around the variation amongst clinics. Four clinics allowed a better basis for initial comparison. I hadn't considered that approval would be needed for this addition of a clinic and so hadn't previously raised this with the committee (please see covering letter).
 - A proposed amendment for the final round of interviews is to increase the overall clinic sample from 4 to 12. This increase will allow the study to explore emerging themes in greater depth and increase the strength and generalisability of the study conclusions.

Amendment 2: see p12, amendment to the study timetable (also summarized in table form on p20 and reflected in table on p11 also).
 -The study originally planned to have two periods of data collection. This has been increased to three separate periods. The number of interviews of days spent observing clinics hasn't been affected. This further separation of the data collection periods allowed further reflection on collected data and emerging themes and so increasing the quality of the final round of interviews. As with the original increase in the number of clinics I hadn't considered that approval would be needed for such a change.

Document: Study information sheet – Andy Guise – March 2010
 Amendment 1: A reference to future interviews has been deleted as interviews conducted in any new clinics included will not be repeated.

HREC office use only (FWA00001837; IRB00001938)			
<input checked="" type="checkbox"/> Approved	<input checked="" type="checkbox"/> Type of review: Expedited	<input type="checkbox"/> Full committee	
This serves as notification that all changes and documentation described above are approved.			
Signature Chairperson of the HREC		Date	17/3/2010

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA



Direkteur: Fakulteitsadministrasie / Director: Faculty Administration
Fakulteit Gesondheidswetenskappe / Faculty of Health Sciences

Research Division
Internal Post Box G40
☎ (051) 4082812
Fax nr: (051) 4444355

E-mail address: gndkhs.md@mail.uofo.ac.za

Ms H Strauss

2009-04-18

MR A GUISE
DEPT OF PUBLIC HEALTH AND POLICY
PUBLIC AND ENVIRONMENTAL HEALTH RESEARCH UNIT
LONDON SCHOOL OF HYGIENE AND TROPICAL MEDICINE
UNIVERSITY OF LONDON
KEPPEL STREET
LONDON WC1E 7HT

Dear Mr Guise

ETOVS NR 02/09

MR AG GUISE DEPT OF PUBLIC HEALTH AND POLICY, LONDON SCHOOL OF
HYGIENE AND TROPICAL MEDICINE, LONDON, UK
PROJECT TITLE: AN EXPLORATION OF CHANGE IN THE ORGANISATION AND
DELIVERY OF NURSING CARE IN PRIMARY HEALTH CARE IN RELATION TO THE
INTRODUCTION OF ART AND TASK SHIFTING IN FREE STATE PROVINCE, SOUTH
AFRICA.

- You are hereby kindly informed that the Ethics Committee approved the above study at the meeting held on 14 April 2009.
- Committee guidance documents: Declaration of Helsinki, ICH, GCP and MRC Guidelines on Bio Medical Research, Clinical Trial Guidelines 2000 Department of Health RSA, Ethics in Health Research: Principles Structure and Processes Department of Health RSA 2004, Dept of Health: Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa, Second Edition 2006, the Constitution of the Ethics Committee of the Faculty of Health Sciences and the Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines
- Any amendment, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.
- The Committee must be informed of any serious adverse event and/or termination of the study.
- A progress report should be submitted within one year of approval of long term studies and a final report at completion of both short term and long term studies.
- Kindly refer to the ETOVS reference number in correspondence to the Ethics Committee Secretariat.

Yours faithfully



Y. Botma
PROF Y BOTMA
ACTING CHAIR: ETHICS COMMITTEE

339, Bloemfontein 9300, RSA ☎ (051) 405 2012
Republiek van Suid-Afrika / Republic of South Africa

gndkhs.md@ufs.ac.za

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
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Fakulteit Gesondheidswetenskappe / Faculty of Health Sciences

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Fax nr (051) 4444359

E-mail address: StrauseHS.md@ufs.ac.za

Ms H Strauss

2010-03-17

MR A GUISE
DEPT OF PUBLIC HEALTH AND POLICY
PUBLIC AND ENVIRONMENTAL HEALTH RESEARCH UNIT
LONDON SCHOOL OF HYGIENE AND TROPICAL MEDICINE
UNIVERSITY OF LONDON
KEPPEL STREET
LONDON WC1E 7HT

Dear Mr Guise

ETOVs NR 02/09
MR AG GUISE DEPT OF PUBLIC HEALTH AND POLICY, LONDON SCHOOL OF HYGIENE
AND TROPICAL MEDICINE, LONDON, UK
PROJECT TITLE: AN EXPLORATION OF CHANGE IN THE ORGANISATION AND DELIVERY
OF NURSING CARE IN PRIMARY HEALTH CARE IN RELATION TO THE INTRODUCTION OF ART
AND TASK SHIFTING IN FREE STATE PROVINCE, SOUTH AFRICA.

- You are hereby kindly informed that the Ethics Committee provisionally approved the changes to the above study and it will be condoned at the meeting scheduled for 13 April 2010.
- Committee guidance documents: Declaration of Helsinki, ICH, GCP and MRC Guidelines on Bio Medical Research. Clinical Trial Guidelines 2000 Department of Health RSA, Ethics in Health Research: Principles Structure and Processes Department of Health RSA 2004, Dept of Health: Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa, Second Edition 2006; the Constitution of the Ethics Committee of the Faculty of Health Sciences and the Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines.
- Any amendment, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.
- The Committee must be informed of any serious adverse event and/or termination of the study.
- A progress report should be submitted within one year of approval of long term studies and a final report at completion of both short term and long term studies.



- Kindly refer to the ETOVS reference number in correspondence to the Ethics Committee Secretariat.

Yours faithfully



CHAIR: ETHICS COMMITTEE

Information sheet given to nurses, clinic staff and patients for consent for interviews

This was also available in Afrikaans and Sotho.

Study information sheet

Study title: An exploration of accounts of change in the organisation and delivery of nursing care in primary health care in the context of the introduction of ART and task shifting in Free State province, South Africa.

Study investigator: Andy Guise

Contact details: 083 431 9503; Aloe ridge B&B, 93 Paul Roux street, Dan Pienaar, Bloemfontein.

andy.guise@lshtm.ac.uk

This information sheet is yours to keep. This is in case you need to refer to it in the future.

The objective of this research is to understand if the antiretroviral treatment (ART) for HIV programme is changing care within clinics. The introduction of ART has led to a change in the work of some nurses within the clinic. The study aims to understand if this is causing other changes in how nurses provide care to clinic clients. The research is listening to the views of nurses, other staff and clients in the clinic through interviews and focus groups and observing the public areas of the clinic. The same research in this clinic is being repeated in other clinics within the Free State province. Through comparing the experiences of the clinics the research will increase our understanding of the ART programme.

We would like you to participate in the study. Your opinions on care in the clinic will allow a greater understanding of the care that is being provided.

You do not have to participate in the study. Taking part in the research is entirely voluntary and withdrawal possible at any time without having to give a reason.

If you choose to take part in the study you will be asked to undertake a short interview with a researcher:

- The interview will last between thirty minutes and an hour.
- Interviews will take place in a private room within the clinic. No one else but the researcher will be able to hear what you say.
- The interview will take place during normal clinic opening hours.
- If you would prefer a different time or location of your choosing for the interview this can be arranged.
- During this interview a series of questions will explore your opinions on how care is provided within the clinic and what may influence this. The researcher may ask to do a second interview in six months time.

If you give permission interviews will be audio-recorded. This allows the researcher to make a complete transcript of the interview. If you take part in a second interview you will be given a copy of the transcript from the first interview.

The researcher will ensure that all data is kept private and confidential. This will ensure that anything you say cannot be linked to you in the future.

- The transcript of your interview will be given an anonymous reference number. Your name will not appear on the transcript. The list of study participants and reference numbers will be kept secure and only the researcher will have access to it.
- Following transcription of the recording of the interview the recording will be destroyed.
- The name of the clinic, all staff and all clinic clients who are involved in the research will not be included in any reports or articles that are written using the data collected.
- Anything you say would only be quoted in a report or article if you give consent for this. You would only be quoted anonymously. If you are concerned anything you say could be identified by others, you can choose not to be quoted at all.

Any data gained through interviews or clinic observation may be used in a final report of the study. This will be included in a journal that will be available to Universities globally.

You will not have to pay anything to participate in the research. You are unlikely to experience any harm as a result of this research. All steps listed above will be taken to protect privacy and confidentiality. If you choose not to participate or withdraw at any time this will not affect your care or work in the clinic. The interview may include discussing issues around healthcare, HIV and HIV treatment. Some people may find discussing these issues distressing. You can choose not to answer any questions asked and end your participation in the study at any time.

You will not directly benefit from taking part in the research. However, we understand that the research may have caused you some inconvenience and the researcher will give you 20 Rands to cover any additional transport costs you have incurred today.

This research has been formally approved by the Ethics committees of the Faculty of Health Sciences at the University of Cape Town (ref: 460/2008; tel: 021 406 6638), the University of the Free State, Bloemfontein (ref: ETOVS 20/09; tel: 051 405 2812) in South Africa and the London School of Hygiene and Tropical Medicine, London, UK (ref: 5447; tel: +44 207 636 8636).

If you would like more information on the research study please ask the researcher, Andy Guise.

Thesis supervisors: Dr Nicki Thorogood nicki.thorogood@lshtm.ac.uk, +44 207 636 8636, Dr Simon Lewin simon.lewin@kumskapscenteret.no

This study is for a PhD at the London School of Hygiene and Tropical Medicine, London, UK.

Consent forms

Below is an example of a consent form, which was also available in Sotho and Afrikaans.

Study Consent form

Study title: An exploration of accounts of change in the organisation and delivery of nursing care in primary health care in the context of the introduction of ART and task shifting in Free State province, South Africa.

Study investigator: Andy Guise

Contact details: 073 291 4889; Aloe ridge B&B, 93 Paul Roux street, Dan Pienaar, Bloemfontein, andy.guise@fshtm.ac.uk

I agree to participate in a research project that is exploring possible changes in nursing care in primary health care clinics following the introduction of antiretroviral treatment (ART) for HIV in Free State province, South Africa.

I have read the information sheet concerning this study and I understand what will be required of me and what will happen to me if I take part in it.

I will participate in the study under the following conditions:

- 1 I will allow interviews to be audio-recorded. I understand that these will be recorded so that nothing is missed and so that my words are not changed or misunderstood.
- 2 I understand that I can turn off the recorder at any time during the study and that I can refuse to answer any specific question posed by the researcher.
- 3 I agree to allow the researcher to use the information gained by my participation in the research in reports and research publications, but understand that my privacy and confidentiality will be protected and that my name will not appear in any report on the study.

I agree to be quoted anonymously in the final study report
(mark the box if this applies)

4 I understand that at any time I may withdraw from this study without giving a reason and without affecting my normal care or work within the clinic.

My questions concerning this study have been answered by

I agree to take part in this study.

..... Date

(NAME IN BLOCK LETTERS) SIGNATURE

As the researcher for this study I confirm that I have explained to the participant named above, the nature and purpose of the study being undertaken.

..... Date

(NAME IN BLOCK LETTERS) SIGNATURE

3 Public notices

I would put a public notice, adapted from the version below, in public areas of the clinic, with Sotho and Afrikaans versions alongside it.

PUBLIC NOTICE OF RESEARCH STUDY

[Insert name of clinic] is involved in a research project. The study is trying to understand if the introduction of the ART programme has changed care within our clinic. The introduction of ART has led to a change in the work of some nurses within the clinic. The study aims to understand if this is causing other changes in how nurses provide care to clinic clients.

In the clinic you may see a researcher. He will be wearing a name badge identifying himself as 'Andy'. You can also ask the clinic staff to help you identify him. He will be in the clinic for a total of four weeks, starting from *[insert date]* to *[insert date]*. He will also return again in *[insert dates]*. He will be interviewing the nurses providing care as well as other clinic staff and clients. He will also be observing the public areas of the clinic.

If you would like more information or are interested in participating in the research please ask the researcher, clinic manager or a member of the nursing staff. Information sheets that explain the study in more detail are available in the clinic.

This research has been formally approved by the Ethics committees of the Faculty of Health Sciences at the University of Cape Town (ref: 460/2008; tel: 021 406 6638), the University of the Free State, Bloemfontein (ref: ETOVS 20/09; tel: 051 405 2812) in South Africa and the London School of Hygiene and Tropical Medicine, London, UK (ref: 5447; tel: +44 207 636 8636).

Letter to be given to NLHIV by contacts

London School of Hygiene & Tropical Medicine
(University of London)

Keppel Street, London WC1E 7HT
Tel: 020 7613 8030 Fax: 020 7430 9390 Web site: www.lshtm.ac.uk



Improving health worldwide

Thankyou for showing interest in this study.

I am a researcher from the UK. I am in the Free State province doing research to understand the impact of the ART programme on nursing care and nurses.

The study is based in clinics within the Free State. I will be talking to nurses and clinic clients in these clinics to understand how care is provided and what is influencing this.

An important issue that is not at all understood is how being HIV positive influences how nurses work. I would like to talk with nurses living with HIV from across the Free State to try and understand this. Understanding these experiences will hopefully lead to improved support for nurses across the Free State and South Africa.

To make sure I can try and include these important experiences in the study I am asking people I know working in the Free State to introduce my research to any nurses who they know are living with HIV. My colleague who gave you this has not told me who they will talk to. I would only find out who you are if you were to contact me.

I would be interested to talk with you to hear how living with HIV influences your work as a nurse. If you were interested in being involved in the research, you can contact me on my cell phone (073 291 4889). You can either phone me, or send an SMS and I can call back. I can then answer any questions you have and explain more about the study.

We could then arrange to talk at a day, time and place convenient for you – this could be in your home, in a restaurant, or anywhere else that is convenient for you. I am in the Free State until the middle of December. I would be available at anytime until then.

If we were to talk, anything you say, including your identity would remain secret. I would not tell anyone I had spoken to you. I would use the information anonymously so that anyone reading my research report would not know who had spoken to me. The study has ethical approval from the University of the Free State, the University of Cape Town and the London School of Hygiene and Tropical Medicine in the UK (my home institution – I am from the UK).

If you are interested in participating or have any questions at all please contact me at any time.

Many thanks,

Andy Cruise

Appendix 4 - Data extracts

I present here data extracts from across the four focus clinics to illustrate the detail of the data I generate. For each extract I remark on how it can be seen as representative of the rest of the data.

Interview data

Sister Terene, Aangekom clinic

This interview was from the first phase and gives an insight in to how I often started an interview, with a general question to ask nurses to tell me about their work, and then we would explore issues they had raised.

- I: **okay, so that'll pick up, so we don't need to, it's quite sensitive, so it'll pick up everything you say. Erm So just to start, erm can you tell me about your work in the clinic, what you do**
- R: **er, I'm a clinic manager in this clinic, I do everything [laughs] because I do managerial work which is 30% and I do a er 70% technical work, you know**
- I: **so when**
- R: **which means I'm 70% hands on**
- I: **okay**
- R: **and 30% I do the administration**
- I: **so when you say, you said technical, that means ...**
- R: **I'm hands on**
- I: **in the clinic**
- R: **I'm dealing with the patients**
- I: **dealing with the patients**
- R: **ja**
- I: **okay, okay – and what do you see all patients, do you do all areas of work in the clinic**
- R: **ja, I'm doing everything**
- I: **right**
- R: **at work. I do minor ailments, that's curative, because now this is a primary health setting**

- I: ja
- R: so we see all the patient, that's the first contact with our patients, yes. So I do the curatives, we do ante-natal clinic
- I: **baby day**
- R: (laughs) yes, and do integrated management of childhood illnesses and I do extended programme of er immunizations
- I: **right, okay**
- R: er I also did, do TB
- I: **yeh**
- R: tuberculosis, er family planning and then chronic patients
- I: **okay**
- R: chronic patients, we do hyper-tension, diabetes, asthma, epilepsy and all the others, mental health, but now this is not mental health clinic, but patients who we do follow-up to, we, we give them treatment here at our clinic (interruption 02 21)
- I: **yeh if you need to, to do something else or go off for 5 minutes, don't worry**
- R: okay, all right Andy
- I: **I know you're, lots of demands on your time**
- R: ja, ja
- I: **um**
- R: so I'm, I'm a clinic manager who is hands on, do everything
- I: **so what does, so the 70% technical involves lots of time and lots of different issues**
- R: different issues, ja, different issues
- I: **how about the, the managerial side, so that 30% managerial issues – what does that involve?**
- R: I, I supervise my subordinates, they are the nurses, I delegate them, yes. I communicate with them with some new issues maybe that develop in the health setting. If there are new developments, then I must inform them because I'm the one who always attend the meetings first, then I come, divulge the, whatever I've got to them
- I: **is that almost like, like training, or (unclear 03 44)**
- R: no, no, not necessarily because some of our, we are all professional nurses but now the professional nurse, you'll find that there are some ranks, there are chief professional nurses, senior professional nurses

....[interview continues]

This additional section from the same interview with Sister Terene gives an example of how I would explore something that had been raised in the interview and try and develop analytical ideas. In this instance I was trying to explore ideas around changes in the clinic, and how that might relate to the introduction of ART, linking to ideas I explore in Chapter 6 of the thesis.

I: **okay, okay – um, so going back to mentioning some of the things that you said in your managerial side – you mentioned communicating new developments**

R: *ja, we communicate*

I: **does that**

R: *ja*

I: **do**

R: I can go for a course sometimes, maybe I am the one who has gone to that course. Then when I come back I must give them the report that “I was from this course, then this is what we were doing on that” then, like last time we went for EPI, but most of us did go there

I: **EPI, what what**

R: EPI – Extended Programme of Immunizations – that’s what I’ve, injecting children and now there is this er, there are 2 immunizations that have been introduced – the ...

I: **I’m testing you now, aren’t I (laughs)**

R: *ja, it’s for the, for the diarrhoea ne*

I: **yeh, okay**

R: *ja, then there’s another one for pneumonia, there’s*

I: **okay**

R: *ja, it’s PC, they called it PCV*

I: **PCV, okay**

R: *ja, and the, RC something – I’ve not yet started using them*

I: **so**

- R: but now, all of us went there. But if there isn't anyone who has gone there, we must give her the information
- I: okay
- R: then we attend the meetings. When we attend the meetings, whatever we have discussed there, we must discuss with our nurses
- I: **and, and so every time something new happens, erm so, does the Department of Health say "you must come and attend this"**
- R: yes, uh huh
- I: **and then you must implement this in your clinics – is that how it works**
- R: ja, we are given, ja, we are given, maybe we are given dates when to attend that course, after we are from there, then we come and implement it in the clinic
- I: **and, how often does that happen, how often do you get something new that you have to add on to your services**
- R: oh, sometimes if maybe they've reviewed, like for example, if they've reviewed the immunization schedule for, for the babies
- I: ja
- R: if something has changed, they review it, they change it, then we are called for
- I: **right**
- R: a refresher course
- I: **so is it, is it quite often that, that you'll have something new or**
- R: no, no, not, not uh huh, not quite often – because when the immunization schedule is there, it's there, but if something changes, they will always inform us
- I: **right**
- R: but it doesn't happen frequently
- I: **right**
- R: it happens if maybe, maybe there's a need to change that
- I: **okay, okay**
- R: sometimes you'll find that in the very integrated management of childhood illnesses that
- I: **yeh**
- R: I told you, they say the biggest killer in South Africa is, er they say it's pneumonia, I don't know. So now, if they find that pneumonia is killing, they'll have maybe to do something about that, like they've introduced that PCV

Sister Mamdala, Dula clinic

This is an extract from a first interview with a nurse working in one of the clinics providing ART, and demonstrates how I approached exploring changes in the context of ART and HIV care, and in particular how I tried to leave questions of what impact ART was having open to minimise my influence on nurses' responses.

- I: **so, it, it sounds like there's a lot of work in ART, erm, has it made a big change to the clinic at all, do you think**
- R: no it, it doesn't change anything, because I think ART has, has to be, to be put in the primary health care core package, it's just like any other programme in, in the, in the clinic, it's not an entity on it's own
- I: **okay, do you think it's, in this clinic it's a, it's well included in that primary health care package**
- R: yes it's, it is well collaborated, it is well collaborated, it's just that we are sectioning them to say let the ARV to come only this side. Even if it can happen that they are, all the patients are coming on one, through one door, it still be a great deal
- I: **oh, so you, sorry just to check, so you think the fact that ART patients have to come to this section is a slight problem**
- R: ja, at some stage it stigmatise them, when they are coming at one, at one section, it sort of stigmatizing them, but seeing that the patient has accepted themselves, they don't even see it as stigma, yes because they are used, and I think that the whole community, it's now having, it's now clever on this that you, you don't have to judge and stigmatise anybody, after all, HIV is for us all
- I: **so the community is understanding HIV better now**
- R: ja, that's what I think because I've never, since I arrive here, I never hear that side scolding the other, this side, I have never heard that
- I: **did you used to hear that in the, so, you worked in a different clinic before September 2007**
- R: yes I worked
- I: **is it, is this clinic very different to that clinic in any way**
- R: yes, yes, we, the clinic I am coming from
- I: **yeh**
- R: we are having only one door, whereby all the patients are queuing on the same, and nobody will (laughs) just see, this is an HIV or what

- I: **do you think that was a better system**
- R: I think it was a better system, it was a better system
- I: **okay, because then patients aren't stigmatised**
- R: mmm, it was a better system

....interview continues

From the same interview is an example of how I would end an interview and ask very open questions and then explore any issues raised. This also shows early parts of my thinking that led to ideas of nurses 'controlling compassion' which features in my analysis in chapter 4.

- I: **okay, okay – um, I'm sort of at the end of my questions um, now, but before we finish, is there, is there anything else you'd like to say about your work in the clinic or how the clinic works that you think is important**
- R: you know how our clinic is working, here it's because what we are saying, that the slogan is – the patient, the patient are not supposed to be turned back
- I: **that's the clinic slogan**
- R: ja, the patients are not supposed to be turned back. But seeing 100 patients, that you are not going to do justice to them, it's really not good
- I: **so do you mean that**
- R: the over, over load
- I: **in**
- R: yes I'm, here I'm talking of an over load
- I: **so because you have, because you can't turn patients back, but because you have so many patients, you don't do those patients justice**
- R: you won't do them justice because I think others, really if you are at the 120, number 120, I think the pace that you are using when you started, won't be the same
- I: **so what do you think, do you think patients um, miss out on something because you're**
- R: you know some of the patient are, are misusing the, the services because you find that this patient, it's here on Monday, it's here on Wednesday and Friday, see only

one patient coming those different days, only one patient, with only one condition
"painful finger" every day

I: to do ART or in the clinic

R: in the clinic as a whole

I: why do they

R: they, they misuse others, it's because of this grant, the disability grant there, they are having a wrong concept that if my file will be like this, I'll be able to get a, a disability grant

I: oh, so

R: that is the only thing that we are having a problem with

I: so patients keep coming so they

R: keep coming

I: that it makes them look like they're very sick so

R: yes

I: so then they can get a dis, okay

R: mmm, and the other thing I think, they need more and more information

I: the patients do

R: ja, so that they know, if I'm at that clinic with the condition that does not exist, sometimes you, you can see this patient, even she says this finger is painful, but if you say "do this" he will just do it without noticing that you are looking at the pain that he is saying "I'm having a pain on that." So if they can be taught, I think maybe they will know

I: so you think um, you think a big problem in the clinic is that patients need education on, on when they should come to the clinic

R: mmm

I: and that they're abusing the services

R: ja

I: and you sort of, sort of mentioned before that you sort of, you mentioned not doing patients justice, do you think, do you think there is more you could do for patients when they're in the room or, I'm trying to understand

R: by justice saying, at that time you are tired, if you are alone, you are really tired, even your, your mind is not working properly if you are tired and this patient need your service

- I: **okay, so, so just sometimes, when it's 3 o'clock in the afternoon, you've seen 40 patients, you're tired**
- R: **you are tired**
- I: **you just can't give as good care as you would like to**
- R: **ja, you just listen and repeat your own question. I said this and the patient answers you and forget that this patient has already answered, you ask again and the patient (laughs), she's getting bored, being asked one question several times and she or he does not understand that the, this sister is, really is tired, mmm, because they were here for the whole day and the, they saw that you are the only one – they won't even say "sister, really you are tired, go and eat"**
- I: **so they say that do they**
- R: **if you, if you go for tea, they will cry, if you go for lunch they will cry – so you are to sit there and help them without eating**
- I: **does that happen a lot, where you work all day with no break**
- R: **sometimes it happen that you work without getting break, but then ...**

Nurse manager, Fontein clinic

This is an example of an interview that wasn't recorded, and so I wrote up afterwards from brief notes; this only happened on a small number of occasions. The interview is with the nurse manager in Fontein clinic, one of the clinics I visited in later phases of fieldwork. The notes show how interviews and extended conversations were conducted amidst the work of the clinic; although this interview was interrupted more than most. In this particular conversation I also allowed the topics of conversation to vary according to what the clinic manager wanted to talk about, and so this interview also gives more insight in to contextual issues of the clinic, rather than the detail of care routines.

"After using the toilet I went and sat in the waiting area again. After a few minutes I heard N1 call out my name, so I stood up and went back to her room. I sat down at approximately 2:15pm and I didn't leave until 3:15. At several points I said I would leave and allow her to carry on with her work but each time she would keep talking or raise new topics. Throughout this time N1s door was open. A number of people came and went: at different times N2, N3, a data

clerk (?), another nurse bringing in a leave form. There were also numerous phone calls: her daughter sent her messages, a call came in from another sister and then also another person in relation to the clinic's oxygen supply. She also herself made outgoing calls. Throughout this we had a general conversation covering a lot of different topics, sometimes topics spurred by whoever was coming in to the room or the phone call that came in. [topics below not necessarily listed in order and written up afterwards, I didn't write as we were talking]:

- I sat down and N1 immediately started talking (I didn't ask any questions). She started by saying how she had been brought up to trust people, and then she said how her manager had lost forms that she had given her for staff appraisals and that the manager wasn't taking responsibility for it. She said she had told the manager 'I'm not a donkey' and then something to the effect of she wasn't going to do things over and over.

- When talking about lost paperwork a little later she said 'If its not written down, its not done'.

- She said she had just argued with her daughter (perhaps she had gone home at lunchtime). She said this after her two mobile phones rang (she had one in each pocket, left and right) and it was a text message. She said how she felt bad after it. I think she said she had three daughters.

- The phone rang and it was someone calling in relation to paying an invoice for the clinic's oxygen supply.

- She spoke for quite a while about how the computers in the clinic were broken. A nurse had visited and when she put in a CD it seemed the computer had crashed. N1 then said how the two men who had been in the clinic earlier were from the Dept of Health in Bloemfontein. She described them as small and large (not black and white). She said she had been calling them everyday asking them when they were going to come out here.

- She tried using the phone at one point and she explained how they only now had one phone line and not three as they used to. She said when someone was sending or receiving a fax or the modem was on you couldn't make a call. She said the manager had got rid of the other two lines without telling her. She said she hadn't realised this and had asked the manager 'which idiot did this' and the

manager had said it was them (she said it was a different manager to the one who had lost the appraisal forms).

- She said she had run up a R2000 phone bill checking her email by using her own mobile phone. She had then been told that she couldn't claim this back.

- Following a point she had made about people in the town not having ambition to leave, she said she didn't really like the people in the town. From memory I think she said she thought they were small minded.

- N4 came in to the room at one point and spoke to N1 in Afrikaans. N1 gave her some keys and she took something out of the cupboard. A little later on N5 also came in and spoke to N1, again in Afrikaans, and N1 gave her some test results that were on N1s desk."

Observation notes

I include here two extracts from my observation data, from Ba Banyane and Christen clinic. Both extracts illustrate how data gathered covered a range of issues, and also how the field notes I made evolved to being more focussed on particular issues within the clinics.

Ba Banyane clinic

The first extract from Ba Banyane clinic is from the start of the study. The data is an example of how nurses lives beyond the clinics would often be a focus for data gained through observation, reflecting how observation involved more informal contact with nurses. Alongside this it shows the detail I initially gathered on care routines in the clinic.

Monday 20th April 2009

I drive to the clinic and give N1 a lift. I collect her just before 7 at the Shell garage behind Bophelo House. We then take the half hour drive to the clinic – the road is fairly quiet and so we get to the clinic at a minute or so before 7:30 (ie when the clinic opens).

On the drive we talk about quite a few things. When I ask her about her weekend this starts a long, open and frank conversation about her relationship with the guy who is the father of her daughter. It seems that they are separated at the moment (presumably never married) although at the moment they are considering getting back together – it seems for the sake of the daughter. As we talk I am careful to include references to my own relationships

so it doesn't seem like an interview. She raises the point on how now women have jobs/salaries they are able to decide to leave men – this after I say before divorce people were forced to stay in unhappy marriages.

She also says a few things about the clinic:

About how sometimes consultations go on too long, for half an hour, yet when she looks through the files she sees that no history has been taken etc etc.

Monday and Tuesday (the day the doctor is in the clinic) are the busiest days.

When I mentioned that the other clinic I worked in was very busy first thing and then dead by 2pm – she said that was a sign of them being committed.

We arrive at the clinic at 7:30. The clinic is open and there are patients sat waiting – perhaps 10. N1 mentioned in the car that the cleaner opens the clinic and allows the patients to come and sit down.

N1 almost immediately goes to the desk behind the opening in reception and starts to register people. As she does this she isn't especially friendly – she doesn't spend time greeting people or talking to them, she just writes down the details.

N3 comes into the reception area to tell N1 about a problem with vaccinations – they have run out of some (this after N3 check in the store room next to reception). N1 doesn't really engage with her, and says that she will take care of it.

At around 8:00 there is a prayer. This seems to be led by two men who come into the clinic. The singing is first led by C, and then a spoken prayer by one of the men. The prayer goes on a long time. N1 then introduces me to the waiting room – she speaks for perhaps a minute or so and there are lots of murmured thankyou's I think from the waiting room.

8:10 N1 goes to the chemist and quite a few people go up to get their medication. They then leave.

N3 spends a few minutes telling me about her health problems. She has been ill for 2 months, including 10 days in hospital. She thinks she caught something from the clinic.

C is outside, seemingly cleaning.

8:25 N1 shows me how to register patients so I set about doing that.

There were no children at the start of the day in the waiting room.

8:30 34 patients registered, but the place seems very quiet, there are maybe 15 people in the waiting area. Generally people seem to register and then wander straight outside – do they actually wait there, or do they go home and come back later?

Several people bring in more than one file – ie register more than themselves.

8:35 N1 comes in and grabs a file left on the desk, for a patient she was talking to earlier. (she later tells me that the patient was referred to another clinic to start ARVs, but the patient didn't go and can't remember why).

Approx 8:45 – N2 arrives. I don't think she is late the rest of the week – on time because I was there?

There are large parts of time where I am in reception alone.

8:55 I've been registering people for about 30minutes now.

N3 at about 9:00 she goes into the waiting area – I think she is explaining she will see babies first – she comes and explains this to me – she sees all the babies first, because they can't say they are very ill.

At about 9:00 N1 comes in with 2 blokes, one old and one young – they are having a meeting of the clinic committee through in the other building.

N3 comes through 5 minutes later – she says N1 has called a clinic meeting, she is quite withering in the way she says this. She isn't hiding her contempt (is that too strong?) for N1

2 policemen come in, with a young man (approx 9:30), they wait for a little while and then leave.

Christen clinic

This extract is an example from later on in the data generation process and illustrates how I focused on particular issues in making field notes, like the queuing system, providing detailed description around that, rather than listing a range of details from the clinic as in the earlier extract from Ba Banyane clinic.

Monday 2nd November 2009

I arrived at 1:30pm. As I drove in there wasn't a single person outside the clinic, by the time I parked there were three people sat on the benches by the door. Inside there were roughly five people sat across the waiting area, but no one sat behind reception.

I walked in, and found Sister Seporo in the kitchen at the bottom. We spoke briefly, she seemed pleased to see me, asking me about my family.

I then went and sat at the top of the corridor, eventually shifting to a seat a little further down, next to the little table, so that I could see the waiting area and the whole corridor and also the reception door (a good all round spot for observation really).

Around 1:45 three school boys walked in. They looked uncertain what to do as there were no staff, they eventually knocked on the door of the 'staff room'/doctors room and the lay counsellor came out and gave them a key. I later saw them working on the allotment. Sister Seporo said that they had six volunteers from the local school.

Sister Vermaak had left the clinic for her lunch, as had Sister Kgaolo it seems, whereas Sister Seporo and Sister Pono and another women in a white uniform who I didn't recognise had stayed in the clinic.

When Sister Vermaak got back from her lunch I went and briefly spoke to her to say hello. She started talking about politics and how money was wasted. I referred to them as being a liberation movement rather than a political party, and she then said how they weren't even that - there was a vote and freedom was given to them - and that it was their decision to give away what they had built.

Outside each of the four consultation rooms at the top of the corridor there is a comfy chair opposite the door. The patients move from the waiting area to these chairs without being told and when there is space, although sometimes they stand next to the chair if there is already someone there. When the previous patient leaves they automatically go in, they don't wait to be told/invited by the nurse. For the chair outside room 4, which Sister Seporo uses, the patients look around the end to the other side of the wall they are sat at. Potentially this is the cause of some anxiety as patients are continually having to look round the corner to see if the seat is free.

When all patients arrive at the clinic they either go straight to reception, or do this after having first sat in the main waiting area until R is free. They go to reception and get their file and a piece of card with a room number on it. These are distributed in batches of 5 by R - so the first group of 5 patients are allocated to Sister Seporo the next 5 to Sister Kgaolo for example. If patients are at the clinic for ART they are still given the piece of card to refer to the room number (usually room 6 for Sister Vermaak) but they get their file from the office at the end of the corridor. All patients are then meant to have their vital signs taken by NA2 before going on to a professional nurse, although it isn't clear whether all ART patients get their files before or after vital signs are taken (due to the potential stigma of being seen with their different file?).

Appendix 5 – Interview schedules

I include here two interview schedules as examples of questions that would guide my interviewing. As discussed in chapter 2, interviews would normally start with the general question of 'can you tell me about your work', as below, and then explore issues that emerged from this. In the course of interviews I would aim to explore themes within the schedule as much as possible, bearing in mind the considerations discussed in chapter 2 about control over interviews.

Interview schedule - first interviews with nurses from the non-ART clinics First period of data collection

Interview day/time:

Nurse name:

Anonymous - Interview reference number (clinic number: nurse number):

Preparation:

Dictaphone

Refreshments available – water/tea, biscuits, fruit

Suitable location – private room with a door that can shut, that the interviewee is comfortable with

Copies of information sheet and consent form

Translation if necessary

Have information on relevant support services available

Interview:

Discuss info sheet and explain research, answer any questions

Explain the interview schedule

Describe process for confidentiality of data

Consent (written, or verbal on the tape recorder)

Explain can stop/turn off Dictaphone at any time

Start Dictaphone – say date, time, interview reference number

[their work – organization and delivery of nursing care]

- Can you tell me about your work and what you do in the clinic?

Job title

Area of work

Main responsibilities

Length of time in the clinic

Qualifications

- How does their work vary day to day
- Description of their daily work
- Description of a patient consultation (with use of vignettes depending on above answers)
 - explore variation of consultations with different patients
 - is care the same for all patients? Any difference between HIV+ and HIV-/untested patients?

[general work in the clinic – organization and delivery of nursing care]

- how does your work relate to the rest of the clinic?
 - what happens elsewhere in the clinic?
 - referrals
 - working with other staff and services
- what influences the work in the clinic? (if too general – refer to pressures, opportunities, difficulties etc – what do they find helpful, what do they find frustrating)
 - clinic conditions – resources, the building
 - tea/lunch time – breaks – different rooms for lay staff?
 - Relationship/support from DoH – other outside orgs
- what happens when a patient arrives at the clinic?
 - triage/prioritizing – numbering system/Different queuing systems for ANC/TB/PHC
 - waiting area (and waiting time) – coping with the large numbers of patients
- how do you cope with the number of patients that you need to see? Has this changed?
- has your work changed since you have been in this clinic?
 -since you have been in nursing?

[relationships]

- how do you feel about your work?
- what does your family say about your work?
- have your feelings about your work changed at all?
 -since the change in your role (see above – if their work has changed)?
- what do other nurses say about their work? Has this changed?
- tell me about how you work with the doctors in the clinic (has this changed)
 - what works well
 - difficulties/pressures
- tell me about how you work with the other nurses (has this changed)
 - variation with different nurses in their clinics by training/work area
 - what works well
 - difficulties/pressures
- tell me about how you work with the lay staff/counselors
 - what works well
 - difficulties/pressures
- tell me about how you work with the admin staff/other staff
 - what works well
 - difficulties/pressures

- tell me about your relationships with patients (refer to earlier discussion about providing care) (have they changed)

- tell me about your relationships with your patients who are HIV positive (have they changed)

are they different to other patients?

- how do you feel about working with patients who are HIV positive? (any change)

- how do the other nurses talk about the patients who are HIV positive? (any change) and other patients

- what do you think it would be like for a HIV positive nurse working in the clinic? (widen to working in the province, SA if little answer)

[if disclosure of their status – ask if OK for more questions on this – otherwise skip]

- Has being HIV positive influenced how you do your work?

- Has being HIV positive influenced your relationships with colleagues and patients?

- how would you describe the local area around the clinic?

Typical patients

Problems in the area

How long have you lived in the area

- what is the relationship like between the clinic and local community? (has this changed)is there anything else you would like to say?

After interview:

1 demographic info:

Sex

Age

2 'next steps':

likely dates for next interview – sharing of transcript

mention a few points that have emerged

Notes after interview:

Interview schedule - interviews with ART clinic clients

First period of data collection:

Recruitment: exit interviews, explain to client that interviewing patients receiving ART and those not, are they comfortable declaring their reason for coming to the clinic today

Sex, Age, Occupation

Preparation:

Dictaphone

Refreshments available – juice, water, biscuits, fruit

Suitable location – private room with a door that can shut, that the interviewee is comfortable with Copies of information sheet and consent form

Interpretation

Have information on relevant support services available

Interview:

Discuss info sheet and explain research, answer any questions

Consent (written, or verbal on the tape recorder)

Explain can stop/turn off Dictaphone at any time

1 can you please describe your experience of visiting the clinic today?

- ART?
- How long did you wait?
- How long was your consultation with the nurse?
- What language did the nurse use in talking to you? Did you understand what was told to you?

2 do you come to the clinic regularly? Yes - Is your experience always the same?

3 Did you come to this clinic before they started providing ART? Has anything changed since then?

4 What do you think of the service that the nurses provide at the clinic?

- What do other people in the clinic or community think of the service that the nurses provide?

5 Do you find it easy to talk to nurses at the clinic about your health issues?

- Do they listen to you?
- Can you tell them your problems?

6 Are the nurses supportive?

7 What do you think of the posters in the clinic that describe your 'rights' as a patient?

8 What do you think could be changed?

9 is there anything else you would like to say about the care you received in the clinic

Appendix 6 – Feedback report



June 2011 - INITIAL FINDINGS: FOR COMMENT AND REVIEW

Exploring change in South African primary health care nursing, in an era of ART and task shifting

Report on initial findings – for comment and review

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Overview of the study

Context:

There has been significant change in primary health care (PHC) and nurses' role, as the antiretroviral treatment (ART) programme is scaled up. Previous research in the Free State suggests that the availability of ART and nurses' changing role is mobilising nurses to provide more patient-centred care.

There have been widely reported concerns by government, media and from the research community over the quality of nursing care in South Africa. The recent convention in 2011 and the issuing of the nursing compact illustrate the attention around these issues.

Need the study responds to:

1 To understand in-depth how care is provided by nurses, to ensure sustainable and effective ART and HIV care, as well as broader PHC.

2 To understand in-depth some of the challenges and opportunities for improving the quality of nursing care in South Africa.

Study methods

Setting: Primary health care clinics, Free State Province, South Africa; clinics sampled included those involved in Free State Dept of Health and UCT led STRETCH trial.

Approach: In-depth qualitative research (ethnography). Interviews with nurses, patients and observation in four clinics, for three extended periods in 2009 and 2010. Interviews with nurses in an additional six clinics in the final period of data collection in 2010 to explore emerging themes.

Summary of initial findings

All services and clinics, in varying ways, show signs of patient-centred care. This includes nurses seeking to orientate care to patient need and interest, as well as seeking to engage with patients' broader psychosocial needs.

However, routines within clinics lead to rushed work and fragmented care, whilst there is also poor communication between nurses and patients.

ART and HIV care are provided in a similar approach to other services across PHC, although some ART nurses report making additional effort with ART and HIV+ patients.

The research also suggests that over time there has been a move to more patient centred approaches to care. In some instances, ART is a factor encouraging more patient centred care. However, other factors and interventions also seem to be encouraging this change: broader reforms to primary health care, the implementation of basic care/patients rights, as well as changes to nurses' role and working conditions.



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Next steps

Discuss initial findings with Dept of Health, clinics and relevant experts in the field.

Continue analysis and revise findings; finalise PhD thesis (Oct/Nov 2011), publish in academic journals (Nov 2011 onwards) and produce final report for Dept of Health and UCT.

In-depth and detailed qualitative research as used in the study does not support broad and definitive conclusions on how care is provided across all FHC clinics in the Free State and South Africa. However, this research does outline a range of approaches and issues that will likely be evident in many clinics. Raising awareness of these with nurses, managers and policymakers to consider the relevance to their work settings and potential solutions will allow the research to influence future care.



Describing care

A detailed description of care is focused around four areas: 1) the organization of the clinic workload, 2) the organization of service delivery, 3) the organization of patients in the clinic, and 4) consultations and direct provision of care.

Routine, behaviour, way of working	Draft recommendations and areas for research to support patient centred care
<p>Organisation of the clinic workload <u>1) volume, pace and scheduling of work</u> Patient care is usually focused in the morning, with clinics quiet or empty in the afternoon. This is tied to nurses frequently delaying or missing breaks and lunch.</p> <p>Separate component services of PHC are often focused on specific days of the week, leading to uneven daily patient loads. Although nurses will still see patients who arrive on the 'wrong' day. This trend towards focusing services on specific days potentially undermines the potential for comprehensive care through fostering a focus on specific health issues/disease, and increases time pressure on nurses.</p> <p><u>2) priority of patient care in relation to other areas of work</u> Nurses do seek to prioritise patient care above other tasks, and demonstrate some flexibility with clinic routines. However, dominant routines on the scheduling of work still lead to long waits for the majority of patients.</p>	<p>Although clinics see large numbers of patients, better spacing and flow of patients may reduce time pressure on nurses (see below) and reduce waiting time for patients (see below). To achieve this ways of making workload more predictable could be explored, through innovative solutions for appointment systems or block bookings (e.g. explore the possible use of mobile phones, re the trend towards 'mhealth').</p> <p>Foster a culture and provide support for nurses to take regular breaks.</p> <p>Services should be explicitly available everyday of the week.</p> <p>A recognition of nurse concern for patient care is frequently overlooked in the broader media discourse around nursing in South Africa. Encouraging recognition of this would support nurse morale and motivation.</p> <p>Prioritisation of patient care in the form of delaying or missing breaks and lunch (as above) also creates anxiety for nurses and may actually undermine care.</p>



Routine, behaviour, way of working	Draft recommendations and areas for research to support patient centred care
<p>Organisation of service delivery</p> <p>3 professional nurse service focus In certain clinics, specific services were delivered by designated nurses implying a professional role fragmentation within PHC (e.g. one nurse would work on chronics, another on minor ailments/curatives etc). This also applied to ART, although HIV care (HIV testing and CD4 counts) were at times integrated with other services. In other clinics, all nurses provided ART.</p> <p>Nurses' reluctance to provide integrated services (ie any patient being allocated to any nurse within a clinic) is attributed to the importance of the nurse patient relationship and continuity of care. A nurse desire to specialise is also a factor, as well as anxiety about providing some services.</p> <p>4 task separation within services ART and HIV care indicates higher levels of task separation, with the involvement of lay counsellors, nursing assistants and professional nurses. When nursing assistants are available basic observations/screening are done by them, in advance of the consultations with nurses.</p> <p>5 working with other health providers and non-nurse led services Nurses are required to work or refer to a range of other health workers.</p> <p>6 Prioritising care Emergency care patients and those perceived to not require in-depth examination are frequently prioritized over other patients, to prevent unnecessary waiting.</p>	<p>Recognise that nurses maintaining a specific focus risks fragmenting care, in the absence of strong links with other services.</p> <p>Recognise the challenges of providing integrated services (in terms of nurses providing all services), and the benefits of having some nurse service focus in terms of continuity of care and efficiency.</p> <p>Existing efforts to train and manage nurses should reflect on the anxiety some nurses feel about working on certain services.</p> <p>Monitor quality of HIV care and ART, recognizing that greater task separation amongst nurses and other clinic staff can undermine opportunities for communication and continuity of care</p> <p>This highlights the complexity of nurses work (in addition to care across PHC), and the consequent need for ongoing training and support</p> <p>'Fast tracking' certain services and not having in-depth examinations potentially leads to lost opportunities for service integration (e.g. family planning patients could be directed towards SRH and HIV services)</p>



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Routine, behaviour, way of working	Draft recommendations and areas for research to support patient centred care
<p>7 Organisation of patients in the clinic <u>7 experience of patients being in the clinic and waiting</u></p> <p>Nurses and patients recognize the long waiting time as a problem. Long waits lead to issues of patient hunger and comfort as well as creating risk of infection.</p> <p>Nurse-patient interaction in public areas of the clinic highlights positive elements of nurse-patient relationships, with friendly and informal contact (not always distant and uncompassionate as suggested by some analysis).</p> <p>8 regulating patient flow in the clinic</p> <p>Some clinics have clear systems for regulating the flow of patients and controlling patient queues. However, in other clinics queuing systems are unsupervised leading to problems of queue jumping. Patients' perceptions of the need to be proactive and negotiate service access, coupled with long waiting times, potentially exacerbates patient ill-feeling towards the clinic.</p> <p>9 health interventions outside the consultation room</p> <p>Long waiting periods facilitate a range of formal and informal health interventions within clinics, such as health talks or creating opportunities for patients to watch TV; patients also share information about their illness (principally HIV) with each other.</p>	<p>Following 1. above, emphasize the need to explore possible systems for smoothing the flow of patients through the day. Dept of Health waiting time audit is already a recognition of the problematic nature of waiting time.</p> <p>Clinics should implement clear queuing systems (numbering, 'ticketing') to ensure patients are seen in an equitable manner.</p> <p>Although some waiting is inevitable, caution should be taken to ensure the range of tasks undertaken do not legitimise the long wait and offset the need for wider change.</p>



Routine, behaviour, way of working	Draft recommendations and areas for research to support patient centred care
<p data-bbox="294 409 665 429">Consultations and direct provision of care</p> <p data-bbox="294 449 665 469"><u>10 Organisation of consultation space and setting</u></p> <p data-bbox="294 473 665 604">A range of factors undermine the privacy and confidentiality of consultations: doors being left open, nurses and other staff (and occasionally patients) interrupting consultations, as well as patients being grouped together for some kinds of health intervention and consultations.</p> <p data-bbox="294 675 665 806">In some clinics, nurses report patients phoning them to seek advice on healthcare – reflecting patients going outside the normal system of seeking a consultation. Nurses seem to respond to this, or at least recognise patient desperation for support.</p> <p data-bbox="294 826 665 846"><u>11 scope of consultations</u></p> <p data-bbox="294 850 665 1008">The time pressure felt by nurses owing to the volume and scheduling of work can lead to nurses feeling pressured to rush consultations and not do everything they consider necessary. This is a tension for nurses as alternatively addressing all need would lead to other patients waiting/not being seen.</p> <p data-bbox="294 1028 665 1159">Nurses do report seeking to provide comprehensive care, but in light of the trend towards nurses focusing on a specific service, and time pressure, it is not clear how often nurses respond to a range of patient health needs in the context of short consultations and rushed care.</p> <p data-bbox="294 1179 665 1270">Consultations for ART and HIV care by some nurses involve more in-depth exploration of the patient's situation, than in comparison with other services.</p> <p data-bbox="294 1290 665 1310"><u>12 nurse-patient interaction</u></p> <p data-bbox="294 1314 665 1405">Communication is potentially limited due to limits on privacy and interruptions, pressure on time and patient frustration and exhaustion after long waits, highlighted above.</p>	<p data-bbox="679 473 1049 645">Although reflecting the demands of a busy clinic and nurses seeking to meet a range of goals, this is potentially problematic in a context of stigma. Encourage nurses to close consultation room doors during consultations, minimise interruption of other consultations and avoid having groups of patients in a consultation through recognising a patient's right to privacy.</p> <p data-bbox="679 675 1049 786">Although a complex issue, potentially explore formalising a system of phone consultations – reflecting the rise of 'mhealth'. This may also be a way of regulating the flow of patients (see 1 above).</p> <p data-bbox="679 856 1049 897">Efforts to smooth the flow of work through the day, as above, may help this.</p> <p data-bbox="679 1179 1049 1249">Although a response to perceived increased need, this additional effort could be fostered in other services.</p>



June 2011 - INITIAL FINDINGS: FOR COMMENT AND REVIEW

Nurses' efforts to communicate with patients included efforts to counsel patients and explore patient's health needs, as well as an openness to patients making decisions about their care. Some nurses were also sensitive to patient's social situation.

Some nurses feel there is too little time or lack confidence in relation to HIV counselling.

Nurses and patients reported patient fear of nurses, as well as instances of nurses and patients arguing and shouting at each other. This was in some instances linked to nurse frustration at patients not complying with treatment or advice.

Nurses and patients frequently face a language barrier, requiring the use of lay counsellors or other staff to help on an ad hoc basis.

Patients are often reluctant to discuss their health issues, in particular around HIV.

Recognise the time constraints and challenges to effective counselling, and consider training and support requirements around this.

This indicates a broad problem of building trust and understanding between nurses and patients. This will require both education and training, but also a recognition of the broader challenges nurses face.

Explore the use of translators in consultations or a more formal role in this by other clinic staff.

This indicates a broad problem reflecting stigma and discrimination but also a perception of nurses and their approach to care. Interventions should focus on education and training with efforts to foster a more supportive nursing culture.



Describing change in care

Findings	Draft recommendations and areas for research to support patient centred care
<p><u>Change in care</u></p> <p>Nurses reports of their care suggest a potential shift towards more patient centred approaches to care. ART is one factor influencing this change, but also broader changes as well such as the wider changes to PHC, the adoption of the batho pele principles and changes in nurses role and working conditions.</p>	<p>Continue current interventions designed to encourage quality of care in relation to patient provider interactions, recognising that there is a long lag time between intervention and impact. This could be accompanied by broader research on this to support efforts to highlight that care is progressively changing for the better, in contrast to the negative discourse around nursing care in South Africa.</p> <p>Avoid the assumption that ART and associated interventions will necessarily improve the quality of care.</p>

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This thesis can only be the start. The real work starts now.