Continuity of care for Tuberculosis patients between hospital and primary health care services in South Africa

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Declaration

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Abstract

Many tuberculosis (TB) patients in South Africa are admitted to acute care hospitals, but large numbers are lost to care after discharge, and few complete their TB treatment. This contributes to ongoing transmission of TB in communities, frequent hospital readmissions, a high mortality rate and avoidable costs to the health system and society.

This thesis studied continuity of care for TB patients discharged from hospital in South Africa. It aimed to describe the problem, identify risk factors for poor continuity of care, synthesise evidence to inform, implement and evaluate an intervention, and produce a policy brief to translate the evidence into policy and practice. The research methods included an observational study, research synthesis, qualitative research, participatory action research, a quasi-experimental study as well as knowledge translation methods to address the various research questions.

The study found that a third of TB patients discharged from hospital did not continue TB treatment, and that inadequate clinical management of TB patients in hospital showed a significant correlation with poorer continuity of care and an increased mortality rate. Evidence of strategies to improve continuity of care for chronically ill patients was identified in high-income countries, but no such evidence could be found for TB patients in low and middle-income countries. Using the available evidence and participatory action research, a multicomponent discharge planning and support intervention was designed and implemented in collaboration with a referral hospital in the Western Cape.

A before-and-after evaluation found that continuity of care for TB patients improved significantly after implementing the intervention. A process assessment revealed that the characteristics of the intervention, the external context, the persons involved and the methods of implementation had a favourable impact on implementation. Yet the internal context of the hospital was unfavourable for implementation, and in-hospital intervention activities were not sustained. In contrast, information linkages and community-based follow-up and support of TB patients continued.

More rigorous studies of interventions to improve continuity of care for TB patients discharged from hospital in similar settings are required. This should be complemented by implementation research to understand and address health systems challenges. Both types of research are needed to effectively translate evidence into practice in the health systems of low and middle-income countries.

Opsomming

Vele tuberkulose- (TB-) pasiënte in Suid-Afrika word in die akute sorg hospitaal opgeneem, maar baie verdwyn uit die sorgstelsel ná ontslag, en weinig voltooi hulle TB-behandeling. Dít dra by tot aanhoudende TB-oordrag in gemeenskappe, gereelde hospitaalhertoelating, ’n hoë sterftesyfer en vermybare koste vir die gesondheidstelsel en samelewing.

Hierdie studie het ondersoek ingestel na die kontinuïteit van sorg vir TB-pasiënte wat uit hospitale in Suid-Afrika ontslaan word. Die doel was om die probleem te beskryf, risikofaktore vir swak kontinuïteit van sorg te identifiseer, bewyse saam te voeg en op grond daarvan ’n intervensie te ontwerp, te implementeer en te evalueer, en ’n beleidsriglyn op te stel om die bewyse in beleid en praktyk om te skakel. Die navorsingsmetodes het ingesluit ’n waarnemingstudie, navorsingsintese, kwalitatiewe navorsing, deelnemende aksienavorsing, ’n kwasi-eksperimentele studie en kennisoordragmetodes om die verskillende navorsingsvraagstukke te ondersoek.

Die resultate dui daarop dat ’n derde van TB-pasiënte wat uit die hospitaal ontslaan word, nie met TB-behandeling voortgaan nie, en dat onvoldoende kliniese bestuur van TB-pasiënte in die hospitaal ’n beduidende verband toon met swakker sorgkontinuïteit en ’n hoër sterftesyfer. Bewyse van strategieë om sorgkontinuïteit vir chroniese siek pasiënte te verbeter is in hoë-inkomstelande geïdentifiseer; tog is daar geen bewyse van soortgelyke strategieë vir TB-pasiënte in lae- en middelinkomstelande nie. Met behulp van die beskikbare bewyse en deelnemende aksienavorsing is ’n ontslagbeplanning- en ondersteuningsintervensie met verskeie komponente derhalwe in samewerking met ’n verwysingshospitaal in die Wes-Kaap ontwerp en geïmplementeer.

’n Evaluering voor en ná die tyd bevind dat sorgkontinuïteit vir TB-pasiënte aansienlik verbeter het nadat die intervensie geïmplementeer is. Volgens ’n prosesbeoordeling het die kenmerke van die intervensie, die eksterne konteks, die betrokke persone en die implementeringsmetodes ’n gunstige uitwerking op implementering gehad. Die interne konteks van die hospitaal was egter ongunstig vir implementering, en die hospitaal het nie met intervensieaktiwiteite volgehou nie. Daarteenoor is inligtingsteun en gemeenskapsgebaseerde nasorg en ondersteuning van TB-pasiënte wél voortgesit.

Verdere wetenskaplike studies van intervensies ter verbetering van sorgkontinuïteit vir TB-pasiënte wat in soortgelyke omgewings uit die hospitaal ontslaan word, word vereis. Dít behoort aangevul te word met implementeringsnavorsing om die uitdagings van gesondheidstelsels te verstaan en die hoof te bied. Albei tipes navorsing is nodig om bewyse in die gesondheidstelsels van lae- en middelinkomstelande in praktyk om te skakel.

List of acronyms and abbreviations

AIDS	Acquired Immunodeficiency syndrome
ART	Anti-Retroviral Treatment
CAH	Central Academic Hospital
CAS	Complex Adaptive System
CBA	Controlled Before After study design
CBS	Community Based Services
CCT	Controlled clinical trial
CHBH	Chris Hani Baragwaneth Hospital
CHF	Congestive Heart Failure
CFIR	Consolidated Framework for Implementation Research
COPD	Chronic Obstructive Pulmonary Disease
CPW	Clinical Pathways
CTF	Care Transitions Framework
DOTS	Directly Observed Treatment Short course
EBM	Evidence Based Medicine
EPOC	Effective Practice and Organisation of Care
EPTB	Extra Pulmonary TB
eCCR	Electronic Continuity of Care Record
ETR.Net	Electronic TB Register
FMHS	Faculty of Medicine and Health Sciences
HAST	HIV, AIDS, STI and TB
HDL	Hospital DOTS Linkage project
HIC	High Income Country
HIS	Health Information Systems
HIV	Human Immunodeficiency Virus
HSR	Health Systems Research
ICD	International Classification of Diseases
ICT	Information and Communication Technology
IEC	Information, Education and Communication
IOM	Institute of Medicine, USA
IR	Implementation Research
IS	Implementation Science
ITS	Interrupted Time Series
KAP	Knowledge, Attitudes and Practice
KNCV	KNCV TB Foundation
LHW	Lay Health Worker
LOS	Length of stay
LMIC	Low and Middle Income Country
MDG	Millennium Development Goals
MDR	Multi-Drug Resistant TB
MRC	Medical Research Council
NDOH	National Department of Health
NPO	Non-Profit Organisation
NHLS	National Health Laboratory Services
NSP	National Strategic Plan
NTP	National TB Control Programme
NRCT	Non Randomised Clinical Trial
PAR	Participatory Action Research
PARIHS	Promoting Action on Research Implementation in Health Services
PHC	Primary Health Care

PHR	Patient Held Record
PI	Principal Investigator
PROMS	Patient Reported Outcome Measures
PTB	Pulmonary Tuberculosis
RCT	Randomised Controlled Trial
SANPAD	The South Africa Netherlands research Programme on Alternatives in Development
SDG	Sustainable Development Goals
SOP	Standard Operating Procedure
STIs	Sexually Transmitted Infections
SU	Stellenbosch University
SUPPORT	SUPporting POlicy relevant Reviews and Trials
SURE	Supporting the Use of Research Evidence
TB	Tuberculosis
TAH	Tygerberg Academic Hospital
TFU	Telephone Follow Up
UIPC	Unit for Infection Prevention and Control
WCGH	Western Cape Government Health Department
WHO	World Health Organisation
XDR	Extensively Drug Resistant Tuberculosis

Definition of terms

Acute care hospitals	An inpatient medical facility providing therapy for severe illness or injury; average length of stay of 30 days or fewer (1).
Continuity of care	The provision of coordinated care and services over time, and across levels and disciplines, which is coherent with the patient's health needs and personal circumstances (2).
NTP treatment outcomes(3)	
	Cure: Client who is smear-negative in the last month of treatment and on at least one previous occasion at least 30 days prior;
	Treatment completed: Client who has completed treatment but who does not meet the criteria to be classified as cure or treatment failure;
	Treatment success (or successful treatment outcome): Client who is cured or treatment completed;
	Died: Client who dies for any reason during the course of TB treatment.
TB bacteriology	A biological specimen tested for evidence of TB infection using smear microscopy, culture or WHO-approved rapid diagnostics (WRD), including Xpert MTB/RIF.
TB case	A bacteriologically confirmed TB case (i.e. TB bacteriology test positive).
TB incidence (rate)	The number of new and relapse cases of TB arising in a population in a given time period, usually one year (4). The TB incidence rate represents the number of cases relative to a population of 100 000. South Africa has not

	conducted any true TB incidence studies, and uses a proxy incidence based on TB patient registrations in the ETR in any one year. I have used the term similarly in this thesis.
TB prevalence (rate)	The number of cases of TB in a population at a given point in time (4). The TB prevalence rate is relative to a population of 100 000.
TB notification	The mandatory notification of a TB patient to health authorities is required of health professionals and services in terms of the Health Act (2003) and regulations for the notification of diseases in South Africa(5). This national diseases notification system preceded and remains separate from the NTP TB registration system in South Africa.
TB registration	TB registration is the reporting of a diagnosed TB patient receiving TB treatment at a NTP health facility in the NTP electronic TB register system (ETR) (6).

Chapter 1: Introduction

Background

The Burden of Tuberculosis (TB)

TB remains a major contributor to the burden of disease in Africa, which along with Asia, contributes two thirds of the global TB burden (7). In 2017 South Africa was one of six countries that accounted for 60% of new TB cases, and was on three World Health Organisation (WHO) lists of high TB burden countries for high incidence, TB/HIV co-infection, and drug resistant TB globally (8).

The TB epidemic in South Africa, with a TB incidencein excess of 900/100 000, has been fuelled by HIV, poverty and suboptimal health systems performance (9–11). The HIV prevalence in incident TB cases remains high at 57%, and TB continues to be a leading cause of death in HIV infected persons in South Africa (8). The introduction of ART and subsequent decline in HIV incidence (12), along with a high Anti-Retroviral Treatment (ART) uptake of 84.5% in co-infected TB/HIV patients (13), may however be contributing to a decrease in TB incidence and TB mortality (14).

South Africa also experienced an increase in multiple drug resistant (MDR) TB since the 1990's, with a national MDR prevalence in new TB patients of 2.8% (95% CI 2.0-3.6), and 4.6% (95% CI 3.2-6.0) in retreatment patients in 2014, and several outbreaks of Extreme Drug Resistant (XDR) TB in health facilities (15). It is estimated that 5.7% of incident TB cases will be MDR TB by 2040, of which 8.5% will be XDR TB cases (16).

The rapidly increasing prevalence of chronic non communicable diseases such as diabetes, further contributes to the risk of latent TB infection converting to active TB in South Africa (17). These multiple

morbidities in TB patients increase the complexities of disease management resulting in less favourable outcomes (7,18).

The absolute numbers and severity of disease in TB, TB/HIV co-infected and drug resistant TB patients, as well as co-morbidities with other chronic diseases, has resulted in substantial increases in acute hospital admission rates for TB patients in South Africa and elsewhere (19–21).

Global and National TB Control Policies

Three phases of global policy since 1994 influenced national TB control and the role of hospitals in TB control in South Africa. In the first phase, the WHO launched the DOTS (Directly Observed Treatment Short course) strategy. This included the delivery of standardised 'evidence based' laboratory TB diagnosis, provision of short course TB treatment regimens, Direct Observation of Treatment (DOT) and a TB recording and reporting system to monitor the progress and outcomes of TB patients (22). The DOT component required health care providers to observe each TB patient taking their medication to improve treatment adherence, but remained controversial with evidence questioning the benefits (23).

South Africa nevertheless adopted the WHO DOTS strategy for the National TB control Programme (NTP) in 1995, and implemented it through municipal TB clinics and specialised chronic TB hospitals. These facilities had traditionally been responsible for the management of infectious diseases of public health importance and became the platform for delivery of the new NTP in South Africa. Over this same period however, South Africa prioritized the integration of health services previously fragmented during apartheid into one national District Health System (DHS) (24). Municipal Primary Health Care (PHC) services including TB Control therefore also became part of the DHS, and responsibility for TB services shifted from local authorities to provincial health departments. The NTP DOTS programme was however maintained as a 'vertical programme' delivered by clinics and specialized chronic TB hospitals, and not integrated at a service delivery level into general curative care or acute care hospitals managed by Provincial health departments.

In the second policy phase, the United Nations (UN) Millennium Development Goals (MDG's) of 2000 included targets for TB, HIV and Malaria control, alongside targets to address poverty and other social determinants of health (25). MDG six specifically aimed to halt TB transmission and reduce the incidence of TB by 50% by 2015. The WHO's 'STOP TB' Strategy launched in 2006 was aligned to achieving MDG six through enhanced and expanded DOTS coverage (26). The STOP TB strategy promoted collaboration between TB and HIV care, improved case finding, and engagement of all health care providers, including hospitals, in TB management. Although the MDG goals for TB were

partly achieved by 2015 with a global decline in TB mortality, TB incidence and TB prevalence (27), numerous challenges remained in terms of missing patients, the spread of MDR and ongoing TB-HIV coinfection.

The third policy phase commenced with the WHO 'End TB Strategy' adopted by the World Health Assembly in 2014, and the launch of the UN Sustainable Development Goals (SDG's) in 2015 (28,29). The End TB Strategy called for a 95% reduction in TB deaths and 90% reduction in TB incidence by 2035. It included several pillars which addressed increased prevention, active case finding, more integrated and patient centred care with involvement of public and private sector providers, and further research to improve implementation and impact. South Africa's National Strategic Plan (NSP) for HIV, TB and STI's 2017-2022 adopted these new global TB Control targets of screening 90% of vulnerable groups, diagnosing and commencing 90% of these on treatment, and achieving 90% successful treatment outcomes by 2022 (30).

Although the WHO DOTS strategy began as a strongly vertical treatment programme delivered by selected public sector PHC services, since 2006 the policies increasingly recognized the role of prevention and 'non-NTP' health care providers including public sector acute care hospitals and the private sector in TB control. This was also reflected in the growing number of publications on the quality of and linkages with the NTP of TB care in acute care hospitals, prisons and the private sector since the mid 2000's (31–33).

In South Africa the TB treatment outcomes of patients registered with the NTP improved from 1995 when less than 60% had successful treatment outcomes to 77% by 2014 (14). However, this remained below the WHO target of 85% successful treatment outcomes to reduce transmission of TB. In addition, a large proportion of TB patients were not detected or treated in the NTP as indicated by a national TB case detection rate of 64% reported in 2015 (34).

A study of the TB cascade in South Africa, provided similar figures for 2013 with an estimated 532 005 TB cases far exceeding the reported 343 780 TB patients in the South African national TB register for the same year (35). It also estimated that of the 532 005 TB cases, 95% accessed TB tests, 82% received a TB diagnosis, 70% were 'notified' and treated, and 53% successfully completed treatment. This TB care cascade was similar for drug susceptible (DS) TB (507 533 cases), and HIV co-infected patients with DS TB (314 491 cases). Greater losses were estimated at every stage for patients with rifampicin-resistant (RIF-R) TB (24 472) for whom the treatment success was 22%.

The NTP's 77% successful treatment outcome in 2014 therefore did not include the outcomes of the 'missing 36%' of TB patients, many of whom were diagnosed and treated in public sector general

hospitals, prisons and private health care services which were not part of the NTP. These facilities did not necessarily comply with the national TB diagnostic and treatment protocols, did not provide information on TB patients, nor have linkages to the NTP for patients to continue treatment.

Despite implementing the WHO DOTS programme for more than 20 years, the South African health system has continued to fail to identify and diagnose TB patients, to retain them in care or to cure them. In order to achieve the ambitious End TB goals, South Africa needs to include 'non-traditional' sites of TB treatment such as acute care hospitals, prisons and the private sector in the NTP and improve integration of TB care with HIV and non-communicable diseases prevention and treatment.

TB in acute care hospitals in South Africa

In 2008 17.2% of patients admitted to public acute care hospitals in Cape Town had TB, and 32% were HIV infected (19). Despite the large numbers of TB patients admitted to acute hospitals in South and Southern Africa, a few studies found that hospitalised TB patients were sub-optimally managed, and experienced poor continuity of care after discharge from hospital (36–38).

The ongoing prioritisation of delivery of the NTP through PHC facilities and specialised chronic TB hospitals, and exclusion of acute secondary and tertiary hospitals contributed to the poor quality and continuity of care for hospitalised TB patients. At Chris Hani Baragwaneth Hospital (CHBH), a large public tertiary hospital in Gauteng province, a 2005 study reported that 46% of TB patients presented directly to the hospital, suggesting that many admissions for TB were not appropriate and did not require tertiary level care, or were potentially avoidable if the patients had been treated earlier at other levels of care (37). Of those admitted, 31% were not notified, and only 50% reached PHC services on discharge to continue TB treatment. The HIV co-infection rate in this setting was high with 80% of PTB patients testing positive for HIV.

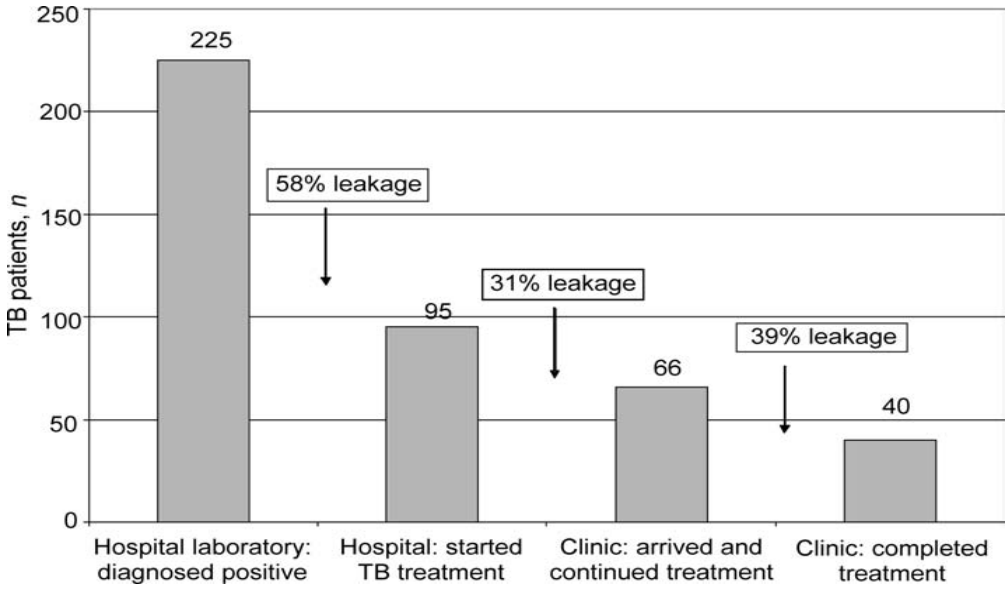

Figure 1: Leakages of TB patients, Edendale Hospital, Kwazulu Natal. Source: Loveday et al 2008

At Edendale Hospital, a public regional hospital in Kwazulu Natal, only 17% of TB patients had a bacteriological diagnosis, with most patients diagnosed on chest x-ray alone (45%), contrary to international and national TB guidelines which require microbiological evidence of TB for a diagnosis in 2008 (36). Of those with laboratory confirmed pulmonary TB (PTB), 42% were started on TB treatment in hospital, 29% reached a PHC clinic after discharge and 18% eventually completed treatment (Figure 1). This drop out or 'leakage' of patients along the TB care pathway represented a significant loss of patients by the health system of patients who had presented for TB treatment. The failure to involve acute care hospitals in TB control and to ensure good quality TB care in such hospitalsthus contributed to poor TB treatment outcomes, and the development of MDR and outbreaks of XDR in South Africa (39).

Lack of information, poor communication with patients, referral policies which result in patients having to make multiple attempts to obtain care at different facilities, and inadequate access to transport and financial resources to access care, create insurmountable barriers in negotiating the transition between levels of health care for patients in these settings (40,41).

The costs of hospital TB management

Hospitalisation of TB patients (excluding patients with MDR TB) consumes a substantial proportion of financial resources spent on TB control in South Africa, representing more than one third of the total expenditure for TB control while providing care for less than 10% of patients (42). South Africa has the second highest per capita expenditure on TB treatment globally, exceeded only by Russia where long

term hospitalisation has been the norm (42). Although TB treatment was recognized as one of the most cost effective interventions to reduce the burden of disease (43), hospitalisation has been the least cost-effective option for the diagnosis and treatment of TB patients (44).

In addition to the costs to the health system, the impact of TB on exacerbating poverty has been well documented, with the costs of treatment and hospitalisation to patients and their families often being catastrophic in poor communities. Patients incur substantial costs to access health care particularly for transport and living costs for those migrating for care; as well as a loss of family income as a result of hospitalisation of breadwinners or carers having to stop work to accompany the patient to seek health care or to take over other family responsibilities (44–47).

Given the high costs of hospital TB care, interventions to reduce unnecessary hospitalisations of TB patients and to improve the quality and continuity of hospital TB care where required can have significant economic benefits for patients and health systems.

Improving quality and continuity of care for TB patients in hospitals in South Africa

Commitments to deliver quality health care were enshrined in the South African Constitution, the Reconstruction and Development Plan (RDP), the White Paper on Transformation of Health Care and various other policies and plans in the new democratic dispensation from the 1990's. However, these had not translated into measurable improvements in the quality of health care and health outcomes of the population (10). A reprioritisation of quality by the NDOH included the establishment of an Office of Health Care Standards (OHCS) (5), the determination of National Core Standards (NCS's) for health facilities, and establishment of six national quality priorities in National Plans. These developments provided a context in which quality of TB care, including continuity of care, began to receive some attention within hospital services.

At Chris Hani Baragwanath Hospital the establishment of a dedicated TB Centre to support the discharge management of TB patients resulted in a dramatic improvement in successful TB patient referrals to PHC from 50% to 93% in 2006 (48). The TB centre functioned as a separate unit, with dedicated staff providing support and counselling to TB patients and managing the links to other levels of care. Unfortunately, if TB patients had co-morbidities with other chronic diseases, continuity of care for these were not managed by the TB Centre reducing the comprehensiveness of the care. The intervention, furthermore, required substantial resources through external funding and could not be sustained after withdrawal of grant funding.

Unpublished reports also provided evidence of interventions to improve continuity of care for discharged TB patients at Edendale Hospital in Kwazulu- Natal and GF Jooste Hospital in the Western Cape. The latter, a district hospital in the Cape Metropole, successfully improved continuity of care for TB patients through lay health workers (LHW's) who provided education and support for TB patients and actively followed up patients discharged to PHC services (49). Once again, despite its success the intervention was not sustained after external funding ended.

The NTP clinical guidelines over the study period

The diagnosis and treatment of TB evolved over the period during which the study was undertaken. In particular the addition of newer rapid TB diagnostic tests such as Xpert MTB/RIF in 2011 and the use of PCR to the traditional sputum microscopy and culture increased on site testing options, decreased the turnaround time for results and increased detection of drug resistant TB. However, the initial uptake of the new tests was slower than anticipated with less than 60% of presumptive TB patients tested with GeneXpert in 2015 (50).

TB treatment regimens for new and retreatment adults with TB remained constant during the study period. A new treatment for drug resistant TB, Bedaquiline, was adopted in South Africa in 2016 reducing the treatment duration for MDR TB from 20 months to 9 months, and improving treatment success from 50% to 90% (51).

Guidance for referral and admissions to non TB acute care hospitals are scanty in the NTP guidelines, specifying severe complications of TB e.g. massive haemoptysis, meningitis; severe dyspnoea or empyema; severe drug reactions; and HIV related disease that require specialised medical care (52). Similarly discharge management recommendations are made for patients admitted to chronic TB hospitals, but not for acute care hospitals.

Reporting TB patients in the ETR.net are specified for the district/sub-district level, but not acute care regional or tertiary hospitals. The Western Cape issued more detailed guidelines for admissions and discharge to TB hospitals in 2013 (H18 2013), and included guidelines for referral from TB hospitals to levels 1 to 3 acute care hospitals (53). For level 2 and 3 hospitals these included 'complex' TB, complicated HIV or paediatric disease, patients requiring further investigations such as CT scans, specialist or sub-specialist consultation, diagnostic or therapeutic dilemmas, specialised interventions, or patients with additional medical problems. **TB in the Western Cape**

The Western Cape Province had the third highest reported TB cases in South Africa at 681/100 000, and an HIV prevalence in adults of 8% in 2016 (14). Although TB and HIV mortality had decreased, they

continued to be leading causes of mortality in the Province (54,55). Most TB patients in the Province were diagnosed and treated at PHC facilities or at six specialised TB hospitals, with an 81.8 % successful treatment completion rate in 2014 (13). However, as with the NTP, this did not include TB patients at 'non' NTP sites such as public acute care hospitals. Little was known about TB patients treated at these hospitals in terms of numbers, the quality of care they received or whether they continued and successfully completed treatment after discharge from hospital.

TB control was largely a 'vertical programme' in the Province with limited integration into comprehensive care at all levels. The Provincial HealthCare 2030 plan however prioritised TB as one of the 'quadruple burden of disease in the province'. The plan also aimed to improve health outcomes and the quality of care including improving integration across the service platform and ensuring continuity of care for patients in the Province (56). The prioritisation of TB control and quality of care was translated into Standard Operating Procedures (SOP's) providing guidelines and specific actions, including TB hospital admission and referral guidelines.

These factors created a context in which clinicians, hospital managers and TB and HIV/AIDS programme managers became concerned about the quality and continuity of TB care between hospitals and PHC services. They were receptive to assessing the quality of care that TB patients received in hospitals, and the care pathways between hospitals and PHC services.

The study setting

Tygerberg Academic Hospital (TAH), an academic tertiary hospital in Cape Town with more than 1300 active beds, is the largest hospital in the Western Cape and second largest hospital in South Africa. As a central hospital it provides specialised medical services, and receives referrals from regional and district hospitals in the Western Cape and from neighbouring Provinces. Within the Western Cape it serves a catchment population of more than three million people, mostly from poor socioeconomic conditions in urban informal and formal housing and from rural areas of the Western Cape. It also functions as an academic hospital through its affiliation with the Faculty of Medicine and Health Sciences of the University of Stellenbosch, serving as a research and training facility for health professionals.

TB patients referred to TAH generally require specialised clinical investigations or treatment which is not available at other levels of care. The hospital therefore sees patients with more complex disease such as chronic (retreatment) or drug resistant TB, Extra Pulmonary TB (EPTB), or patients with co-

morbidities with other diseases such as HIV and diabetes. Patients may also be referred for another primary problem, and a secondary diagnosis of TB is made in hospital.

TAH provides acute care for adult and paediatric patients, with an average hospital length of stay (LOS) of 13 days (57). Newly diagnosed PTB patients are managed on standardised treatment regimens for a minimum of six months, retreatment TB patients for 9 months, and drug resistant TB patients for up to 18 months or longer. They cannot be retained at TAH for the full duration of treatment, and are therefore referred for ambulatory TB treatment at PHC facilities or for further hospitalisation at specialised TB chronic care hospitals. Hospital clinicians were concerned whether patients reached these NTP services to continue their treatment, particularly as many TB patients were re-admitted to hospital and no information was available to confirm whether they continued or completed TB treatment after discharge.

It is within this context that this study of the continuity of care for TB patients discharged from Tygerberg Hospital in the Western Cape, South Africa was undertaken.

Statement of the problem

TB patients who are discharged from hospital do not continue and complete TB treatment at other services and experience poor TB treatment outcomes. This is largely due to a lack of integration of public acute care hospitals with the NTP. Poor continuity of care and failure to complete TB treatment and be cured increases the risk of chronic disease, TB drug resistance, and avoidable re-hospitalisation. This increases the costs of care to the patient, the community and health system and contributes to the ongoing spread of TB in communities.

Continuity of care was defined as ‘the provision of coordinated care and services over time, and across levels and disciplines, which is coherent with the patient’s health needs and personal circumstances’ (2). The main outcome measure of continuity of care used in this study was whether TB patients discharged from hospital were registered at NTP services to continue TB treatment within one month of hospital discharge. A secondary outcome was the patients’ TB treatment outcome as recorded in the national TB register system.

Rationale for the study

Poor continuity of TB care between hospitals and NTP services contributes to poor TB treatment outcomes of TB patients admitted to acute care hospitals in South Africa.. There is insufficient understanding of continuity of TB care between hospitals and NTP services, and a lack of good quality evidence of interventions to improve continuity of TB care to inform policy and practice in South Africa.

Local research is needed to describe, understand and improve continuity of care for TB patients discharged from acute care hospitals in South Africa. This research should describe the quality and continuity of care for TB patients discharged from acute hospitals; identify factors affecting continuity of care between hospitals and NTP services; identify evidence of effective strategies to improve continuity of care; and develop, implement and evaluate appropriate evidence informed strategies in the South African context.

Research questions

Can evidence informed discharge management interventions be implemented to improve continuity of care for TB patients discharged from acute care hospitals in South Africa, and what are their effects on TB patient treatment outcomes?

1.1.1 Do TB patients discharged from an acute hospital reach PHC TB services or specialised TB hospitals to continue TB treatment? What risk factors are associated with poor continuity of care for TB patients?

1.1.2 Which strategies are effective in improving continuity of care for TB and other chronic disease patients discharged from hospitals in low and middle income countries (LMIC's)?

1.1.3 What are the effects of a package of 'evidence informed' interventions implemented at TAH on continuity of care for adult TB patients discharged from an acute public hospital in Cape Town?

1.1.4 Which factors facilitate or impede implementation of an 'evidence informed' intervention to improve continuity of care for TB patients discharged from an acute public hospital in Cape Town?

1.1.5 How can the knowledge from this study be translated into policy and practice to assist health care decision makers to improve continuity of care for TB patients discharged from general hospitals?

Aims of the study

The study will describe the continuity of care for TB patients between TAH and secondary and primary levels of care, and identify risk factors for poor continuity of care. It will identify and synthesise evidence of interventions to improve continuity of care for TB patients discharged from hospital; develop, implement and evaluate an 'evidence informed' intervention to improve continuity of care at TAH, and develop a policy brief to translate the findings into policy and practice in the Western Cape, South Africa.

Objectives

1. To describe continuity of care and risk factors for poor continuity of care for TB patients discharged from a public acute care hospital in the Western Cape, South Africa;
2. To synthesise evidence from systematic reviews on continuity of care between hospitals and PHC services for patients with chronic diseases, particularly TB and HIV, in low and middle income countries (LMIC's);
3. To conduct an outcome evaluation of an intervention to improve continuity of care for TB patients discharged from a public acute care hospital;
4. To conduct a process evaluation of the implementation of an intervention to improve continuity of care for TB patients discharged from a public acute care hospital;
5. To develop a policy brief to facilitate the transfer of knowledge on strategies for continuity of care for TB patients discharged from hospital.

Study methods

This study used appropriate research methods to answer each research question and achieve each objective as illustrated in Figure 2. These included descriptive and analytic quantitative methods, research synthesis, qualitative research methods, and mixed methods. These are described in further detail in the relevant chapters. The study applied participatory action research (PAR) methods by including decision makers and service providers in every stage of the research from defining the research questions, selecting the methods, conducting the research, interpreting the findings and translating the findings into policy and practice.

The knowledge generated is based on an 'evidence informed' intervention which is locally relevant, applied and evaluated within the context of health services in the Western Cape. The study aimed to ensure that the intervention was integrated in routine services, was sustainable after the withdrawal

of the researchers, and that health service providers would be in a position to scale up the intervention.

Knowledge gained through the study has been 'packaged' in a policy brief for communication to policy makers.

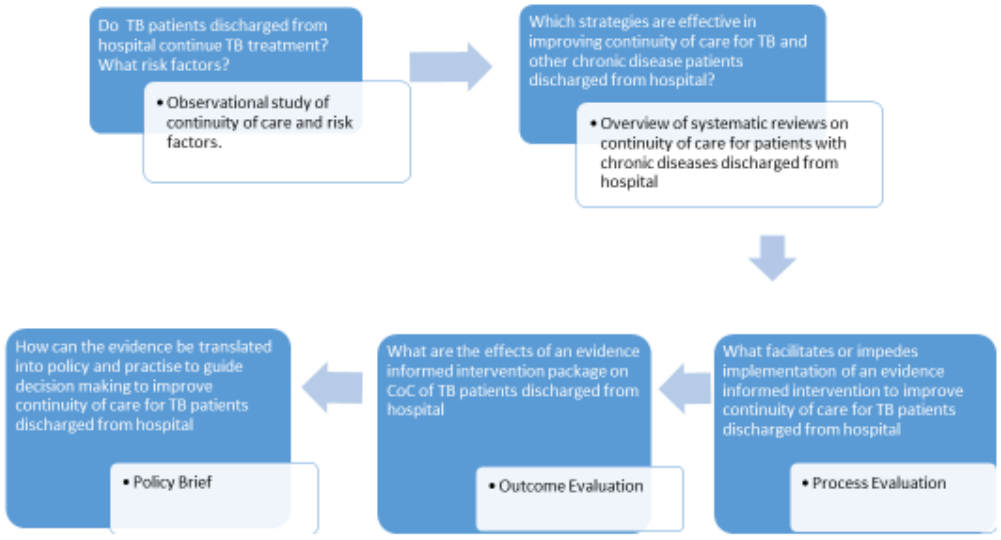

Figure 2: Flow diagram of research questions and studies on continuity of care for TB patients discharged from hospital in the Western Cape.

Chapter outline

Chapter 2: Literature review

The literature review aimed to describe and understand the current knowledge on continuity of care for TB patients discharged from hospitals to other levels of the health system, and to identify the gaps in knowledge particularly as it related to LMIC's. It also aimed to clarify definitions and key concepts, to provide a theoretical framework and to inform the research methods to be used in the study.

Chapter 3: Descriptive study

Title: Mind the gap! Risk factors for poor continuity of care of TB patients discharged from a hospital in the Western Cape, South Africa

This retrospective observational study used routine information to describe continuity of care and risk factors in TB patients discharged from an acute referral hospital in the Western Cape. The study described hospitalised TB patients, their clinical management, whether they arrived at PHC services after discharge, and the outcomes of TB treatment. An analytic component assessed associations between the outcomes and explanatory variables.

Chapter 4: Overview of systematic reviews

Title: Overview of strategies to improve continuity of care for chronic diseases between hospitals and primary care services in low and middle income countries.

This overview sought to identify and collate the evidence from systematic reviews of interventions to improve continuity of care for chronic diseases, including chronic communicable diseases, in all settings which may be appropriate for application in LMIC's. The overview followed the approach to conducting an overview of reviews as described by Becker and Oxman in the Cochrane Handbook for Systematic Reviews.

Chapter 5: Outcome evaluation

Title: An outcome evaluation of an intervention to improve transitions in care for TB patients discharged from hospital in the Western Cape, South Africa

This outcome evaluation was conducted after the implementation of a complex intervention to improve continuity of care for TB at an acute referral hospital. The main outcome which the intervention aimed to achieve was to increase the proportion of discharged hospital TB patients who continued TB treatment at PHC services and specialised TB hospitals. A secondary outcome was to improve TB treatment outcomes as per the NTP. The evaluation used a 'before and after' controlled (quasi-experimental) study design to assess whether these outcomes were achieved.

Chapter 6: Process evaluation

Title: Understanding the Implementation of an Intervention to Improve Coordination of Care for TB Patients in South Africa: A process evaluation.

A lack of understanding of how interventions work to improve coordination of TB care between hospitals and PHC services limits our ability to replicate and scale up interventions. This study sought to understand the implementation of a complex intervention to improve coordination of care of TB patients discharged from a referral hospital to PHC services in the Western Cape, South Africa. The

process evaluation was guided by an adapted Consolidated Framework for Implementation Research (CFIR), and included a directed qualitative content analysis of documents, semi-structured key informant interviews and analysis of process monitoring data which were triangulated to identify barriers and facilitators of implementation.

Chapter 7: Policy brief

Title: A Policy Brief on Continuity of Care for TB patients discharged from hospital.

This chapter is a policy brief on continuity of care for TB and chronic disease patients to facilitate the transfer of knowledge on strategies for continuity of care to health decision makers and service providers. The development of the policy brief draws on best practice and evidence from the field of knowledge translation. The brief was based on all the studies in this thesis, including the overview of evidence from the literature, workshops with health service providers and the findings of the above study of an 'evidence informed' intervention to improve continuity of TB care for patients discharged from a hospital to PHC services in the Western Cape.

Chapter 8: Discussion

This chapter highlights and discusses the key findings of each of the studies in chapters 2-7. It compares the results to what is known, and reflects on reasons for similarities and differences in the findings to previous studies. Limitations of the studies, and the relevance and application of the findings to improving continuity of TB care in different settings are discussed.

Chapter 9: Conclusion and future directions

This chapter discusses the overall contribution of the study to the knowledge and practice of continuity of care for TB patients discharged from hospital in South Africa. It identifies gaps in our knowledge and new research questions which emerge from this study to inform further research and practice to improve continuity of care for TB patients discharged from hospital in South Africa.

Chapter 2: Literature review

This literature review aimed to assess the current knowledge on continuity of care for TB patients discharged from hospitals to care at other levels of the health system, and to identify the gaps in knowledge particularly as it related to LMIC's. It also aimed to clarify definitions of key concepts, to provide a theoretical framework for the study, and to inform the research methods to be used in the study. The review focused on four main topics:- i) The management of TB as a chronic disease; ii)

Defining Continuity of Care; iii) Experiences of high TB burden countries of continuity of care for TB patients between hospitals and national TB control programmes; and iv) Health systems complexity and implementation science.

The management of TB as a chronic disease

> "the relevant distinction is no longer between communicable and non-communicable diseases, but rather between chronic and acute. There are more similarities between the way we deal with AIDS and diabetes than between AIDS and acute infection. Indeed the epidemiological transition is associated with a change in the temporal nature of most ill health." (58) Julio Frenk, 2009

The HIV epidemic brought a new perspective on chronic infectious diseases including TB and malaria. The need of HIV infected individuals for care over a long term basis, particularly since the advent of ART, led to a recognition that the delivery of health care for chronic infectious diseases has much in common with that of chronic non communicable diseases (58). TB behaves as a chronic disease because of the long duration of drug treatment particularly for 'retreatment' disease and drug resistant TB disease, and the large proportion of TB patients who remain chronically infected and experience disease relapses across their lifetime (59).

Chronic diseases, both communicable and non-communicable, are a leading cause of morbidity and mortality, and a major reason for utilization of health services in South Africa and other LMIC's (18,60,61). The co-morbidities of TB with HIV and other chronic diseases such as diabetes and chronic obstructive pulmonary disease further highlight the potential impact on the health system, and importance of rethinking approaches to the management of the 'colliding epidemics' of NCD and chronic communicable diseases in LMIC's (20,62,63). There is a need to reform health care services, currently largely geared to the needs of acute care, to cater for the ever-growing need of the many patients with chronic conditions in LMIC's (58,61,64). Chronic disease patients require multiple interactions with health services, involving numerous service providers and levels of care, over their lifetime. The linkages between providers and levels of care within the health system for chronic diseases are therefore critically important to ensure continuity of care, optimise health outcomes and ensure efficient utilisation of scarce health care resources.

Numerous interventions to improve coordination of care between providers and across levels of care for chronic disease patients have been identified in well- resourced health systems (65–67). However, much of this evidence has focused on interventions for specific diseases, resulting in fragmentation of

care and inefficient use of resources. Models for integrating care across chronic diseases management such as the 'Chronic Care Model' (CCM) were developed and widely adopted in response to fragmented and poor quality care for chronic diseases in the USA (68,69). The model proposed extensive reorganisation of the system of health care delivery to respond to chronic care and has been modified and adopted in many other high income settings (70). The CCM inspired WHO's 'Innovative Care for Chronic Diseases Framework' (ICCDF), which emphasise the importance of coordination and continuity of care in all health care settings (71).

In LMIC's, where poor linkages and a lack of coordination of care between levels for chronic diseases undermine access to and the quality of care, little research has been undertaken to describe and understand the problems or to test interventions to improve continuity of care for chronic diseases (40,48,64). However there is a growing interest and adaptions of the ICCDF and models of care for chronic diseases to address this increasing burden and complexity attempt to respond to the different contexts of LMIC's (18). LMIC's differ both in the chronic diseases that are most prevalent, the nature of the co-morbidities, and the demographics of patients such as the younger age of HIV and TB patients as compared to chronic disease patients in High Income Countries (HIC)(18). These are further compounded by differences in health systems accessibility, resourcing and organisation of care in LMIC's to respond to chronic diseases (64).

In researching the problem of continuity of care for TB patients between hospitals and other levels of care in South Africa, I have therefore searched the literature from LMIC's and HIC's on continuity of care for chronic communicable and non-communicable diseases to understand current concepts and evidence, and to identify gaps in knowledge which may be relevant for research on continuity of care for TB in South Africa.

Continuity of care for chronic diseases

Patients with chronic diseases are seen by an array of health care providers, in different organisations, places and levels of the health care system, often resulting in fragmentation of care. Many different terms are used interchangeably in the literature to describe the relationships and the organisation of care between hospitals and other levels of the health system which seek to reduce such fragmentation.

Commonly used terms were **integration of care**, coordination of care, **continuity of care**, and **care transitions**. In this section I discuss the definitions and use of these terms, in order to identify

appropriate terminology for the problems and potential solutions of fragmented care for TB and other chronic disease patients in the South African context.

Integration of health care is defined as the "bringing together of inputs, delivery, management and organisation of services as a means [of] improving access, quality, user satisfaction and efficiency" (72).

> ' integration is the "glue" that bonds the entity together. It includes structures, processes and activities within the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between health care sectors. The goal is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long term problems cutting across multiple services, providers and settings. The result of such multi-pronged efforts to promote integration for the benefit of these special patient groups is called "integrated care." '

This recognises that organisations and health systems consist of multiple separate components, organised in hierarchical structures. These components are however interconnected and are required to function in a complementary fashion, but separations in divisions, departments and specialized functions, often mitigate against efficient collaborative functioning within the system. Therefore particular strategies are required to facilitate improved cooperation and collaboration between different components of the organisation or system to promote efficient and effective care.

A review commissioned to inform 'integration' in the Canadian health system found that a wide range of definitions, descriptions and measures of integration existed, and there was little evidence in the literature of its effects on quality of care (73). A systematic review on integration of health care delivery in LMIC's focused on the integration of service delivery within PHC settings (74). The included studies were mainly vertical programmes for priority diseases, and did not address integration related to chronic diseases across different providers or levels of care. However as in the Canadian review, a range of different types of integration were found, as well as stages of integration ranging from simply sharing of information (linkages), to a more structured 'coordination', to full integration of systems, services and resources under a common structure and management (75).

A comparison of integration studies in HIC's and LMIC's similarly found that definitions and descriptions covered a very wide range of activities within the health system (76). It also found that the literature on integration of care from HIC's focused on issues related to chronic diseases, whereas LMIC's research on integration was focused mainly on the issues of vertical programmes for acute

diseases, and suggested that there were lessons which could be shared from these respective focus areas.

In exploring the concept of **continuity of care**, Haggarty et al undertook a literature review and consultation process across a wide range of disciplines, diseases, and settings to develop a common understanding of the concept of continuity of care (77). They found that the term continuity of care had meanings which differed across disciplines and settings. In primary care settings it was defined as continuity in the relationship between one care provider and the patient over one or more episodes of care. In mental health care the term emphasized coordination of services between different providers, with whom the patient developed a stable relationship over time. This introduced the concept of a care team within which continuity is maintained through a common or shared care plan and included a wide range of service providers, including social services, housing and others.

Continuity of care in nursing emphasized the transfer of information, particularly communication between nurses over time, with a focus on discharge planning after acute care, usually from hospital to community, home or self-care. A disease management perspective, mainly from specialist clinicians in response to the complexities of managing chronic diseases between different providers, focused on patient management in terms of care protocols to ensure timeous and coherent links in care.

Two core elements of continuity of care which emerged as a common feature in the review were a focus on the care of an individual patient, and care over time. The unit of measurement of continuity of care was therefore the patient (as compared to services or programmes which are the focus of 'integration' or 'coordination'), and the chronology over time which could be short as in post-acute hospital care or longer term.

Three types of continuity were found to be common to all disciplinary perspectives. This included **informational continuity**, linking care from one provider to another, and one episode of care to another; **management continuity** involved the coordination of care across providers to ensure complementary and timeous care for complex conditions; and **relational continuity** addressing the consistency of care by an individual or team of providers, with whom a relationship of trust was established over time with coherence and predictability in the care process (77). This review proposed a definition of continuity of care as 'the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's needs and personal context' (77).

This was updated and modified in a more recent scoping review of the definition and use of 'continuity of care' for chronic diseases in resource constrained settings. I have applied this modified definition in this study:-

> 'Continuity of care is the provision of coordinated care and services over time, and across levels and disciplines, which is coherent with the patient's health needs and personal circumstances' (2).

The third concept which was useful to describe the links between the hospital and other levels of care for the patient, was **'transitional care'** defined by Coleman as:-

> 'the set of actions designed to ensure coordination of care received by patients as they transfer between different locations or levels of care' (78).

A care transitions measure, aligned with the concept of patient centredness, was developed to assess performance in ensuring transitions in care which aligned with the Institute of Medicine (IOM) definitions of quality (79,80). This measure included assessment of actions like discharge planning, but also assessed patients' readiness for 'self-care' in the community, including knowing which services to access, and how to do so. In applying the measures in the USA, they found that patients with poorer self-assessed health status, had significantly lower care transition scores. This was consistent with previous studies and suggested that care transitions are particularly important for individuals with a high burden of illness.

In selecting the appropriate terms for my study, the broad scope and range of definitions and descriptions of integration as well as its focus on the organisation of health care and not directly on the effects of care on the individual patient, made it too broad for the kind of integration and effects on patient care which I wanted to study. The concepts of continuity of care and transitions in care provided a clearer description of the nature of the links between hospitals and other levels of care and the patient related outcomes that this study was concerned with. I have therefore used the latter terms, continuity of care and care transitions, to discuss the problem and the interventions in subsequent sections and chapters.

Continuity of care for TB patients in high TB burden countries

This section describes the experiences in care transitions for TB patients in other high burden TB countries, including factors that affected continuity of care, and interventions or strategies used to improve continuity of care. Most of the literature described experiences in Indonesia, India and China,

the three countries with the highest global TB burden. These countries had assessed the role of general hospitals in TB Control, and implemented interventions since 2000 to improve the linkages with the NTP.

The WHO STOP TB Strategy of 2006 emphasised the importance of engaging health care providers that had not traditionally participated in NTP's (26). Hospitals, both public and private, were identified as important sites of case detection and care of TB patients that remained unreported through NTP's. This was motivated by several studies in LMIC's which documented the large number of TB patients seen at private and public hospitals, and the poor quality and continuity of care for TB patients at these facilities. A 2005 survey of 539 urban hospitals in six Asian countries and Egypt found that the quality of TB care in hospitals with no links with the NTP was unsatisfactory, with poor follow up of patients (31). Hospitals involved with the NTP complied more closely with the NTP diagnostic and treatment guidelines, and had better referral links and follow up for TB patients, but still achieved <70% successful treatment outcomes.

In India, after the Madras study in 1959 found that TB treatment could be offered on a domiciliary basis (81), the NTP had focused almost exclusively on delivery of TB care through PHC services. India's adoption of the WHO DOTS programme in 1998 was also directed at PHC services and did not include hospitals. A national survey in 2004 found that large numbers of TB patients were in fact being treated in secondary and tertiary hospitals, that the TB treatment offered did not comply with NTP guidelines, and that the costs of treating TB patients in hospital exceeded the annual NTP budget (82).

In response, medical colleges attached to teaching hospitals in India became actively involved in contributing to TB control policy, and integrating the NTP into hospitals and the teaching of health professionals (83). The NTP also provided support for operational research by medical colleges on the integration of the NTP, and effects on the quality of care. Several studies reviewed components of this, mostly finding that there was good compliance with NTP treatment guidelines, and that the quality of TB care had improved. In a tertiary hospital in Hyderabad, 98% of TB patients were treated in line with the NTP, and there were good links to peripheral services with 74% of TB patients continuing care after discharge from hospital (83).

In China, prior to 2000, TB treatment through the NTP was limited to dedicated public TB dispensaries and specialist TB hospitals which were funded by government. A national survey in 2000 however found that 34% of TB patients initially presented to general hospitals, and only 13% of these were referred to and continued TB treatment in the public health system. The general hospitals were only partially funded by government, and the quality of TB treatment and continuity of care was poor (84).

From 2004, interventions were piloted in 9 counties in China to improve the reporting, referral and follow up of TB patients between the general hospitals and public health TB services. The interventions included the introduction of the NTP clinical guidelines for management of TB as well as the recording and reporting system, and standard TB referral forms into general hospitals and training of staff in referring patients. A national internet based disease reporting system also allowed hospitals to report all TB suspects and cases. The local Centre for Disease Control (CDC) checked the internet reporting system to assess whether the patients had arrived at the public health facilities, and followed up any who had not arrived. A coordinating group consisting of representatives of the hospitals, public health facilities and CDC, facilitated collaboration across the levels of health care.

These interventions resulted in a significant increase to more than 80% of TB patients successfully referred from the general hospitals to public health facilities to continue TB treatment (85). These successful pilot studies informed the development of national guidelines for the management and referral of TB patients from general hospitals, and integration of the general hospitals with the public health TB control system.

In Indonesia, ranked third in terms of high TB burden, public and private hospitals treated three times as many TB patients as government health centres in 1999, but did not use NTP guidelines or report on these patients (86). The hospitals provided poor quality of TB care, had inadequate infection prevention and control practices, and lacked linkages for TB patients to other health services.

A pilot Hospital DOTS Linkage (HDL) project was established in a partnership between the Ministry of Health and the Hospital Association in Yogyakarta Province, as well as three other Provinces between 2000 and 2005. The objectives were to i) address human resource development for TB control; 2) to establish a uniform recording and reporting system for TB patients in hospitals and health centres; 3) to establish tracing and referral mechanisms for patients moving between sectors; and 4) to integrate the laboratory network between hospitals and the provincial reference laboratory (86). Monitoring and evaluation of the Yogyakarta pilot found that TB case finding, notifications and treatment outcomes improved in the hospitals. The pilots influenced the NTP strategies including a policy on Public Private Mix (PPM) for which the main focus was integration of hospitals with the NTP.

A subsequent multiple case study review of quality of TB care was conducted in eight hospitals including public teaching and non-teaching hospitals and private hospitals in Yogyakarta Province and another ‘non HDL’ Province. The hospitals in Yogyakarta had implemented more of the structure and process components for TB care, and achieved better TB treatment outcomes than the non HDL Province. The study identified important processes, such as commitment (by clinicians in particular)

and good systems and communication between facilities as factors contributing to improved outcomes (87).

There were similarities and differences in the strategies to integrate general hospitals into the NTP across these three countries. They all introduced the national standardised clinical guidelines for TB, integrated laboratory systems, reporting and referral of TB patients, and provided training of personal in general hospitals. They also established coordinating structures either within the hospitals or at higher levels of the local health system to facilitate collaboration within and across institutions and sectors to support continuity of patient care. All the countries also promoted operational research on the quality of TB care in general hospitals.

China enhanced their strategy by providing an internet linked disease reporting information system which facilitated information sharing between the general hospitals, 'TB dispensaries' and TB hospitals, and allowed for active follow up of missing TB patients. India actively involved medical colleges and clinicians as champions of improving quality of care for TB patients in tertiary and secondary hospitals. The medical colleges influenced the national NTP guidelines which were then integrated into the curricula for health professionals to improve compliance of clinicians with the NTP management of TB patients.

There is some evidence that the interventions improved hospital TB care and continuity of care for TB patients in these three countries. However the studies were mainly observational, and it's difficult to attribute improvements to specific interventions during periods when numerous other health systems changes occurred in these countries. Several studies subsequently documented substantial gaps in the care and continuity of care for TB patients in general hospitals which had not been adequately addressed (88–90).

Few studies have been conducted on the management and care transitions of TB patients in general hospitals on the African continent. A Zimbabwean prospective study of quality of care using TB management as a tracer condition in four tertiary hospitals, found that the hospitals did not meet local and international standards for TB care (38). The study however focused on the acute inpatient management, and did not address the quality of discharge management and continuity of care.

South Africa's experiences appear to be similar to that of India, China and Indonesia, with acute care hospitals not being included in the NTP prior to and following the implementation of the WHO DOTS strategy in 1995. Two South African studies also found poor quality and continuity of care for TB patients in acute care hospitals (36,37). Although interventions were implemented at these two hospitals, only one was evaluated and found substantial improvements in continuity of care for TB

patients (48). The evaluation was designed as a before after study of a package of activities, and it was difficult to assess which components of the package contributed to changes, or if there were other changes in the environment which may have resulted in the improved continuity of care. The TB care cascade in South Africa provided estimates of the missing cohort of unregistered TB patients at 36%, with losses occurring at multiple levels of the cascade, contributing to an underestimation of the TB burden and overestimation of the performance of the NTP (35). Many of the missing TB patients were postulated as receiving care at non NTP services in the public health sector, as opposed to India where most are in the private sector (91). As the TB patients admitted to public sector acute hospitals in South Africa have more complicated and severe TB disease with a higher mortality rate, their absence in the NTP information contributes to an underestimation of the overall TB burden and an overestimation of the performance of the NTP.

A recent systematic review on public private partnerships for TB control included studies of interventions to create links between private and public hospitals and the NTP's in several countries (32). Most of the studies were in Asia, and the few studies from South Africa and other African countries did not include public hospitals. The review provided little evidence on effectiveness of interventions to improve transitions in care for TB patients treated in public acute care hospitals.

The studies of interventions in other high TB burden countries provided useful information about the types of interventions, processes of implementation, and challenges experienced. However, they provided insufficient quality evidence of effectiveness of interventions to improve the quality of care and continuity of care for TB patients between levels of care.

In order to inform the development of an intervention to improve continuity of care at TAH, we therefore conducted an overview of systematic reviews of interventions to improve continuity of care for all chronic diseases, communicable or non-communicable, to identify interventions which may have relevance for TB policy and practice with respect to the role of general hospitals in South Africa. This overview is described in chapter 4.

Health systems complexity and implementation science

> 'Every system is perfectly designed to get the results it gets'. W. Deming

This section reviews relevant literature to understand factors contributing to fragmentation of health care, how interventions to improve continuity of care between levels of care might work, and to identify appropriate study designs to address the research questions raised in this study.

Health systems and health care institutions are among the most complex and interdependent entities known to society (92). Health institutions are typical of early 20th century organisations which were designed mechanistically with 'bureaucratic hierarchies, centralized control, discipline, division of labour, standardized procedures, with emphasis on planning rather than improvisation, and minimal relationships to those outside the organisation – closed systems are artefacts of this era' (93). The various components of the health system or of health institutions function in isolation or are not coordinated resulting in fragmentation rather than harmonisation of the delivery of health care. Health care has also been organized to provide episodic management of acute illnesses in response the burden of disease of earlier centuries. With increased life expectancies and the epidemiological transitions to a higher burden of chronic diseases, the design of health systems in LMIC's has responded poorly to the need for continuity of care over time and health care providers (58).

Developments in medicine and technology over the past century have also contributed to increased complexity in health care. Complexity is broadly defined as 'interdependencies of many parts which interact with each other in multiple ways, culminating in a higher order of "mergence" where the whole is greater than the sum of its parts' (93). With the growing recognition that mechanistic thinking was not able to explain the unpredictability of health care organisations, 'Complex Adaptive Systems' (CAS) theory provided a better understanding of how health systems behave (94). CAS was originally developed from studies of the natural world in physics, biology and philosophy but increasingly applied to understand how organisations function. A CAS 'consists of many individual agents, which are free to act in ways which are not totally predictable, and whose actions are interconnected so that one agent's actions changes the context for other agents' (95).

Health systems are typical of CAS's, in that they are dynamic, consist of many components and 'agents' which behave and interact in ways which are not predictable (95). This perspective of health systems suggests that there may be substantial challenges in implementing interventions and innovations. Reductionist thinking and mechanistic models of development, implementation and evaluation of interventions do not sufficiently anticipate the kinds of difficulties which invariably occur, and are not designed to explain why interventions work or fail within the context of organisations.

Greenhalgh's systematic review of 'Innovations in Service Organisations' drew on the literature from the health sector, but also across a wide range of disciplines to develop a framework to understand and explain why and how innovations were implemented in complex health systems (96). In particular it was informed by CAS theory and attempted to take into account the many agents and factors within the health system which determined whether innovations are adopted, implemented and diffused. (Figure 1).

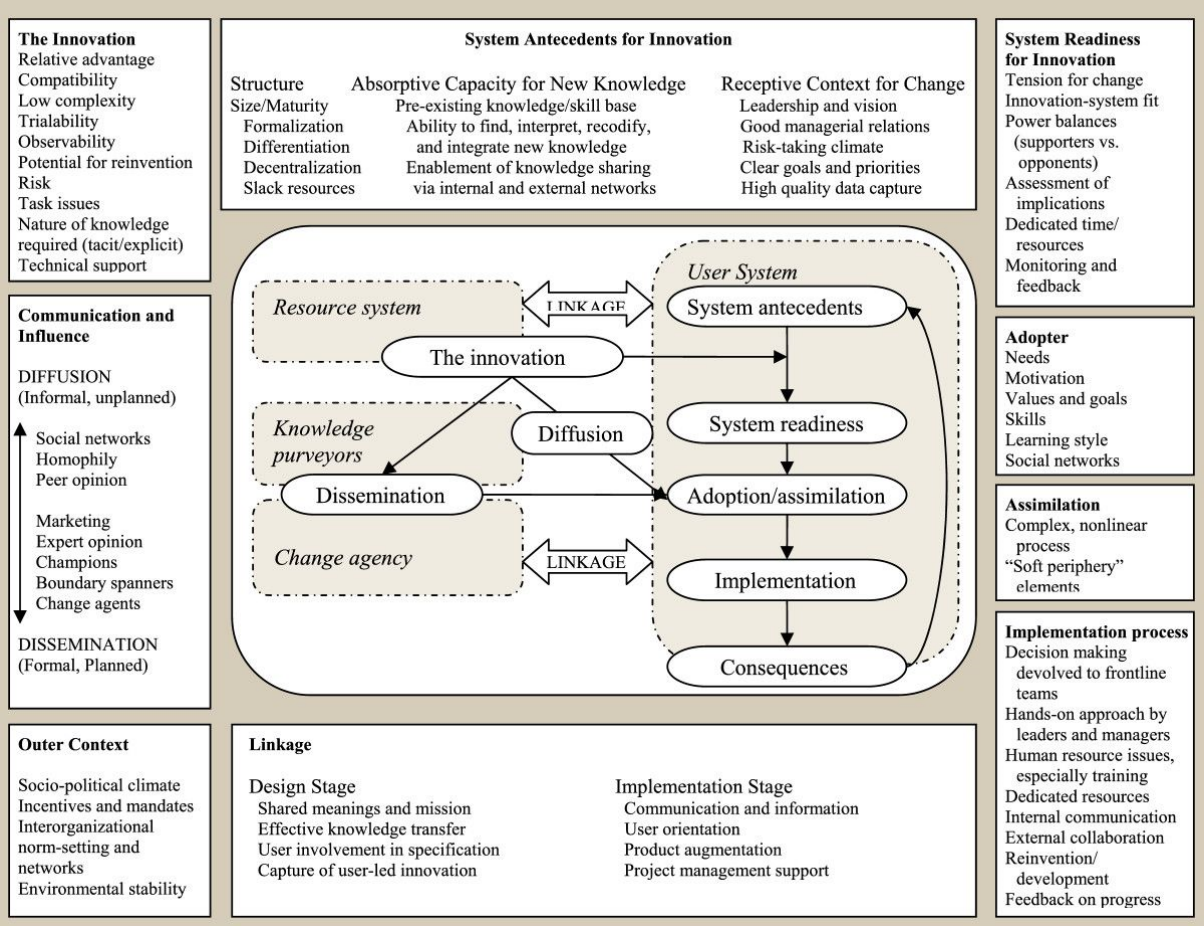

Figure 1: Conceptual model for the determinants of Diffusion, Dissemination and Implementation of Innovations in Health Service Delivery and Organisations, Based on a Systematic Review of Empirical Research Studies. Greenhalgh 2004.

This framework identified factors related to the innovation itself, the implementers, the context, and the process of implementation which influenced if and how innovations or interventions were implemented or not. The framework helped to shift thinking of implementation of interventions as single clinical processes, based on the adoption of practices by individual health professionals which failed to recognise and address the complexities of adoption, implementation and diffusion of innovations within organisations.

Building on CAS theory, Anderson and McDaniel in studies of health care organisations, tested a hypothesis that management practices which encouraged interaction, learning and innovation facilitated the development of relationships and cooperation between staff in the organisations, and ultimately improved patient outcomes (97). In essence, the interventions facilitated 'dynamic interactions of diverse agents who self-organise and produce adaptations in organisations in ways which cannot be predicted or controlled to create positive outcomes' (97). Holden's 2005 analysis of

the application of CAS to health systems proposed that 'The application of an understanding of a health care organisation as a CAS involves cultivating an environment of listening to people, enhancing relationships, and allowing creative ideas to emerge by creating small non-threatening changes that attract people' (98).

A similar approach of engaging research 'subjects' or 'participants' was established in the social sciences, informed by 20th century social movements in community development, education, civil and women's rights (99,100). The aim of these 'emancipatory' research approaches was to link research and social action while addressing unequal power relationships in research through collaboration between researchers and participants in defining the research problems, developing, implementing and assessing the solutions. It also aimed to facilitate learning for participants and researchers, and to empower individuals and communities to sustain interventions beyond the research (101). Described as Participatory Action Research (PAR) these methods enabled research to be:-

- Participative, in that it engaged research subjects and users throughout the research process;
- Democratic, in that it used techniques of consensus to decide how research should be directed;
- Action focused, because the research question was framed explicitly by the needs of the individuals or communities themselves. The research was problem focused, context specific and future oriented, involved a change intervention, aimed at improvement and involvement, and involved a cyclic process of research, action, and evaluation.

PAR is therefore a systematic investigation, with the collaboration of those affected by the issue being studied, for the purposes of education and action or effecting change (102).

The field of Implementation Science (IS) has begun to draw on complexity science as well to understand the factors that affect implementation of interventions. This relatively new but broad field has involved scientists and practitioners from a wide spectrum of research paradigms and schools of thought.

Evidence based medicine (EBM), recognising that many interventions found to be effective in trials are not implemented (103–105) or take a very long time to be adopted (106), has increasingly explored mechanisms of 'research translation' to promote the uptake and implementation of research findings (107). An EBM definition of implementation science is 'the scientific study of the determinants, processes and outcomes of knowledge translation.' (107) This perspective starts with the synthesis of

knowledge through systematic reviews as a product which can be translated into practice. It also seeks to identify barriers and enablers of implementation, and interventions to change behaviours of patients, health professionals or decision-makers (108,109). Approaches from evaluation research have been adopted by EBM, including applying theory of change, conducting feasibility studies, and measuring 'processes' or intermediate indicators of success rather than clinical outcomes only. Approaches to knowledge translation have also increasingly recognised that participatory processes from the point of identifying a research question, to developing the research methods, undertaking and interpreting the research, are important in facilitating adoption of research findings (110).

In the USA, Implementation Science was linked to and influenced by Improvement Science and Quality Improvement research. In response to the Institute of Medicine (IOM) 'To Err is Human' and 'Crossing the quality chasm' reports which identified the failings in the quality of health care, researchers and practitioners explored different theories and approaches to improve the quality of health care in USA (68,80,111). Improvement Science which had been extensively used in industry was adopted by the health sector to inform quality improvement approaches. Improvement Science, based on Deming's 'System of Profound Knowledge', included systems thinking, studying variation, theory of knowledge and psychology (112). His inclusion of psychology sought to explain and change how individuals behaved within a system, and in interaction with others. Implementation science in the USA therefore included a focus on individuals' behaviours, but also an understanding of broader processes, and the nature of organisations and systems which impact on improvements in health care.

Implementation Research (IR) as described by WHO is 'the systematic approach to understanding and addressing barriers to effective and quality implementation of health interventions, strategies and policies' (113). It is demand-driven, with research questions framed on the basis of needs identified by relevant stakeholders/implementers working together in the health system'. WHO takes a health systems perspective of implementation research, describing it as 'an ongoing process that provides continuous feedback of results back to the health system, facilitating adaptation of services and interventions'. IR is therefore characterized by the complex, iterative, systematic, multidisciplinary and contextual processes that take place at multiple levels in order to identify and address implementation problems.

Evaluation methods for interventions in complex health systems have also evolved to respond to shifts in research paradigms over the past decade. Early evaluation research used quantitative methods exclusively to attribute or describe causality (114). With the recognition that this was insufficient to understand why or how interventions were implemented, social science research methods to support 'process evaluation' approaches to programme evaluation were adopted. These addressed the

importance of measuring and understanding the processes by which interventions are implemented (115,116). Thus a wider range of qualitative and quantitative research methods were used in a complementary way to measure processes and outcomes, and to understand mechanisms and actions which impact on implementation of interventions.

Realist evaluations went further by seeking to answer the questions of 'what works for whom in what circumstances, in what respects, and how?' (117). A realist evaluation therefore seeks to understand the intervention, the Context in which interventions are implemented, the Mechanisms of implementation, and the Outcome configurations (CMOc). Subsequent development of realist evaluations recognised that people are not passive recipients of interventions, and sought to explain how an intervention (I) is expected to work for which group of actors (A), modifying the approach to evaluating the Intervention Context-Actors-Mechanism and Outcome (ICAMO) (118).

Models and frameworks for implementation of innovations in practice environments (119–122), have also influenced approaches to evaluations of implementation of interventions (123,124). The Consolidated Framework for Implementation Research (CFIR) (122) and Promoting Action on Research Implementation in Health Services (PARIHS) (121), drew from Greenhalgh's framework and realist evaluations to assess characteristics of the intervention, the context, the actors, the process or mechanisms of implementation, as well as the outcomes. A 'Care Transitions Framework' (CTF), illustrated in Figure 2, was subsequently adapted from the CFIR to plan, implement and evaluate interventions to improve continuity of care (125). These tools for evaluating the implementation of innovations have been used extensively in high income settings but had little application in LMIC settings (126).

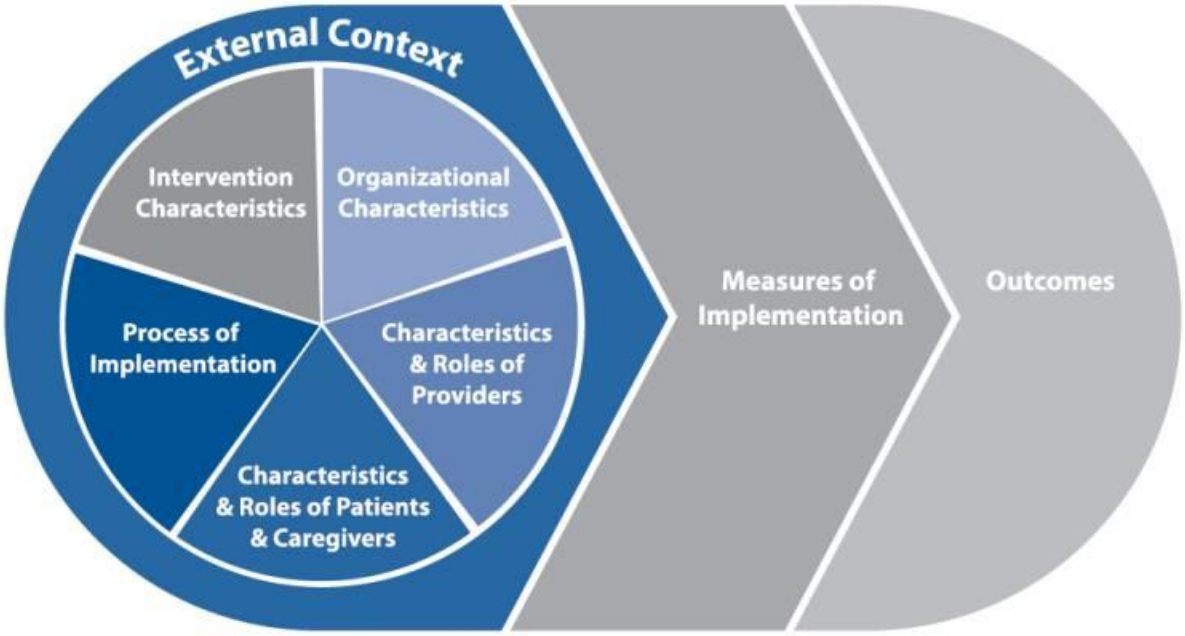

Figure 2: The Care Transitions Framework, adapted from the CFIR by Dy SM et al, 2015 (125).

Summary

This literature review has provided an understanding of TB as a chronic disease, for which continuity of care and transitions of care are important aspects of the quality of care. Although the problem of poor linkages between hospitals and other levels of TB care is well described in high TB burden countries in Asia, very little research has been conducted in Africa to describe and understand the problem. The few observational studies of interventions to improve continuity of care for TB patients conducted in high TB burden countries do not provide strong evidence of effect. And few studies have been conducted to understand the implementation of interventions to improve continuity of care for TB patients in LMIC's.

Poor continuity of care is related to the organisational design of health systems, in which fragmentation undermines integration of care, exacerbated by a focus on treatment of acute episodes of disease without consideration of the multiple contacts required by chronic disease patients.

Health systems are CAS's with multiple components and actors, whose interactions create unpredictability for the implementation of innovations. Various frameworks and theories of implementation of innovations in health systems attempt to identify the components and actions which are needed to improve implementation, and to evaluate the implementation of interventions in complex health systems. Research methods such as PAR, realist evaluations and implementation

research have also responded to the complexities of implementing interventions within health systems.

The approach and research methods used for this PhD research study have therefore been influenced by the thinking and framing by complexity sciences, and drew on these methods to develop, implement and evaluate appropriate interventions to improve continuity of care for TB patients between hospitals and other levels of the health systems in the Western Cape, South Africa.

Chapter 3: Observational study of continuity of care for TB patients discharged from hospital in Cape Town, Western Cape.

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RESEARCH ARTICLE

Mind the gap! Risk factors for poor continuity of care of TB patients discharged from a hospital in the Western Cape, South Africa

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Abstract

Background

TB patients discharged from hospitals in South Africa experience poor continuity of care, failing to continue TB treatment at other levels of care. Factors contributing to poor continuity of TB care are insufficiently described to inform interventions.

Objective

To describe continuity of care and risk factors in TB patients discharged from a referral hospital in the Western Cape, South Africa.

Design

This retrospective observational study used routine information to describe continuity of care and risk factors in TB patients discharged from hospital.

Results

788 hospitalized TB patients were identified in 6 months. Their median age was 32 years, 400 (51%) were male, and 653 (83%) were urban. A bacteriological TB test was performed for 74%, 25% were tested for HIV in hospital, and 32% of all TB patients had documented evidence of HIV co-infection. Few (13%) were notified for TB; 375 (48%) received TB medication; 284 (36%) continued TB treatment after discharge; 91 (24%) had a successful TB treatment outcome, and 166 (21%) died. Better continuity of care was associated with adults, urban residence, bacteriological TB tests in hospital and TB medication on discharge. Fragmented hospital TB data systems did not provide continuity with primary health care information systems.

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Conclusions

Discharged TB patients experienced poor continuity of care, with children, rural patients, those not tested for TB in hospital or discharged without TB medication at greatest risk. Suboptimal quality of hospital TB care and a fragmented hospital information system without linkages to other levels underpinned poor continuity of care.

Introduction

Tuberculosis (TB) remains a leading cause of preventable morbidity and mortality globally [1, 2]. South Africa, with an estimated TB incidence of 834/100 000 is ranked by WHO as one of the 30 high TB burden countries [1]. The country adopted the DOTS TB control strategy in 1995, delivering

ambulatory TB treatment at primary health care (PHC) facilities. However, the HIV epidemic in the 1990's drove a rising TB incidence rate [3], resulting in an HIV prevalence of 57% in incident TB cases in 2016 [4, 1]. The HIV epidemic and growing TB drug resistance with 3.5 % of new TB cases having multiple drug resistant (MDR) TB) [1] has increased hospital TB admissions in South Africa since the 1990's [5].

Hospitalized TB patients in many countries receive poor quality of care and are lost to follow up due to weak linkages between hospitals and other levels of care [6-9]. South African studies found that less than 50% of TB patients discharged from public hospitals continued treatment at PHC facilities [10, 11]. Socio-demographic, epidemiologic and health system differences across Provinces [12], and a lack of analysis of risk factors for poor continuity of care of patients discharged from hospitals limited generalisation from these earlier studies. This study was therefore undertaken in a 1300 bed Central Academic Hospital (CAH) receiving up to 50% of tertiary referrals from a catchment population of 5.4 million (2009) in the Western Cape. In the pre-HIV era this Province had the highest TB prevalence in South Africa, largely due to poor socioeconomic conditions and failed public health responses before and during apartheid [13].

The Provincial TB incidence of 906/100 000 at the time of this study remained one of the highest in the country [12]. Given the increasing role of hospitals in responding to the TB epidemic, we aimed to describe risk factors for poor continuity of TB treatment on discharge from hospital to inform local interventions to improve continuity of care for TB patients.

Study population and methods

This observational study was a retrospective review of records of CAH TB patients over a six month period (November 2008 to April 2009) and their outcomes post discharge (November 2008 to April 2010). Patient demographic and treatment data were extracted from routine hospital information systems, including a clinical administrative information system (Clinicom), the hospital's National Health Laboratory Services (NHLS) information and a national NHLS data warehouse, the hospital pharmacy database, notifications and death certificates in a hospital administration file. The collated data were validated against a 10% random sample of patient folders. This revealed unreliable ICD classification in Clinicom [14], and patients with a TB ICD code in Clinicom which was not verified by NHLS, pharmacy, notification or death certificate data were excluded from the study.

Outcome data on continuity of care, defined as whether discharged TB patients continued treatment at public sector PHC service or specialised TB hospitals in the Western Cape, were collected from the ETR.net (Electronic TB Register) and EDR.web (Electronic Drug Resistant TB Register). A one year follow

up period allowed for completion of National TB Programme (NTP) treatment regimens for new and retreatment TB patients and ETR.net reporting timeframes. Hospital information and TB registers did not share patient identifiers, and patient records were matched using probability data linkage on name, gender, age, area of residence, and date of treatment [15]. The ETR.net and EDR.web data were extracted by two data managers and compared for completeness. Discharged TB patients not found through electronic data linkage were sought by manually searching the ETR.net and paper-based quarterly TB registers at district offices. Data were collated, cleaned and quality checked in Excel, and analysed in STATA 13 [16]. A biostatistician provided statistical support.

Patient demographic variables included gender, age, race, employment status, and area of residence. Disease variables included HIV status, type of TB disease , and TB drug sensitivity. Hospital clinical management included length of stay (LOS), number of admissions during the study period, TB and HIV diagnostic tests, treatment for TB and HIV, and TB notification.

The main continuity of care outcome variable was patient registration for TB treatment at another public health facility in the Western Cape. Secondary outcomes included NTP treatment outcome in the TB registers, and mortality as captured in all data sources.

All data except age were treated as categorical variables. Age was treated as a continuous variable and categorised into patients < 15 years old (children) and those >= 15 years (adults). We report univariate analyses of explanatory and outcome variables; bivariate analyses using Chi^2 tests for associations between explanatory and outcome variables; and multiple logistic regression analysis.

Ethical approval was obtained from the Faculty of Medicine and Health Sciences, University of Stellenbosch (Ref: N09/05/149), and IRB exemption for data analysis from Harvard TH Chan School of Public Health (IRB17-0109). Permission for the study was also obtained from the CAH, the Health Departments of the Provincial Government of the Western Cape and the City of Cape Town.

Results

A total of 874 TB patients were identified from hospital information systems for the six month period based on an ICD code for TB and/or a record of TB diagnosis, treatment, notification or death. Of these, 86 (9.8%) lacked sufficient proof of TB and were excluded from the study.

Of the 788 included TB patients, 381(48.2%) were in Clinicom, 548(69.4%) in the NHLS database, 383(48.5%) in the hospital pharmaceutical information system, and 105(13.3%) from hospital TB notifications. Although the data sets overlapped, none included all TB patients. **Fig 1.**

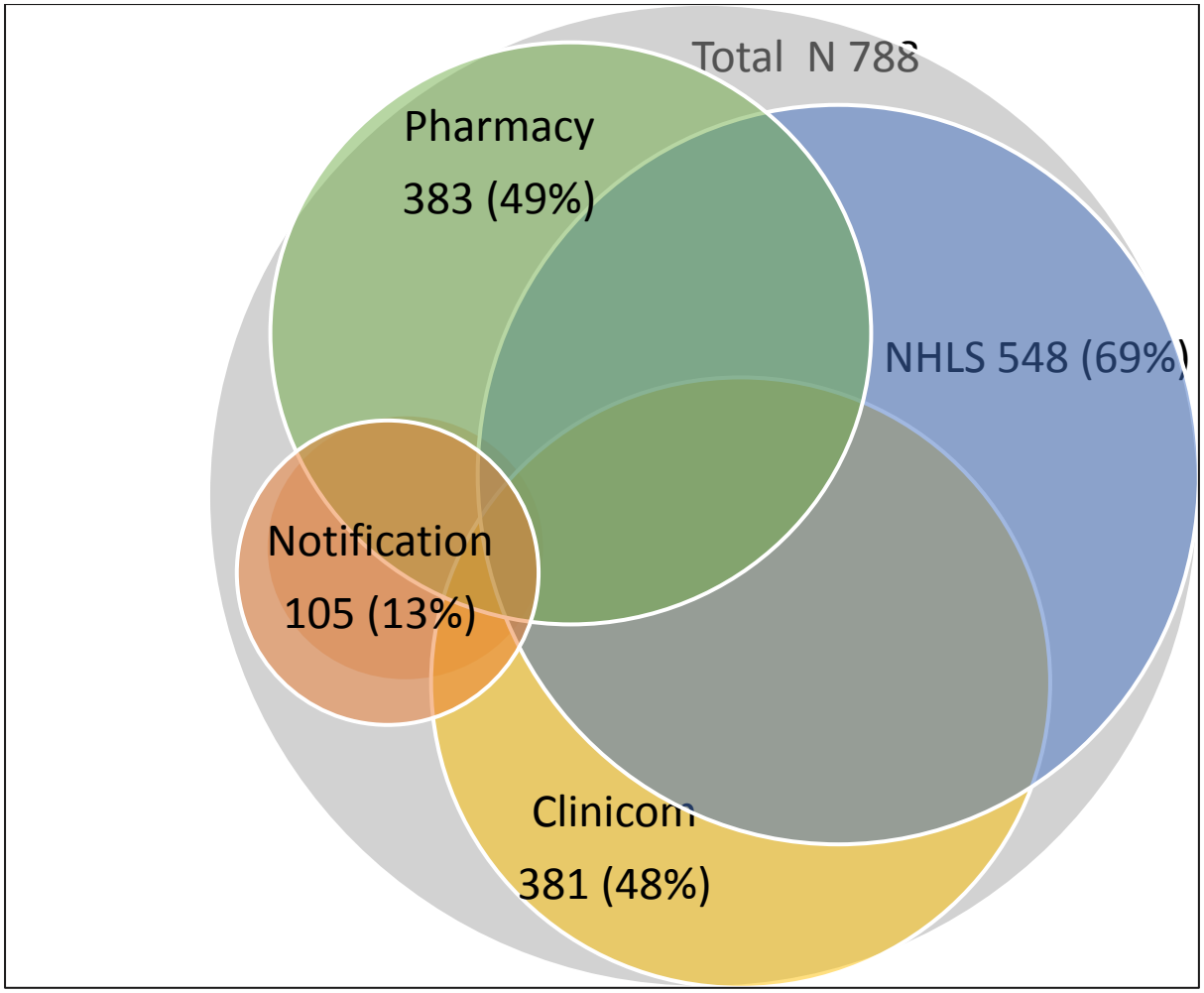

Fig 1: Percentage of hospital TB patients (N = 788) identified from different hospital databases. NHLS = National Health Laboratory Services.

The mean and median age of hospital TB patients was 30.6 and 32 years (IQR 21-42), with 150 (19%) under 15 years of age, 400 (50.8%) male, and 429 (54.4%) had race categorised as black and 342 (43.4%) as mixed race. Most (653, 82.9%) lived in the City of Cape Town, with 135 (17.1%) from rural areas. **Table 1**. Males represented 63% of rural TB patients, differing significantly from urban TB patients which included more females (52%) (Chi^2 $p<0.001$). Of the 497 adults (77.7%) with employment information, 286 (57.5%) were unemployed and 47 (9.5%) received a social grant.

Table 1: Description of TB patients treated in hospital in a 6 month period, outcomes after discharge, and associations between continuity of care and explanatory variables.

Variables	Hospital TB patients (N=788)		Main Outcome		
			Continued TB care (N = 284)	Did not continue TB care (N=504)	Chi^2 P value
	n	%			
Age (years)					
<15	150	*19*	28	122	< 0.001
>=15	638	*81*	256	382	
Gender					0.537
Male	400	*50.8*	140	260	
Female	388	*49.2*	144	244	
Race					0.646
Black	429	*54.4*	160	269	
Mixed race	342	*43.4*	120	222	
Other	17	*8.5*	4	13	
Residence					<0.001
Urban	653	*82.9*	255	398	
Rural	135	*17.1*	29	106	
Single Admission	431*	67.3	-	-	
LOS† (median, IQR)	11*	5.0-23	-	-	

TB Bacteriology			112	103	<0.001*
Smear &/or culture	586	*74.4*			
Drug sensitivity	358	*45.4*			
Mono -R	24	*6.7*‡			
MDR	20	*5.9*‡			
XDR	7	*2*‡			
TB Medicine Provided	375	*47.6*	131	244	0.537
TB Notification	105	*13.3*	40	65	0.638
HIV co-infection	253	*32*	106	147	0.024
Arrived PHC	284	*36*			
Completed TB Rx	125	*15.9*			
Cured	66	*8.3*			
Died	36	*4.6*			
Defaulted	26	*3.3*			
Transferred out	11	*1.4*			
Treatment failure	7	*0.9*			
Total Died	166	*21.1*	58	108	0.740

* n = 640.

† Length of Stay.

‡of patients tested.

Continued TB care:

A total of 586 (74.4%) patients had TB bacteriology tests, 550 in hospital and an additional 36 in the NHLS warehouse reflecting tests done in hospital or PHC services. Of these 513 (65.1%) had a positive TB smear and/or culture result, with 19 with positive smears alone. Urban patients (75%) had more hospital TB bacteriology tests than rural patients (57%) ($p<0.001$). Of the 358 (45.4%) patients tested for mycobacterial drug susceptibility ~~testing~~, 307 (86.0%) were sensitive to all TB drugs, 24 (6.7%) were mono resistant to Rifampicin or INH, 20 (5.9%) had MDR, and 7 (2.0%) had XDR TB. **Table 1**.

Only 196 (24.9%) TB patients had an HIV diagnostic test in hospital, of whom 69 (35.2%) were positive. A further 141 (17.9%) had a CD4 count or viral load test in hospital. HIV co-infection was documented for 253 (32%) TB patients based on hospital HIV related tests or ART treatment. This differed significantly by race, with 169 (39.4%) black and 80 (23%) mixed race patients HIV co-infected ($p<0.001$). Females had non-statistically significant higher HIV infection rates (35.5%) than males (28.5%) ($p=0.09$). Rural TB patients had significantly lower HIV infection rates (18.5%) than urban patients (34.9%) ($p=0.001$).

TB medication was issued to 375 (47.6%) of all TB patients. However only 224 (40.7%) of the 550 hospital bacteriologically diagnosed TB patients had a hospital TB medicine prescription. Of the 159 patients issued TB medication without a hospital bacteriology test, many were children (30%) or from rural areas (28.3%). Of the 105 (13.3%) notified TB patients, 64 were female (16.5%) and 41 male (10.3%) ($p=0.01$). More patients with hospital bacteriological TB tests were notified (78, 13.8%) than patients without such tests (25, 11.6%), (Fisher's Exact $p=0.035$).

Of 640 (81.2%) TB patients with information on number of admissions, 431 (67.3%) had one, 129 (20.2%) two and 80 (12.5%) ranged from 3 to 15 admissions during the six months. Their median LOS was 11 days, ranging from 1 to 143 days (IQR 5.0 to 23.0).

Outcomes

Only 284 (36%) of the 788 TB patients continued TB treatment in the Western Cape. Of these, 207 (72.9%) were recorded in the ETR.net or EDR.net, and 77 (27.1%) in the facility TB register, but not in the electronic registers. Three patients (1%) were discharged to the Eastern Cape without records of outcomes.

A total of 125 (15.9%) patients completed TB treatment and an additional 66 (8.3%) were cured, totalling 191 (24.2%) with successful treatment outcomes. Another 36 (4.6%) patients died, 26 (3.3%) defaulted, 11(1.4%) transferred out, and 7(0.9%) were treatment failures based on the TB registers. **Fig 2** illustrates the proportions of hospital TB patients with the respective outcomes.

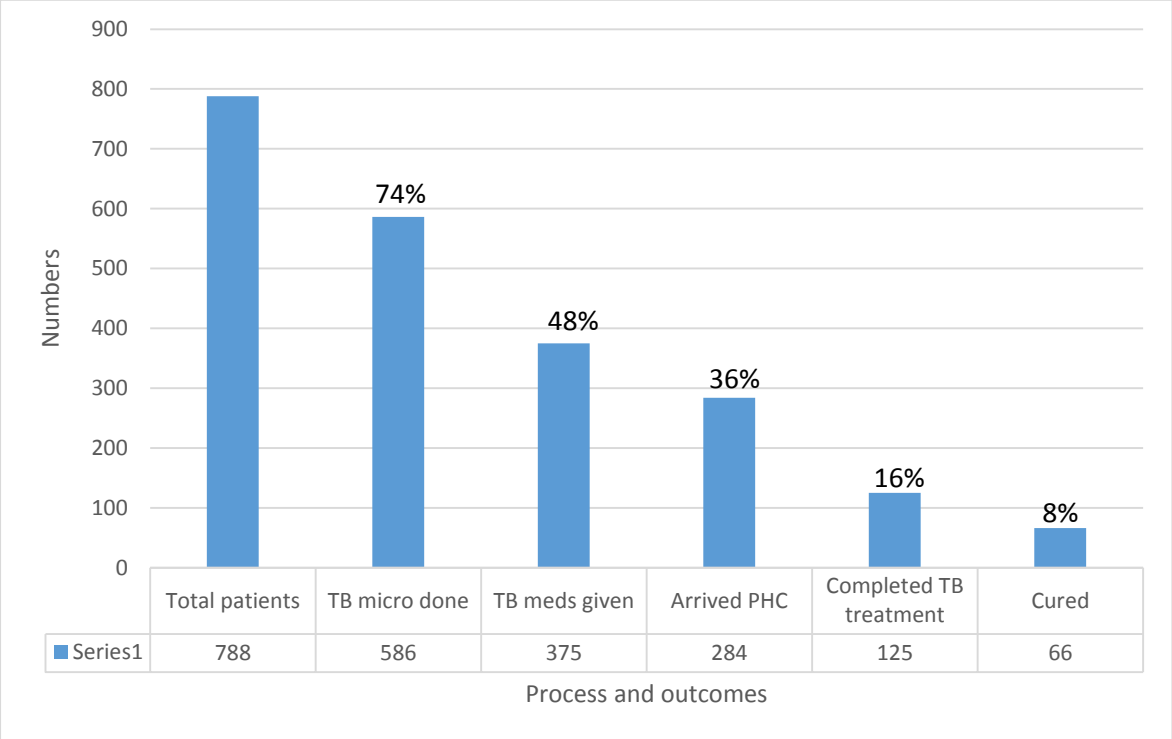

Fig 2: Outcomes of TB patients (N= 788) treated in a hospital in the Western Cape, South Africa.

More adults (256; 40%) than children (28; 18.7%) (p<0.001); urban patients (255; 39.0%) compared to rural (29; 21.5%) (p <0.001); more known HIV co-infected patients (106; 40.1%) (p=0.024); and patients who had a TB bacteriology test in hospital (p<0.001) continued TB care at other facilities. Continuity of TB care was not associated with gender, race, or notification status. **Table 1.**

A total of 166 deaths (21.1%) were captured from all data sources. Mortality was higher in HIV co-infected patients (27.7%) than in patients without evidence of HIV infection (16.4%) (p=0.006). Adults (134, 21.5%) were more likely to die than children (16, 9.6%) (p=0.001), and notified patients (11.4%) less likely than those not notified (22%) (p=0.009). There were no significant associations between mortality, gender, race, area of residence, and TB bacteriology tests.

An analysis excluding 91 (11.5%) patients who had died in hospital or within 14 days of discharge, found similar demographic, treatment and outcomes to the overall patient group, with only 262 (37.6%) continuing treatment at other levels of care. Improved continuity in this group was associated with adults (p <0.001), urban residence (p<0.001), and TB bacteriology in hospital (p<0.001). Risk factors for death after discharge included adult age (p = 0.042) and HIV co-infection (p = 0.005). **Table 2.**

Table 2: Outcomes of hospital TB patients who were discharged and alive 14 days post discharge.

Variables	Hospital TB patients discharged and alive 14 days post discharge (N = 697)		Continued Care (N= 262)	Chi² P value	Died (N = 77)	Chi² P value
Age (years)	n	%	n		n	
<15	143	20.52	27	<0.001	9	0.042
>=15	554	79.48	235		68	
Gender				0.590		0.667
Male	355	50.93	132		41	
Female	342	49.07	130		36	
Race				0.525		0.316
Black	383	54.95	152		48	
Mixed race	299	42.90	106		28	
Other	15		4		1	
Residence				<0.001		0.591
Urban	573	82.21	234		65	
Rural	124	17.79	28		12	
TB Bacteriology	500	27.40	100	<0.001	28	0.245
TB Medicine Provided	334	47.92	120	0.385	29	0.056
TB Notification	101	14.49	40	0.651	8	0.278
HIV co-infection	218	31.28	95	0.053	35	0.005

Arrived PHC	262	37.59				
Completed TB Rx	119	17.07				
Cured	65	9.33				
Died	26	3.73				
Defaulted	23	3.30				
Transferred out	11	1.58				
Treatment failure	6	0.86				
Total Died	77	11.05				

Multiple logistic regression models found that adults ($p < 0.001$), urban residence ($p < 0.001$), TB bacteriology tests ($p<0.001$), and receiving TB medication ($p = 0.021$ and $p= 0.037$ respectively) were predictors of continuity of care for TB patients (including and excluding hospital deaths). An interaction term for age and bacteriology tests for TB was also significant ($p=0.02$) for both groups, indicating effect modification between age, TB bacteriology (i.e. children had less bacteriology) and the outcome. Not receiving TB medication was a significant predictor of death for discharged patients ($p = 0.032$). **Table 3.**

Table 3: Multiple logistic regression of continuity of care for TB patients comparing all TB patients (N=788) and discharged TB patients who were alive 14 days post discharge (N=697).

Explanatory Variable	**Arrived at another level of care to continue TB treatment**					
	All TB patients (N = 788)			TB patients alive 14 days post discharge (N = 697)		
	OR	P value	95% CI	OR	P value	95% CI
Age	7.14	<0.001	3.04-16.79	7.64	<0.001	3.23 -18.03
Residence	0.36	<0.001	0.22-0.58	0.35	<0.001	0.21-0.58
TB bacteriology	11.59	<0.001	4.25-31.62	10.63	<0.001	3.87-29.18

TB medicine provided	0.678	0.021	0.49-0.94	0.69	0.037	0.48-0.98
HIV co-infection	0.96	0.037	0.93-0.99	0.96	0.091	0.92-1.01
Interaction (Age & TB bact)	0.28	0.02	0.1-0.82	0.28	0.02	0.10-0.82
Cons	0.09	<0.001	0.04-0.22	0.12	<0.001	.05-0.27

Discussion

Hospitalised TB patients were mostly young, as in previous studies [10, 17], urban and unemployed. The dominance of women in the urban TB population reflects the higher HIV prevalence in female urban TB patient [18]. Re-admissions of a third of TB patients during the six months suggests complex disease and poor quality care [19], and illustrates the dynamic relationship between levels of care.

More CAH patients (74%) had TB bacteriology tests, but a similar proportion received TB treatment (40.7%) to a Kwa-Zulu-Natal study (50% tested and 42% treated) [11]. The higher TB bacteriology testing at CAH did not translate into more patients receiving TB treatment. This study however preceded the introduction of the rapid onsite Gene-Expert TB test in South Africa, which was expected to increase TB testing and TB treatment initiation in hospitals and PHC settings [20]. Only 45.3% hospital TB patients had TB drug sensitivity tests, with TB drug resistance levels similar to the national MDR prevalence of 3.5% in new TB patients, and 7.1% in retreatment patients [1].

HIV testing of hospitalised TB patients (24.9%) was lower than the 76% in Gauteng [10] and especially low at the peak of the HIV epidemic [18]. In Africa TB is a leading cause of hospitalisation of people living with HIV, ranging from 8.1% to 41%, and is the cause of 29.3% of deaths in hospitalised adults with HIV [21]. Poor integration of TB and HIV care for co-infected hospital patients contributed to the increased in hospital mortality [21]. The low HIV testing and high mortality in our study suggests more attention needs to be paid to integrating TB and HIV care in hospitals.

The proportion of patients who received TB treatment was based on hospital prescriptions and did not include known TB patients admitted with medication. Treatment practices however did not comply with local policy to provide all TB patients with at least seven days of treatment on discharge from hospital [22].

TB notifications of 13% confirmed previous CAH findings [17], and were lower than the 69% reported elsewhere [10]. This contributes to the large gap between actual incidence of TB and notifications of

cases in South Africa [1]. Countries with electronic notification systems have increased TB reporting [23], while South Africa continues to use a paper based notification system not linked to the ETR.net, requiring duplication of reporting by clinicians.

One third of discharged TB patients continued treatment, and one quarter successfully completed treatment, reflecting a failure of TB care pathways. Demographic factors associated with poor continuity of care included children and rural residence. Both groups had less bacteriological confirmation, and more were initiated on treatment without bacteriological confirmation. Hospitals tend to follow up children in outpatient care rather than discharging them to community care, which may have contributed to fewer children in the TB registers [24].

Appropriate clinical management, particularly TB bacteriology testing was strongly associated with better continuity of care. Lack of TB medication on discharge was a predictor of poor continuity of care and patient death in multiple logistic regression models. Culture confirmed paediatric patients < 13 years at CAH had better continuity of care in another study, highlighting the importance of a bacteriological TB diagnosis for continuity of care [24].

Shortcomings in health information systems included the absence of a reliable, integrated hospital TB surveillance system, limiting planning and management of inpatient TB care, hospital infection control, and continuity of care. The hospital and PHC information systems were not linked, impeding follow up of patients and communication between levels of care. We also confirmed findings of low TB notification rates [17], gaps between the ETR.net and facility based TB records in the Western Cape [25], and underreporting of hospital TB patient deaths in the ETR.net [10].

Low numbers of hospital discharged TB patients arriving at PHC services or successfully completing TB treatment reflects poor quality of care, and inefficient linkages between levels of care. The high cost of treating a TB patient in the CAH hospital, $2373 for an average 10 day LOS compared to between $823 and $1362 for community based care per patient cured, further emphasises the need to ensure these scarce resources are used efficiently and effectively [26, 27].

Strengths and Limitations

This study used several sources of routine data, none of which was complete, and extensive data verification was required. Only patients with proof of TB were included, and routine hospital data was verified against patient folders. In the data linkage between hospital data and TB registers, we matched records closely in the electronic systems, and hand searched electronic and paper based TB registers for missing patients.

Only three patients had residential addresses outside the Western Cape, despite evidence that many patients seeking healthcare in the Western Cape originate from neighbouring Provinces [28]. The impact of migration for treatment on continuity of TB care could not be assessed in this study.

Implications for practice and research

Some groups had an increased risk, but all TB patients experienced poor continuity of care. Health systems interventions are needed to improve the quality of hospital TB care, integrate TB and HIV care, establish integrated hospital TB surveillance systems and strengthen referral links between levels of care. The association of TB testing and medication with better continuity of care and patient outcomes warrants further intervention research.

Conclusion

Most discharged TB patients did not continue care or successfully complete TB treatment with potentially serious implications for patients, the community, and health system. South African hospitals should improve the quality of care of TB patients, develop integrated hospital TB surveillance systems linking to the national TB information system, and strengthen care pathways for TB patients across levels of care.

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Chapter 4: Overview of strategies to improve continuity of care for chronic diseases between hospitals and primary care services.

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Abstract

Background

Chronic diseases, both communicable and non-communicable, are a leading cause of morbidity and mortality, and a major reason for utilization of health services in LMIC's. Chronic disease patients require multiple interactions with health services, involving numerous service providers and levels of care, over their lifetime. The linkages between levels of care within the health system for chronic diseases are therefore critically important to ensure continuity of care, optimise health outcomes and ensure efficient utilisation of scarce health care resources. This overview aimed to identify and synthesise research evidence on continuity of care for chronic diseases in all settings to inform strategies to improve the continuity of care for chronic diseases, including TB and HIV, in LMIC's settings.

Methods

We followed the Cochrane approach to conducting an overview of reviews, and looked for and included all systematic reviews and overviews on coordination or continuity of care for chronic diseases between hospital and PHC services in all settings. We conducted electronic searches of several registers and databases to identify reviews on information or communication, behaviour change or organisation of care interventions. We assessed the quality of the systematic reviews, and summarised each using an approach developed by the SUPPORT Collaboration. The quality of evidence for each main outcome was assessed using GRADE.

Results

16 articles consisting of 13 systematic reviews and three overviews were included in the overview. The studies were mainly of older adult chronic non-communicable disease patients in high income countries. No reviews included studies of continuity of care for tuberculosis patients. Of the few information and communication interventions included, telephone follow up and interactive communication between primary and secondary care providers may improve some health care utilisation and patient outcomes. Discharge planning, including pre and post discharge activities, and

shared care between secondary and primary providers probably improve health care utilization and may improve patient outcomes. Disease management programmes and integrated care probably improve several patient outcomes and health care utilization. The evidence on costs was uncertain in all reviews.

Discussion

In the absence of studies on continuity of care for communicable chronic diseases in LMIC's, the applicability of evidence from non-communicable chronic diseases in high income countries for patients and health systems in LMIC's needs to be carefully considered. Further research is needed on the effects, costs and implementation of interventions to improve continuity of care for patients with chronic communicable and non-communicable diseases in LMIC's.

Background

Chronic diseases, both communicable and non-communicable, are a leading cause of morbidity and mortality, and a major reason for utilization of health services in LMIC's (60,127). With a rapidly aging population and lifestyles predisposing the population to chronic diseases, the impact of chronic diseases is expected to increase substantially in LMIC's, including South Africa (60,128).LMIC's already carry the highest global burden of HIV/AIDS and TB (8,129), which are increasingly regarded as chronic diseases with similar challenges for care as for non-communicable chronic diseases. The evidence of co-morbidities between patients with TB, HIV and other chronic diseases is also growing in South Africa and Sub-Saharan Africa and there is a need for services to respond appropriately (18,20,130).

> "the relevant distinction is no longer between communicable and non-communicable diseases, but rather between chronic and acute. There are more similarities between the way we deal with AIDS and diabetes than between AIDS and acute infection. Indeed the epidemiological transition is associated with a change in the temporal nature of most ill health." Julio Frenk, 2009 (58)

This high burden of chronic communicable and non-communicable diseases has highlighted the urgent need to reform health care services, currently largely geared to the needs of acute care, to cater for the needs of the increasing number of patients with chronic conditions in LMIC's (18,60,127). Chronic disease patients require multiple interactions with health services, involving numerous service providers and levels of care, over their lifetime. The linkages between levels of care within the health system for chronic diseases are therefore critically important to ensure continuity of care, optimise health outcomes and ensure efficient utilisation of scarce health care resources.

In developed countries, the need for continuity of care has influenced the development of models for integrated chronic diseases management, such as the 'Innovative Care for Chronic Diseases Framework', which emphasise the importance of coordination and continuity of care (71). Numerous interventions to improve coordination of care between hospitals and primary care levels for chronic disease patients have been identified in such well- resourced health systems. In LMIC's, where poor linkages between levels of health care for chronic diseases undermine access to and quality of care, very little research has been undertaken to describe and understand the problems or to test interventions to improve continuity of care (37,40,130). In this context, we also wanted to explore the potential for LMIC's to learn from evidence from High Income Countries (HIC), and considered ways of applying evidence from HIC to LMIC settings (76).

This overview aimed to identify and synthesise research evidence on continuity of care for chronic diseases in all settings to inform strategies to improve the continuity of care for chronic diseases, including TB and HIV, in LMIC settings. We were guided by an earlier policy brief on integrated care for patients with chronic diseases in Norway (131), but conducted updated and expanded searches to identify reviews of evidence on continuity of care for communicable chronic diseases in LMIC's. We also explored the application of evidence from HIC to LMIC settings.

Methods

We used the Cochrane approach to conducting an overview of reviews (132), and looked for and included systematic reviews and overviews on coordination or continuity of care for chronic diseases between hospital and PHC services in all settings. Both communicable and non-communicable chronic diseases in adult and paediatric patients were included. Reviews which focused only on continuity of care within one level of care i.e. within PHC or within a hospital level were not included.

The types of interventions we searched for were grouped around three main approaches to improving continuity of care guided by the Effective Practice and Organisation of Care (EPOC) taxonomy for interventions (https://epoc.cochrane.org):-

- Improved communication and information systems e.g. use of computers, telephone or short message service (SMS) follow ups or reminders;
- Behaviour change e.g. training of health care providers; use of discharge or referral guidelines and forms for health care providers; patient education; and incentives for patients or providers;

- The organisation of care e.g. shared care, care pathways, and disease management programmes.

Communication and information systems interventions use technology to facilitate the flow of information between hospital and PHC providers and patients. Behaviour change interventions focus on getting health care providers or patients to adopt new and better practices in order to improve continuity of care. The organisation of care interventions mainly support the development of multi-disciplinary health care teams which include hospital and PHC health care providers, the development of care plans to ensure the transition between levels of care and health care providers, and active involvement of patients in decision making regarding their care.

The primary outcomes of interest were measures of continuity of care (e.g. treatment interruption, delays in seeking care); clinical outcomes (e.g. TB cure or treatment completion; hypertension and diabetic control, quality of life) and patient satisfaction or Patient Reported Outcome Measures (PROMS) (e.g. quality of life). Secondary outcomes included compliance with treatment (e.g. drug adherence, nutrition, or appointments), provider satisfaction with referral processes, and costs of care.

We conducted electronic searches of several registers and databases including the Cochrane Database of Systematic Reviews, the EPOC specialised register, the McMaster Health Forum for Health Systems Evidence (www.healthsystemsevidence.org), the SUPPORT database of summaries of systematic reviews (www.supportsummaries.org), and MEDLINE. No language restrictions were placed on the search strategy. Reference lists of included studies were checked to identify any other systematic reviews, and international experts in the field were contacted. The last search was conducted in July 2019 and we excluded systematic reviews and overviews conducted before 2000.

Two authors independently screened abstracts to identify all reviews that potentially met the inclusion criteria (types of reviews, participants, settings, types of interventions and outcomes of interest) to be retrieved. The same two authors independently assessed each full text article that was retrieved to determine whether it met all of the selection criteria. Any disagreements and uncertainties were resolved by discussion, and/or the involvement of a third author.

We assessed the reliability of systematic reviews that met the inclusion criteria using criteria developed by the SUPPORT and SURE collaborations (133). Based on these criteria, each review was categorised as either reliable (only minor limitations), having important limitations, or fatally flawed. The latter were excluded from the overview. We summarised each included review using an approach developed by the SUPPORT Collaboration (http://www.supportcollaboration.org/index.htm) (133,134).

Standardised forms were used to extract data on the background of the review, including a description of the interventions, participants, settings and outcomes. Data was double entered and managed using Excel.

The quality of evidence for each main outcome, that is the extent of confidence in the estimate of effect across studies, was assessed using GRADE and an overall assessment of the risk of bias (high, moderate or low risk of bias) assigned to each main outcome in the included studies (135,136). A checklist was used to assess the quality of the overviews (137).

We recorded outcomes in each comparison group included in systematic reviews where a meta-analysis had been undertaken. Where possible we recorded risk ratios (RRs) for dichotomous outcomes and weighted mean differences (WMDs) for continuous outcomes. Where a meta-analysis had not been done, we reported the findings as documented by the systematic reviews. We summarised the main results of the included systematic reviews by type of intervention, and identified important uncertainties and questions for which we could not find a systematic review. Results were summarized in overview of reviews tables.

Results

We identified 118 studies from 1327 titles and abstracts from the database searches. After reviewing the full manuscripts we selected 30 articles which met the inclusion criteria. Of these articles we excluded seven which did not meet quality criteria for inclusion, and a further seven that had been updated in a more recent review or included in a recent overview (Annexure 4.1). The remaining 16 articles consisting of 13 systematic reviews and three overviews were included in this overview. **Figure 1**.

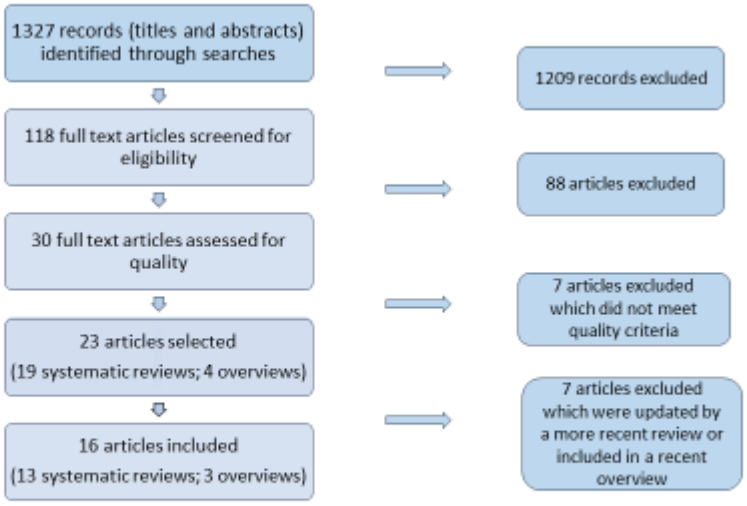

Figure 1: Flow diagram of study selection

The 13 systematic reviews included a total of 374 primary studies consisting of 300 (80.2%) Randomised Control Trials (RCT's), Clinical Controlled Trials (CCT's) or cluster RCT's, 35 (9.4%) quasi-experimental studies, and 39 (10.4%) observational studies. Three systematic reviews were on information and communication (138–140), three on Discharge Planning (65,141,142), three on Shared Care (143,144) or Care Pathways (145), two on Disease Management Programmes (DMP) (146,147) and two on Integration of Care (148,149). The DMP and 'Integration' studies described multicomponent interventions which overlapped extensively. **Table 1**. The three overviews included a total of 92 systematic reviews, of which 44 included only RCT's, CCT's or cluster RCT's; 39 included other study designs alongside trials; and six were health technology assessments, economic evaluations or not defined. One overview was on Discharge Planning (150) and two on Integration of Care (151,152).

We did not find reviews of stand-alone education interventions to improve continuity of care, although most of the multicomponent interventions included patient or provider education. Nor did we find reviews of patient or health care provider incentives, and none of the reviews specified this as an activity in primary studies.

The study populations were mainly older adult chronic non-communicable disease patients. Several studies included a mix of chronic diseases, but others focused on specific diseases such as heart failure, cancer, diabetes, mental illnesses and HIV. No reviews included studies of continuity of care for tuberculosis patients. Almost all the primary studies were undertaken in a few high income countries,

particularly the USA, UK, Canada and Australia. Only two were in Africa (Kenya, Uganda); 12 in Asia; three in the Middle East; and two in Central or South America.

Of the continuity of care outcomes of interest, almost all the reviews reported clinical outcomes and health care utilisation. Most reported costs, and about half reported patient satisfaction or compliance with treatment, either adherence to medication or keeping of appointments. Only two reported provider satisfaction. Most comparisons of interventions were with usual or standard care.

Six systematic reviews were assessed as good quality reviews with only minor limitations and seven had important limitations in the methods used to identify, include and critically appraise studies, and in the methods used to analyse the findings relative to the primary question addressed in the review (Annexure 4.2). The overview by Martinez-Goncalez was assessed as a good quality overview, but Mistiaen 2007 and Damery 2016 had important limitations.

Eight systematic reviews conducted a meta-analysis of some or all of the primary studies, and five reviews provided only a narrative reporting of results. In the overviews, a meta-analysis was done in 18 (67%) of the 27 systematic reviews included in Martinez Goncalez 2014, and 26 (52%) of the 50 reviews in Damery 2016. Mistiaen 2007 did not report the methods of analysis in the 15 systematic reviews. **Tables 2-5**. The results are reported under the following categories 1) information or communication strategies; 2) discharge planning 3) shared care or care pathways; and 4) disease management programmes or integration of care.

Effects of Information or Communication Strategies

Definition
Interventions to improve information transfer and communication between hospitals or specialist care, primary care providers and patients to improve continuity of care and patient outcomes.

Three systematic reviews assessed the evidence on information or communication strategies **Table 2**). These included patient-held records (PHR's) in the management of cancer patients (138), telephone follow up (TFU) post hospital discharge (139), and interactive communication between primary care physicians and specialists in the management of patients(140).

Effects of using Patient Held Records (PHR's)

The review by *Gysels 2006* included seven RCT's and six non RCT's. The interventions using PHR's varied widely. All the studies included cancer patients as participants (sample size ranged from 21 to

450) and five studies included health professionals as participants (sample size between 66 and 229). Few studies found strong evidence of effectiveness for continuity of care outcomes. The summary findings from the seven RCT's were that PHR's may improve patients' knowledge, preparedness for appointments and ability to monitor own health, but may not improve patient satisfaction or health outcomes.

Effects of Telephone Follow Up (TFU)

The review by *Mistiaen 2008* included 33 RCT's with a total of 5110 patients. The intervention was mainly TFU from hospitals directly to discharged patients. Overall there was insufficient evidence of an effect. However, in certain patient groups, such as cardiac and surgery patients the use of TFU improved compliance (making and keeping PHC appointments); and the findings suggested it may reduce re-admissions, and emergency department visits. The summary findings are that TFU of patients discharged from hospital may improve adherence with keeping PHC appointments, but it is uncertain whether it has any effects on patient psychosocial or physical outcomes, or hospital re-admissions and emergency department visits, or if it reduces health service costs.

Effects of Interactive Communication between collaborating primary care physicians and specialists

Foy 2010 in a review of 23 studies (11 RCT's, 1 CT, 3 CBA's, 8 BA's) including more than 6000 patients found that interactive communication as part of a collaboration or shared care between specialists and primary care clinicians for patients with diabetes or mental health illness was associated with improved clinical outcomes. Effect sizes were in the range seen for other chronic illness care interventions, and was further enhanced by interventions to improve the quality of information exchange. There was statistically significant heterogeneity across all comparisons. The summary findings on interactive communication between specialists and primary care clinicians are that it probably improves clinical outcomes in patients with depression and may improve clinical outcomes in diabetic patients. The effects may be enhanced by interventions to improve the quality of information exchange.

Effects of Discharge Planning and Support

Definition
Discharge planning is the development of individualised discharge plans for the patient prior to leaving hospital, with the aim of improving patient outcomes, improving coordination of services, and containing costs (153)

We identified three systematic reviews and one overview on discharge planning and support **Table 3**). *Lambrinou 2012* assessed nurse driven discharge planning (141), *Hansen 2010* reviewed interventions to reduce 30 day re-hospitalization (142), and *Goncalves 2016* assessed discharge planning from hospital to home (65). *Mistiaen's 2007* overview assessed interventions aimed at reducing problems in adult patients discharged from hospital to home (150).

Mistiaen 2007 aimed to synthesize evidence on the effectiveness of interventions to reduce post-discharge problems in adults discharged home from hospital. Fifteen systematic reviews were included covering a range of conditions (congestive heart failure, stroke, surgery, elderly), and focused on discharge preparation, education interventions and post discharge support. A narrative summary of the results by intervention groupings was reported. The effects of interventions aimed at reducing problems in adults within three months after discharge from hospital to home on patient health status, health care use or health care costs were uncertain in the overview.

Hansen's 2010 systematic review of 43 studies (including 16 RCT's) assessed pre and post discharge interventions to reduce 30 day re-hospitalisation in the USA and other HIC's. Patients were mainly from general medicine wards, or had heart failure, chronic lung disease, or were geriatric. 24 studies had single component interventions, and 12 assessed 'discharge' bundles of three or more components. Most bundles included patient education, discharge planning and TFU. Heterogeneity precluded a meta-analysis. Pre-discharge planning alone when targeted at a high risk group reduced re-hospitalisation in one RCT; patient education, post-discharge TFU and home visits alone did not. Multicomponent interventions which included TFU with patient centred discharge instructions and other activities (e.g. patient education, discharge planning, home visits, or a transition coach), significantly reduced re-hospitalisation in four RCT's.

Lambrinou's 2012 review of 19 RCT's in 4171 heart failure patients provided high quality evidence that nurse driven discharge planning compared to usual care reduces all-cause and heart failure related hospital re-admissions for heart failure patients.

A good quality systematic review by *Goncalves 2016* included 30 RCT's with discharge planning interventions aimed at medical, surgical, psychiatric, and orthopaedic patients. Key findings were that discharge planning probably reduces the hospital length of stay and re-admissions for patients with a medical diagnosis at three months; and that it may improve patient and provider satisfaction. They also found that it may improve use of primary care services, and adherence to medication; but did not affect mortality. There was very low certainty about reduction in costs.

Effects of Shared Care and Care Pathways

Definitions

Shared Care

A structured system for achieving integration of care across multiple autonomous providers and services, with both primary and secondary care practitioners contributing to elements of a patient's overall package of care (153,154)

Clinical Pathways

Shared care which involves the joint participation of primary care and speciality care physicians in the planned delivery of care, informed by an enhanced information exchange over and above routine discharge and referral notices (145)

We identified three systematic reviews on the effects of shared care and care pathways **Table 4**). *Smith 2017* assessed the effects of shared care across the interface between primary and specialty care in chronic disease management (144), *Mitchell 2015* assessed integration of care across the primary secondary interface and *Rotter 2010* assessed the effects of clinical pathways (CPW's) for hospitalized patients (143,145).

Effects of Shared Care

Smith's 2017 good quality review of 42 studies of shared care interventions for chronic disease management included 39 RCT's, two CBA studies, and one non randomized clinical trial (NRCT). The studies assessed a wide range of complex multi-faceted interventions' that involved continuous collaboration between specialist and primary care physicians, including liaison meetings, shared records, and Information Communication and Technology (ICT) supported information sharing. The methodological quality of studies varied considerably with confidence in findings being moderate to high. A meta-analysis across 41 studies found that shared care leads to clinical improvements in mental health; probably has limited or no effect on other clinical outcomes, apart from modest effects on improving blood pressure management; and probably has mixed effects on patient reported outcome measures, medication prescribing and use, and participation in shared care services.

Mitchell's 2015 review assessed integrated models of health care at the primary secondary interface which involved direct interaction between primary and secondary care providers. They included 14 papers, describing 10 studies, of which four were RCT's and three were quasi-experimental studies. A narrative reporting of results was provided. They found that integrated multidisciplinary care across the primary and secondary care interface may improve patient satisfaction; patient attendance of

visits; and reduce defaulting from treatment. It is uncertain whether it improves clinical outcomes. This review had important limitations.

Effects of Care Pathways

Rotter 2010 conducted a good quality systematic review of the effects of CPW's for hospitalized patients with a range of clinical problems. Of the 27 studies, including 19 RCT's, two CCT's, four CBA's and two Interrupted Time Series (ITS) studies, 20 compared a standalone CPW and seven compared a multifaceted intervention including CPW's to usual care. About half the studies were on CPW's for patients with chronic diseases. Patient outcomes, professional practice, and health care utilization and costs were assessed. Subgroup analysis was attempted but was not possible due to heterogeneity. They found that CPW's may improve documentation and reduce in-hospital complications in hospitalised patients. It is uncertain whether CPW's reduce length of hospital stay (LOS), in-hospital mortality, hospital re-admissions or hospital costs.

Effects of Disease Management Programmes and Integration of Care

Definitions

Disease Management

Programmes designed to prevent or manage chronic conditions using a systematic approach to care and potentially employing multiple ways of influencing patients, providers or the organisation of care (153).

Case Management

A collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote quality cost-effective outcomes (155).

Transitional care is a broad term for care interventions that promote safety and timely transfer of patients between levels of care and across care settings. It includes pre-discharge hospital activities and immediate post discharge follow up at the next location (148,153).

Integration

Provision of multidisciplinary interventions at different stages of the care process in two or more institutional areas (76,151)

We included four systematic reviews (146–149) and two overviews (151,152) on the effects of disease management programmes (DMP) and integrated care **Table 5**. *Takeda 2019* evaluated the effects of DMPs on heart failure patients, *Handford 2017* reviewed the organization of HIV care, *Aubin 2012* reviewed integrated cancer care, and *Allen 2014* assessed older people with chronic diseases transitioning from hospital to home.

Effects of DMPs in HIV Care

Handford's 2017 systematic review of 33 studies of the organization of care for persons living with HIV included 11 RCT's and 22 observational studies, most of which were conducted in USA (27), with only three in LMIC's. Interventions were grouped as case management, multidisciplinary or multi-faceted treatment, outreach and health information systems (HIS). None of the multidisciplinary or outreach studies involved hospitalized patients or were across levels of care. A meta-analysis was not done due to heterogeneity, and a narrative report described results by individual studies. A summary of the results are that i) case management for HIV infected patients may improve receipt of ART, may reduce mortality and improve continuity in appropriate medical care; ii) HIS interventions, in particular computer prompts, probably hasten initiation of recommended treatment, but the other effects of HIS interventions are uncertain; and iii) the effects of multifaceted treatment for HIV infected patients are uncertain. The review had important limitations.

Effects of DMPs in Heart Failure

Takeda 2019 assessed clinical service organization for heart failure and included 47 studies in a good quality review. Disease management interventions were categorized into case management, multidisciplinary care, and clinic based interventions, and a meta-analysis done across each group. Most interventions included TFU (40), education (31) or self-management (33). Overall, DMP's for heart failure probably reduce all-cause mortality, and may reduce heart failure related and all cause readmissions. It is uncertain whether DMP's reduce heart failure related mortality, improve quality of life, or reduce costs.

Effects of Integrated Care in Cancer

Aubin's 2012 good quality review of interventions to improve continuity of care in the follow up of patients with cancer included 51 studies, of which 49 were RCT's and two were CCT's. Interventions included case management, shared care, interdisciplinary teams; PHR's, and TFU amongst others. Due to heterogeneity between studies, a modified form of meta-analysis based on the median change in outcomes in studies was conducted. Some differences in global quality of life and patient satisfaction

were found, but not in patient clinical outcomes. The quality of evidence was very poor across all categories of outcomes, and it is uncertain whether interventions to integrate care for cancer patients improve clinical outcomes, global quality of life, care processes and provider satisfaction.

Effects of Transitional Care interventions for Older People

Allen 2014 reviewed 13 RCT's on transitional care interventions for older people from hospital to home. The pre-or post-discharge transitional care interventions were mainly discharge planning with shared care or multidisciplinary planning, case management, patient and carer education, TFU or home visits. A meta-analysis was not done and a narrative report of results on a range of outcomes was provided with limited information on sample or effect sizes. Although individual studies reported benefits, from the review evidence it is uncertain if transitional care interventions for older patients reduce re-hospitalisation, improve patient satisfaction, quality of life or processes of care. The review has important limitations.

Overviews of Integrated Care

Martinez Goncalez 2014 conducted a good quality overview of integrated care programmes for adults with chronic diseases. They included 27 reviews of which seven included only RCT's, 17 had RCT's and non RCT's, and three did not specify study designs. 18 studies conducted a meta-analysis of primary studies. Chronic diseases were mainly congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), diabetes, asthma, and hypertension. Interventions included mostly DMP's, case management, shared care, multidisciplinary teams, comprehensive care, and chronic care models. They found that integrated care programmes for CHF reduced mortality, hospital admissions and re-admissions, and emergency department visits. For diabetes integrated care improved glycaemic control, adherence to treatment guidelines, patient satisfaction, quality of life, and reduced hospital admissions. For COPD patients integrated care improved patient satisfaction, adherence to treatment guidelines, hospital admissions, LOS and emergency department visits; and for asthma patients it improved adherence to treatment guidelines and reduced hospital admissions. Few reviews provided evidence of reduced costs.

Damery's 2016 review aimed to assess the evidence on interventions which integrated care across two or more settings to reduce hospital activity in chronic disease patients. They included 50 reviews, 21 of which were narrative and 26 included a meta-analysis. The reviews included patients with chronic diseases in general, heart failure, COPD, stroke and mental illnesses. Interventions were case management, chronic care models, discharge management, multidisciplinary teams (MDT), self-management, and other complex packages. They found that interventions based on MDT that

included a disease specialist; discharge management that included post discharge rehabilitation and follow up; and multicomponent strategies were most likely to significantly reduce hospital activity for patients with single conditions such as heart failure, or COPD. This overview had important limitations.

Discussion

We found a large number of systematic reviews and overviews on strategies to improve continuity in care for non-communicable chronic disease patients in HIC's, particularly USA, UK, Australia, Canada and countries in Europe. Very few systematic reviews included primary studies from LMIC's, and we found none for continuity of care of TB patients in any settings and one for HIV patients with primary studies mainly from HIC's. The population were largely older people with chronic non communicable diseases. The health professionals were mainly specialists (nurses and physicians), primary care physicians and nurses, and pharmacists, in hospitals and primary care services in well-resourced health systems.

Most reviews focused on reducing hospital activity (admissions, re-admissions, LOS, emergency department visits) and associated costs, as well as improving patient outcomes (clinical, quality of life and patient satisfaction). Few reviews specifically assessed continuity of care between levels, and when they did they used a range of definitions and outcome measures. The lack of clear definitions and measures for continuity of care has been a constraint in conducting reviews on the topic (149,156).

We found a few reviews of single component and several of multicomponent intervention strategies. Of the single component strategies, information and communication interventions were limited. Despite many articles on information and communication interventions in the literature, very few focused on continuity of care for chronic diseases, and of those even fewer met the quality criteria for inclusion. Of the included information and communication reviews, PHR's increased patient involvement in and satisfaction with care, but had little effect on health care utilisation or clinical outcomes (138). TFU's of discharged patients improved compliance with primary care appointments, and interactive communication between specialists and primary care providers improved patients' clinical outcomes (139).

Discharge planning alone, with post-discharge support or as part of a multicomponent intervention was found to reduce hospital re-admissions and improve patient satisfaction in several reviews and overviews (141,142,152). Findings on primary care use and medication adherence were less consistent, and there was little evidence of improvements in clinical outcomes or reductions in health

service costs. Shared care improved selected clinical outcomes, patient's attendance at visits, patient satisfaction, and reduced patient defaulting. Findings were mixed on medication prescribing and use, and uncertain on hospital re-admissions, mortality and costs (143–145).

DMP's and integration of care reduced re-admissions to hospital and improved clinical outcomes, patient satisfaction and quality of life for heart failure, diabetic and COPD patients; but not for cancer patients. For selected diseases, including HIV, it improved uptake and adherence to treatment, and retention in care (146,147,149,151).

Strengths and Weaknesses

Our search was extensive and screening and selection of articles thorough, but it is possible that we missed or excluded some relevant reviews. The categories of interventions were not mutually exclusive with most containing common elements e.g. TFU's were part of most discharge planning interventions and DMP's, and discharge planning, shared care and information and communication activities were part of DMP and integrated care. Despite using the EPOC taxonomy to guide categorization of the interventions it was often difficult to allocate studies and it is possible that other authors may have grouped the reviews differently.

The measurement and attribution of outcomes within a synthesis of a synthesis of complex multicomponent interventions was challenging (157). As the unit of analysis was the synthesised data and not primary studies, the detail of interventions and effects were often not available. In our narrative reporting we tried to provide as much detail as possible, but the findings are broad and lack specificity.

The findings of the overview were also dependent on the quality of the included reviews. We managed this by excluding reviews which had serious methodological limitations or were out of date, reported on the reliability of reviews we included, and weighted and interpreted the evidence on the outcomes using Grade (136). However, certain interventions such as education, incentives and ICT may be absent or under-represented in the overview because of the lack of good quality primary studies and systematic reviews.

The inclusion of overviews of reviews was helpful but may have created some weaknesses (157). We excluded overviews of questionable quality, but as the methodology of overviews is still developing these were not easy judgements. We also tried not to duplicate systematic reviews and only included additional systematic reviews not covered by the overviews. However, there were differences in the research questions of the three overviews, and they included reviews which were not relevant to this

overview. Their synthesis also provided less detail on the populations, settings, intervention activities, and effects than would have been available in data extraction from the original systematic reviews.

Implications for practice in LMIC's

Strategies to improve continuity of care for chronic disease are needed in LMIC's to respond to the poor continuity of care experienced by chronic communicable and non-communicable disease patients. This overview unfortunately did not find systematic reviews of continuity of care for chronic diseases in LMIC's to inform such strategies. In applying the findings of the overview to LMIC settings we were guided by the Support framework and tools to assess applicability of findings of systematic reviews in different settings (158).

The problems underlying poor continuity of care across levels of care may appear to be similar across HIC and LMIC's, but numerous differences in the context and populations need to be considered. The patient population in LMIC's, particularly for chronic communicable diseases, is younger and poorer than the chronic disease patients in the systematic reviews (18). They generally have less access to hospital and PHC services, and may have different health care and support needs during and after hospital discharge.

The structure and organisation of HIC health systems may also differ substantially from those in LMIC's. The interventions were implemented in systems that were relatively well resourced, had good infrastructure at hospital, primary care and community level, and strong patient involvement and advocacy. This may not be the case in many LMIC health systems.

Most of the interventions depended on the availability of specialist physicians and nurses, pharmacists, and primary care physicians. In LMIC's, these health professionals are relatively scarce, with generalist nurses providing most primary care services supported by lay health workers who provide outreach support or home based care (159). Task-shifting from doctors to nurses, or nurses to lay health workers for certain roles may be required in implementing the interventions in these settings (160–164). The barriers to shared care, and multi-disciplinary teams between hospital specialists, primary care nurses and other health professionals in these settings are substantial.

Although many primary studies included a costing, few reported full economic evaluations and the findings on the economic implications of interventions was uncertain in all reviews. More reliable evidence on the economics of continuity of care for chronic diseases particularly in LMIC contexts could assist such decision making (165). None of the reviews considered the differential effects of the interventions on disadvantaged populations. Although the elderly were a strong focus, other

underserved and marginalized groups were not. In applying the interventions in LMIC's, decision makers should consider how to address the needs of disadvantaged populations.

Health information systems may not be as strong in public sector health systems in LMIC's, and ways of obtaining good quality data to measure the key outputs and outcomes of the interventions need to be considered to monitor implementation and assess effects in LMIC settings.

Implications for research

The scarcity of reviews on continuity of care for chronic diseases, both communicable and non-communicable, in LMIC's suggests that more rigorous primary research on this topic is needed in LMIC's. Adapted frameworks from the Chronic Care Model for communicable chronic diseases have been proposed, and formal evaluations of their implementation could generate valuable knowledge to inform their application in LMIC's (18).

Despite the growth in the use of ICT in health care, we found very few studies of acceptable quality on information and communication interventions to improve continuity of care for chronic diseases. Good quality research is needed on the effects of ICT on continuity of care for chronic diseases in all settings to address this gap.

Most reviews were designed to assess effectiveness of interventions, and not to describe or understand the implementation processes. In attempting to replicate the interventions the detail required is largely absent from the reviews. More implementation research is needed to understand the characteristics of the interventions, the settings, populations and the mechanics of implementation, to inform replication or adaptation in different settings (107,166). Lastly, good quality economic evaluations are needed of the comparative economic benefits of the different interventions to inform policy making (165).

In conclusion, this overview of systematic reviews of interventions to improve continuity of care for chronic disease patients found evidence of effects of several single component and multicomponent strategies from studies in HIC's. Of the few information and communication interventions for which evidence was available, TFU and interactive communication between primary and secondary care providers may improve some health care utilisation and patient outcomes. Discharge planning, including pre and post discharge activities, and shared care between secondary and primary providers probably improve health care utilization and may improve patient outcomes. DMP's and integrated care probably improve several patient outcomes and health care utilization. The evidence on costs was uncertain in all reviews.

Although the evidence from HIC's may be relevant to LMIC's, decision makers need to consider which options are appropriate, affordable and feasible for their context. In the application of the evidence in settings which may differ substantially from those in which the primary studies were conducted they should consider ways in which people with chronic diseases differ in their settings, and whether their health systems have the necessary governance, infrastructure and resources to implement the models or whether adaptations may be required in the local settings. Further research is needed on the effects, costs and implementation of interventions to improve continuity of care for patients with chronic communicable and non-communicable diseases in LMIC's.

Table 1: Description of Included Studies

Study	Date assessed as up to date	Studies	Population	No. of participants	Settings	Intervention	Comparison	CoC Outcomes for which data is reported
Gysels M 2006	2004	7 RCT's and 6 non-experimental studies	Cancer patients in hospital and outpatient clinics	7 RCT's included 1250 patients (range 21-450), and 638 health professionals	UK, Netherlands, Canada, Sweden	Patient held records in cancer care	Not stated	Health status; Quality of Life (QoL); Patient and provider satisfaction; Health care utilisation.
Mistiaen P 2008	2003	33 studies (RCT's and CCT's)	Mixed including cardiac, diabetic, oncology and neurology patients.	5110 patients	USA mostly, Canada, Netherlands, Saudi Arabia (1)	TFU from hospital to patient. Varied by health professional, frequency, structure and duration.	Usual care	Psychosocial, physical, consumer oriented, and health service oriented.
Foy R 2010	2008	5 RCT's, 6 cluster RCT's, 1 nonrandomised controlled trial, 3 controlled before after studies, 8 uncontrolled before after studies	Patients with diabetes and mental health illnesses	>6000 patients (range 61 – 984)	Mainly USA, UK, Canada, Europe, Australia, Israel (1)	Interactive communication including face to face meetings (9), paper letters or notes(8), telephone discussions(7), videoconferencing(3), electronic records or letters(2) or combinations (14).	Shared care or collaborations without interactive communication	HbA1c; depression scales
Mistiaen P 2007	2004	15 systematic reviews (265 primary studies). 7 included only RCT's, 8 included RCT's and other study designs.	Adults discharged home from hospital, mainly elderly with chronic diseases	Not reported	Not reported	The range of interventions to reduce post-discharge problems, included discharge planning, patient education, and post discharge support	Usual care	Within 3 months post discharge: Discharge status (incl LOS); patient status (physical, emotional, social and health status); health service use and costs
Hansen LO 2011	2010	43 articles, included 16 RCT's, 20 quasi-experimental or cohort studies; and 7 BA without controls.	Hospitalised patients, mainly general medicine, heart failure, chronic lung disease, and geriatric patients	>4600 patients in RCT's	USA mostly, Europe, UK, Ireland, Australia, New Zealand, Canada, Hong Kong (2), Israel (1), Taiwan (1)	Pre and post discharge interventions to reduce 30 day rehospitalisation. 24 studies had single component interventions; 12 had 3 or more components. Most	Usual care	Re-hospitalisation within 30 days

						included patient education, discharge planning and TFU.		
Lambrinou 2012	2009	19 RCTs	Heart failure patients	4171 patients (range of 70 to 1023)	USA 6, UK/Ireland(4), Canada (1), Europe (6), China (1), Australia (1)	Nurse driven discharge planning	Usual care	All-cause and heart failure related Re-hospitalisation
Goncalves C 2016	2015	30 trials.	Hospital inpatients	18,859 patients	USA, UK, Europe, Canada, Australia, Taiwan (1)	Discharge planning included inpatient assessment, discharge plan tailored to patients' needs; implementation and monitoring of plan. Also included patient education, and follow up.	Standard discharge care	Length of Stay (LOS), readmissions, mortality, patient and provider satisfaction, costs.
Smith SM 2017	2015	42 studies included 39 RCT's, 2 CBA's, 1 NRCT.	Chronic disease patients enrolled in shared care by primary or specialist physicians	18,859	USA, UK, Europe, Australia, New Zealand, Ireland, Puerto Rico (1)	Complex multi-faceted interventions' that involved continuous collaboration between specialist and primary care physicians. Included liaison meetings, shared records, ICT supported information sharing.	Usual care	Clinical outcomes; PROMS, process outcomes, hospital admissions, default, patient satisfaction, patient health behaviours, costs
Mitchell GK 2015	2012	10 studies (14 papers) including 1 RCT, 4 cluster RCT's, 3 quasi-experimental and 2 before after uncontrolled studies.	Adult chronic disease patients excluding mental health and oncology. Most were diabetic (6 studies)	7697 participants	New Zealand (3), Australia (2), UK (2), USA (3)	Integrated models of health care at the primary secondary interface which involve direct interaction between primary and secondary care providers	Usual Care	Clinical, process and economic outcomes
Rotter T 2010	2009	27 studies, including 19 RCT's, 4 CBA's, 2 CCT's, 2 ITS	Hospitalised patients, health care professionals	11,398	USA mostly, Australia, UK, Japan, Canada, Thailand (1), Taiwan (1)	Standalone Clinical Path Way's or CPWs as part of a multifaceted interventions	Usual care	Patient outcomes, professional practice, LOS, hospital costs
Takeda A 2019	2018	44 RCT's	Heart failure patients during or following hospital admission. Most	10,869 participants	Mostly Europe and USA, China (3), Canada (2), Australasia (2)	Disease management incl. case management, multidisciplinary care, clinic-based interventions. Most included	Usual or routine care	Mortality: readmissions; adverse effects; QoL; costs.

			between 67 and 80 years old.			TFU (40), education (31) or self-management (33).		
Handford C 2017	2011	33 studies, including 11 RCT's and 22 observational (mainly cohort) studies.	HIV infected patients in all settings	> 31000 in total; RCT's included 3385 patients	Mostly USA, 3 in LMIC's – Peru (1), Uganda (1), Kenya (1)	Case management (10); Multidisciplinary care (4); Multifaceted treatment (5); Outreach (8); HIS (3); Hours of Service (3).	Standard Care	Immunological/virological; medical (incl. mortality); psychosocial (incl. QoL); and economic outcomes.
Aubin M 2012	2009	51 studies, including 49 RCT's and 2 CCT's.	Adult cancer patients or providers of cancer care	Ranged between 28 and 1388 patients per study	USA mostly, UK, Europe, Australia, Canada, Taiwan (1)	Case management, shared care, interdisciplinary teams; PHR, telephone follow up + others.	Usual care	Patient outcomes; Health care processes.
Allen J 2014	2013	12 RCT's	Older people (>60years) with chronic diseases transitioning from hospital to home	5269 older people	USA, Australia, Denmark, France	Pre or post discharge 'transitional care' interventions including discharge planning, communication between providers, preparation for the person and care for the transition, reconciliation of medications, community based follow up, and patient education in self-management.	Standard hospital discharge	Quality of care outcomes for effectiveness, efficiency,timeliness, safety, equity, and patient centred care. Reported on a range of patient outcomes, processes, health care utilisation, and costs.
Damery 2016	Dec-15	50 reviews: 21 narrative, 26 included meta-analysis; 3 reviews of reviews	Adult patients with one or more chronic (non-communicable) diseases. Chronic diseases (15), heart failure (14), COPD (12), stroke (5), Mental health (1)	Not all reviews provided numbers. But of 31 that did, all had > 1000 participants	Any health or social care setting, which crossed the boundary between two or more settings. Mostly published in Canada, USA. UK, Europe -two in Asia	Case management (8), CCM(9); discharge management (15);multidisciplinary teams (10), self management (5); complex (3)	Usual care; no intervention; or comparison to another intervention	Hospital activity i.e.admission or re-admissions; LOS; accident and EMD use; health care costs
Martinez Goncalez 2014	2012	27 systematic review (824 primary studies): 17 included RCT's and non RCT's; 7 only RCT's; 3 did not report study designs. 18 conducted a meta-	Adults with chronic non communicable conditions except addiction and mental health disorders: CHF	19 studies reported numbers of participants, ranging from 669 to 35 484	Varied widely from inpatient to outpatient care, and included home care, nursing home, rehabilitation centre, community hospital,	DM most common form of integrated care; also case management, shared care, multidisciplinary teams, comprehensive care, chronic care models.		Patient centred outcomes, process quality, use of healthcare resources and costs using integrated care framework to categorise

		analysis of primary study data	12; DM 7;COPD 7; Asthma 5		and secondary and tertiary settings.			

Table 2: Effects of Information and Communication Interventions

Study	Description of Analysis	Primary outcomes: Continuity of care, Clinical outcomes, Patient satisfaction	Secondary Outcomes: Compliance with treatment, Provider satisfaction, Costs of care	Summary of Results	Review limitations
Gysels 2006	A meta-analysis of the RCT's was not done. A narrative synthesis on the RCT's was reported.	1 study found fewer psychosocial problems, but 3 found no effect on other health status outcomes. There was no identifiable benefit in information flow between primary and secondary care, quality of care, participation in care, and patient satisfaction with communication and care *(Grade quality of evidence was low).*	Three studies found that PHR's improved patients knowledge. Four studies found little evidence of provider satisfaction.	Patient Held Records: • May improve patients knowledge, preparedness for appointments and ability to monitor own health • May not improve patient satisfaction or health outcomes • The effects on other continuity of care outcomes are very uncertain	This review has important limitations.
Mistiaen 2008	Analysis was done on different groupings (by interventions, by patient population and by outcomes). Most were described in narrative reporting due to heterogeneity. A meta-analysis was done on studies of TFU for cardiac and surgical patients compared to usual care.	The effect of TFU on emergency department visits in 2 studies with 333 participants was RR 1.47 (0.85-2.53); on readmissions in cardiac patients in 3 studies (616 participants) was RR 0.75 (0.41, 1.36). *(Grade quality of evidence was low).* Studies reported improved patient satisfaction (3 studies); and re-admissions (2 studies) in favour of the intervention groups	TFU effects on compliance in making an appointment (3 studies, 1039 participants) was RR 1.70 (0.92-3.14); and in keeping an appointment (3 studies, 820 participants) was RR 1.58 (1.01 - 2.48). One study found reduced costs in the intervention group.	TFU of patients discharged from hospital: • May improve compliance in keeping PHC appointments; • The effects on patient satisfaction are uncertain. • The effects on hospital re-admissions and health service costs are uncertain.	This is a good quality review with only minor limitations.
Foy 2010	A meta-analysis was done of 11 RCT's, and of other experimental studies separately. Descriptive reporting of the results of all other studies.	The meta-analysis found that interactive communication improved depression scores (-0.41, CI -0.73, 0.10) in 11 RCT's; and in 7 non-RCT's (-0.47, CI -0.84, -0.09). *(Grade quality of evidence was moderate).*		Interactive communication between specialists and Primary Care clinicians: • Probably improves clinical outcomes in patients with depression;	This is a good quality review with only minor limitations.

		The pooled effect on HbAIc across 5 non Randomised studies was -0.64, CI -0.93,-0.34 i.e. improvement of 1.4% in HbA1c. *(Grade quality of evidence was low).* Interventions to improve the quality of information exchange were effective (9 studies) (-0.84, CI -1.14, -0.55) *(Grade quality of evidence was low).*		• May improve clinical outcomes in diabetic patients. • Effects may be enhanced by interventions to improve the quality of information exchange.	

Table 3: Effects of Discharge Planning and Support

Study	Description of Analysis	Primary outcomes: Continuity of care, Clinical outcomes, Patient satisfaction	Secondary Outcomes: Compliance with treatment, Provider satisfaction, Costs of care	Summary of Results	Review limitations
Goncalves 2016	The primary analysis of pooled data was for LOS and hospital admission. Risk ratios and 95% confidence intervals using fixed effects model were calculated for dichotomous variables (mortality, re-admissions, and discharge destination). Mean differences were calculated for hospital length of stay. Data for other outcomes were not combined due to variability across studies. Grade was used to assess the certainty of the evidence.	Discharge planning reduced unscheduled re-admissions in patients with medical conditions within 3 months of discharge in 15 studies with 4743 participants (RR 0.87, CI 0.79, 0.97) *(Grade moderate)*; reduced hospital length of stay in medical admissions in 12 studies of 2193 patients (0.73 lower, CI 1.33-0.12 lower) *(Grade moderate)*; and 6 studies reported improved patient satisfaction *(Grade low)*. Mortality was not reduced in older people with a medical condition at 4 to 6 months follow up across 7 studies (RR 1.02 CI 0.83, 1.27), and results of other health outcomes was mixed.	5 studies reported reduced health service costs *(Grade very low).*	Discharge planning: • Probably decreases hospital LOS and readmissions for patients with a medical condition; • May improve patient and provider satisfaction; • May not reduce mortality in older people with a medical condition; • It is uncertain whether discharge planning reduces health service costs.	This is a good quality review with only minor limitations.
Lambrinou 2012	A meta-analysis was conducted of 19 RCT's. The pooled effect (RR, relative risk) of the intervention group compared to the control group was estimated by using a random effects analysis for the outcomes.	Nurse driven pre-discharge interventions significantly reduced all cause (RR 0.85, CI 0.76-0.9) and heart failure (RR 0.68, CI 0.53-0.86) related re-admissions. *(Grade quality of evidence was high).*		Nurse driven pre-discharge interventions: • Reduce all-cause and heart failure related hospital re-admissions for heart failure patients	This is a good quality review with only minor limitations.

Hansen 2011	The main outcome assessed was 30 day re-hospitalisation after discharge. Heterogeneity across the 43 articles precluded a meta-analysis, and results were reported as a narrative synthesis of categories of intervention types.	Pre-discharge planning alone when targeted at a high risk group reduced rehospitalisation in one RCT; patient education, post-discharge TFU and home visits alone did not. Multicomponent 'bridging' interventions which included TFU with patient centred discharge instructions and other activities (e.g. patient education, discharge planning, home visits, or a transition coach), significantly reduced re-hospitalisation in 4 RCT's *(Grade quality of evidence was low).*		Discharge planning and multicomponent interventions: • May reduce rehospitalisation of patients within 30 days of discharge from hospital.	This review has important limitations.
Mistiaen 2007	This overview included 15 systematic reviews of discharge planning, with the most recent published in 2004. A narrative summary of the results of pre discharge, post discharge support and education interventions.	No evidence that discharge interventions have a positive effect on LOS, physical status, emotional status, health status (mortality), health care use within 3 months after discharge.	No evidence that discharge interventions have a positive effect on costs after discharge	The effects of interventions aimed at reducing problems in adults within 3 months after discharge from hospital to home on patient health status, health care use or health care costs are uncertain.	This review has important limitations.

Table 4: Effects of Shared Care and Care Pathways

Study	Description of Analysis	Primary outcomes: Continuity of care, Clinical outcomes, Patient satisfaction	Secondary Outcomes: Compliance with treatment, Provider satisfaction, Costs of care	Summary of Results	Review limitations
Smith 2017	A meta-analysis using random effects models and forest plots were undertaken where it was possible to synthesise data from studies. Outcome variables were used as defined in primary studies. Standard Mean Difference was used where different scales were used to report findings. The quality of evidence was rated using Grade.	Little or no difference in physical health in 16 studies with 6977 patients but some improvement in hypertension across studies (MD 3.47, CI 1.68, 5.25) *(Grade: moderate);* improvements in mental health in 18 studies of 6243 patients including improved response to depression treatment (RR 1.40, CI 1.22, 1.62) and recovery from depression (RR 2.59, CI 1.57, 4.26) *(Grade high)*. Effects on PROM's was mixed *(Grade moderate)*; and little or no difference were reported in processes of care and hospital admissions.	Effects on patient participation and default were modest in 7 studies with 1639 participants *(Grade moderate).*	Shared care interventions: • Lead to clinical improvements in mental health; • Probably have limited or no effect on other clinical outcomes, apart from modest effects on improving blood pressure management; • Probably have mixed effects on patient reported outcome measures (e.g..QoL), medication prescribing and use, and participation in shared care services.	This is a good quality review with only minor limitations.
Mitchell 2015	No meta-analysis was done, and the authors provided a narrative reporting of results.	Clinical outcomes (8 studies): HBA1c, blood pressure and serum cholesterol reduced significantly in some intervention groups but others not *(Grade very low quality evidence)*. Process outcomes (7 studies): individual studies reported significantly improved attendance of clinics and annual specialist reviews; decreased patients defaulting from treatment; improved patient satisfaction. No significant difference in hospital re-admissions in several studies *(Grade low quality evidence).*		Integrated multidisciplinary care across the primary and secondary care interface: • May improve patient satisfaction; • May improve patient attendance of visits; • May reduce patients defaulting from treatment It is uncertain whether it improves clinical outcomes.	This review has important limitations.
Rotter 2010	20 studies compared stand-alone clinical pathways with usual care. Studies were heterogeneous but meta-analysis of subgroups of comparable studies was done. Summary estimates and pooled results were displayed graphically. Both fixed and random effects models were used.	Clinical pathways reduced in-hospital complications (OR 0.58; 95% CI 0.36, 0.94) in 1 study of 163 patients, and improved documentation (OR 11.95: 4.72, 30.30) in 2 studies of 241 patients *(Grade evidence low)*. There was no evidence of differences in readmission to hospital (OR 0.60, CI 0.32, 1.13) in 6 studies with 672 participants, or in-hospital mortality (OR 0.84, CI 0.64, 1.11) in 3 studies with 1187 participants *(Grade evidence very low)*. Length of hospital stay was not significantly different in multifaceted interventions including CPW in 3 RCT's with 1796 patients (OR -0.86 CI -2.52, 0.81), or CPW's alone	Hospital costs were significantly reduced in 8 studies of 965 patients (OR -0.52, CI -0.78, -0.26). *(Grade evidence very low).*	Clinical pathways: • May improve documentation; • May reduce in-hospital complications in hospitalised patients. It is uncertain whether clinical pathways reduce length of hospital stay, in-hospital mortality, hospital re-admissions or hospital costs.	This is a good quality review with only minor limitations.

		compared to usual care (multiple comparisons). *(Grade evidence very low).*			

Table 5: Effects of Disease Management Programmes and Integrated Care

Study	Description of Analysis	Primary outcomes: Continuity of care, Clinical outcomes, Patient satisfaction	Secondary Outcomes: Compliance with treatment, Provider satisfaction, Costs	Summary of Results
Takeda 2019	Twenty-eight of the 44 studies were case management interventions, seven were clinic-based models, nine were multidisciplinary interventions, and three could not be categorised as any of these. A meta-analysis was conducted for each category of intervention.	Case management reduced all-cause mortality (RR 0.78, CI 0.68, 0.90); hospital re-admissions for heart failure (RR 0.64 CI 0.53, 0.78) (subgroup analysis found specialist nurses increased effect, and that a strong educational component is an advantage); and hospital re-admissions for all causes (RR 0.92 CI 0.83, 1.01). Clinic Management resulted in little to no difference in all-cause mortality (7 studies); heart failure re-admissions (2 studies), all cause re-admissions (4 studies) with significant effect in the first 6 months post discharge but reduced in longer follow up studies; and little or no difference in QoL. Multidisciplinary DMP decreased heart failure mortality (RR 0.46 CI 0.23,0.95) in 2 studies (Grade very low quality evidence), reduced all-cause mortality in 8 studies (RR 0.67, CI 0.54,0.83) (moderate quality evidence); reduced the risk for re-admission for heart failure RR 0.68, CI 0.50, 0.92) in 5 RCT's (low quality evidence), slightly reduced re-admissions for all causes (RR 0.85,CI 0.70, 1.01) in (5 RCT's) and had mixed effects on QoL (2 studies).	Case management may reduce costs and improve cost-effectiveness slightly compared with usual care. Clinic Management may reduce costs slightly. Multidisciplinary care may be cost effective from a societal perspective, but less so from a health services perspective (1 study).	Disease Management Programmes: • Probably reduce all-cause mortality *(Grade: moderate quality evidence);* • May reduce heart failure related re-admissions *(Grade: low quality evidence)*, • May slightly reduce all cause readmissions *(Grade: low quality evidence).* It is uncertain whether DMP's reduces heart failure related mortality *(Grade: very low quality evidence)*.
Handford 2017	A meta-analysis of the 33 included studies was not done. A narrative reporting of results by type of intervention was provided.	Cohort studies of case management found significantly improved continuity of care with any medical provider; and improved one and two year survival *(Grade quality of evidence was low)*. Cohort studies of multifaceted treatment found increased PHC use, retention in care, and ART uptake *(Grade quality of evidence was low).*Computer prompts (1 study) and discharge information and telephone access to specialists (1 study) for primary care providers accelerated commencement of appropriate treatment (ART and prophylaxis) and reduced hospital LOS.		Case management for HIV infected persons • May improve one and two year survival; • May improve continuity in appropriate medical care. Multifaceted treatment • May increase PHC visits and retention in care

				Computer prompts for PC providers • May acceleration commencement of appropriate treatment The effects of organisation of HIV care on other outcomes is uncertain.
Aubin 2012	A formal meta-analysis was not done due to heterogeneity. A modified form of meta-analysis based on the median change in outcomes in studies was conducted. Studies were analysed by groups in terms of interventions to improve informational, management and relational continuity; or by the model of the intervention e.g. shared care.	Based on median effect size estimates, no differences in patient functional (16 studies, 3966 patients), physical (25 studies, 5070 patients) and psychological (20 studies, 4634 patients) status were found between the intervention and usual care. The median patient satisfaction was 6.7 (6.7-11.5) higher in 2 studies of 378 cancer patients; and median global quality of life was 2.05 higher (0.05 lower to 2.14 higher) in 10 studies of 2622 cancer patients. *(Grade quality of evidence for all comparisons was very low).* Process of care outcomes was limited and of poor quality.		It is uncertain if Integration of care for cancer patients improves patient outcomes, patient satisfaction, QOL or care processes.
Allen 2014	Methods of analysis not described. A narrative reporting of lists of outcomes of individual studies without details of sample or effect sizes.	Transitional care interventions reduced rehospitalisation (6 studies) (Grade quality of evidence was low). Some studies found improved QOL and patient satisfaction (3 studies), and improvements in timeliness of communication and access to CBS (3 studies). (Grade quality of evidence was very low).		Transitional care interventions for older people with chronic diseases: • May reduce re-hospitalisations. It is uncertain if transitional care interventions improve clinical outcomes, patient satisfaction, quality of life, processes or costs of care.
Damery 2016	Heterogeneity prohibited a meta-synthesis across the 50 reviews. A narrative synthesis of interventions and outcomes was done.	Case management reviews (8) showed mixed findings or no association with outcomes; discharge management reduced hospital re-admissions for specific diseases in 6/13 reviews, particularly for those that included pre and post discharge support; multi-disciplinary teams (10) reduced admissions for heart failure and COPD, and reduced heart failure re-admissions and LOS. MDT for general chronic diseases had mixed effects or no association with outcomes. Complex interventions reduced admissions, hospital readmissions and LOS in a review of reviews.	25 reviews assessed costs but evidence was poor. Discharge management and MDT's were cost-effective.	Interventions based on multidisciplinary teams that include a disease specialist; discharge management that includes post discharge rehabilitation and follow up; and multicomponent strategies were most likely to significantly reduce hospitalisation for patients with single conditions such as heart failure or COPD.

Martinez Goncalez 2014	A meta-analysis was not performed, and a descriptive analysis of the 27 studies was provided. The results of 'integrated care' were reported by chronic condition as a proportion of reviews which reported statistically significantly improved clinical, functional, patient centred, process of care, use of health care, or cost outcomes for each condition.	Integrated care for congestive heart failure (CHF) patients reduced mortality (5/8 reviews), hospital admissions (4/6) and re-admissions (5/9), and emergency department visits (2/3). For diabetic patients it improved glycaemic control (4/7), quality of life (4/5), patient satisfaction (4/4) and reduced hospital admissions (2/3). For COPD patients it improved exercise capacity (2/4) and patient satisfaction (2/2), and reduced hospital admission (2/5), re-admissions (2/3), LOS (4/4) and EMD visits (2/3). For asthma patients it reduced hospital admissions (2/3).	Integrated care improved adherence to treatment guidelines for diabetic patients (4/6), COPD patients (3/3) and asthma patients (5/5). Few reviews (3/17) found reduced costs of health services.	Most reviews of integration found beneficial effects including reduced hospital admissions and re-admissions (CHF, Diabetes), improved adherence to treatment guidelines (Diabetes, COPD and asthma), patient satisfaction or quality of life.

Chapter 5: An outcome evaluation of an intervention to improve transitions in care for TB patients discharged from hospital in the Western Cape, South Africa

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Abstract

Introduction

Large numbers of TB patients are admitted to acute hospitals in high burden TB countries, but often experience poor continuity of TB care after discharge. An intervention to improve TB patient discharge management and linkages between levels of care was implemented at an acute referral hospital in the Western Cape, South Africa. This study aimed to evaluate the effects of the intervention on continuity of care for TB patients discharged from hospital under routine service conditions.

Methods

The outcome evaluation used a before after controlled 'quasi experimental' study design. We compared continuity of care for discharged TB patients in 2009/2010 and 2013/2014 before and after implementation of an intervention respectively. We also compared intervention to control ward patients in 2013/2014. All adult hospital admissions with a primary or secondary TB diagnosis during each period were included. Patient data from routine health information systems were analysed in STATA 15.0. We compared before-after and intervention-control groups using bivariate analysis and Chi^2 tests; and conducted a binary regression to assess associations.

Results

Significantly more discharged adult TB patients continued TB treatment after (548/595, 92.1%) compared to before (256/636, 40.3%) the intervention (OR 17.3, p <0.001). A binary regression of the 2013/14 patients indicated that younger age group (less than 38 years) (p = 0.02) and discharge from an internal medicine ward (p = 0.02) predicted continuity of care, but discharge from intervention wards did not (p = 0.07).

Conclusion

A multifaceted evidence-informed intervention to improve discharge management and linkages between levels of care contributed to significantly improved continuity of care for discharged TB patients in a before-after comparison. Contamination as a result of diffusion

effects reduced the validity of comparisons across intervention and controls wards. Further research is required to evaluate interventions to improve continuity of care for TB patients discharged from hospitals in similar settings.

Introduction

Large numbers of TB patients are admitted to acute care hospitals in high burden TB countries, with many failing to arrive at other levels of care to complete TB treatment after hospital discharge (31,82,84). This failure contributes to the development of chronic TB infection, drug resistant TB, ongoing community TB transmission, and increased hospital readmissions with associated economic and social costs to the patient and health system (41,45,167–169).

The WHO DOTS (Directly Observed Treatment Short Course) Strategy was adopted by the South African National TB Programme (NTP) in 1994, and implemented in primary health care (PHC) clinics and specialised TB hospitals throughout the country. Despite large numbers of TB patients being admitted to acute hospitals (19), these hospitals did not participate in the NTP and many TB patients discharged from hospitals did not arrive at NTP facilities to continue or complete TB treatment (36,37,170,171). A TB care cascade in South Africa corroborated WHO estimates of missing TB patients at 36%, with losses occurring at multiple stages of patient identification and care (4,35). Many of the missing TB patients were postulated as receiving care at non NTP services in the public health sector, particularly acute hospitals, in South Africa (91).

An observational study at a Western Cape acute referral hospital found that 36% of discharged TB patients arrived at NTP services, and 24% successfully completed TB treatment (170). The study also found that suboptimal compliance with TB diagnosis and treatment guidelines and poor information linkages undermined continuity of care for TB patients. In a subsequent qualitative study, hospital staff felt that a lack of patient centredness in clinical and referral processes, insufficient interdisciplinary collaboration, and inadequate communication within the hospital and with other levels of care contributed to poor continuity of care for TB patients (172).

Strategies in other high TB burden countries to improve linkages between hospitals and NTP's included adopting NTP clinical guidelines, recording and reporting systems, integrating laboratory services and training of clinicians and other hospital staff (83,86,173). Improvements in processes and continuity of care of discharged TB patients were reported in these settings (83,85,87). An observational study which evaluated a TB Coordination Centre established to improve management of TB patient discharges in a referral hospital in Gauteng Province in South Africa also documented substantial improvements in the proportion of patients who continued TB treatment after discharge (48).

We searched for but did not find any systematic reviews of interventions to improve continuity of care for TB patients. We therefore reviewed systematic reviews of strategies to improve continuity of care for other chronic disease patients discharged from hospital (65,146,147,151,174). Informed by the experiences in South Africa and other high TB burden countries, and the evidence from systematic reviews, we used Participatory Action Research (PAR) methods (101) to co-design an intervention package with health service providers to improve continuity of care for TB patients discharged from hospital. We used Coleman's definition of transitions in care 'the set of actions designed to ensure coordination of care received by patients as they transfer between different locations or levels of care', and Haggerty's definition of continuity of care 'the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's needs and personal context' to frame our approach to continuity of care between the hospital and other levels of care (77,78).

This study aimed to evaluate the effects of an intervention package to improve continuity of care for TB patients discharged from hospital under routine service conditions. Continuity of care was defined following Meiqari as 'the provision of coordinated care and services over time, and across levels and disciplines, which is coherent with the patient's health needs and personal circumstances' (2). The main objectives were to assess if continuity of TB care had improved since the baseline observational study, and if continuity of care was better for TB patients admitted to intervention compared to control wards.

Methods

The outcome evaluation was conducted at a 1300 bed public sector Central Academic Hospital (CAH) and PHC in the Western Cape, South Africa. The Province had the third highest TB incidence[1] in South Africa at 681/100 000, an HIV prevalence in adults of 8%, and TB and HIV were leading causes of mortality between 2009 and 2014 when this study was conducted (14,54).

A before after controlled 'quasi experimental' study design was used, as randomisation of patients or hospital wards was not feasible under routine service conditions (175). The before-after study compared adult TB patients admitted to hospital 2009, to adult TB patients admitted in 2013. The 'before' and 'after' samples included all adults over 15 years old admitted to any wards of CAH with a primary or secondary TB diagnosis in 2009 and 2013 respectively (170). We extracted routine data on adult TB patient ward admissions through the hospital's unit for infection prevention and control, TB diagnostic tests from the National Health Laboratory Services, patient details and management from Clinicom (ICD 10 coded hospital patient administration system) and TB notification forms in the hospital. In terms of the latter, TB is legislated as a notifiable disease requiring all health practitioners in South Africa to notify any cases of TB to the relevant public health authorities (5). This national notification system preceded and has remained separate from the NTP register system.

Patient outcome data were extracted from the provincial Electronic TB Register (ETR.net) and a provincial integrated web information system of all health service records to assess whether patients arrived at NTP services and their clinical treatment outcomes.

For the 2009 sample we included all hospitalised adult TB patients for whom complete data had been collected in an observational study as the pre-intervention baseline (176). In 2013, six internal medicine wards were conveniently selected in consultation with senior hospital staff as intervention wards. All adult TB patients admitted to and discharged from these wards were exposed to the intervention package which included:-

1. The development and implementation of a TB patient discharge guideline and checklist.

[1] Patients reported in the ETR.net

2. The adoption of NTP patient referral forms and NTP patient held records in the hospital;
3. Training of ward staff in the NTP, TB notification and improved TB patient discharge management processes;
4. The development of information, education and counselling (IEC) tools for TB patients being discharged from hospital;
5. Supervisory visits to provide guidance and support for ward staff;
6. Weekly emailing of lists of discharged TB patients to PHC and Community Based Services (CBS) for follow up. (The ETR.net was tested but could not be adapted for hospital use due to propriety registration of the software);
7. Monthly meetings of a coordinating committee of hospital and PHC staff to improve internal (hospital) and external communication, and to provide oversight to the intervention.

The demographic profile and continuity of care of TB patients discharged from internal medicine and wards for other adult clinical disciplines were similar in the baseline study. We therefore designated 'non-intervention' internal medicine, surgery and obstetrics and gynaecology wards as the controls in consultation with hospital managers. The intervention was implemented under the guidance of the coordinating committee between January and December 2013, and outcomes were assessed between January 2013 and December 2014. TB patients who died in hospital were excluded from the outcome assessment.

The main outcome assessed was the proportion of discharged adult TB patients who were registered to continue TB treatment at NTP services within one month of hospital discharge. A secondary outcome was the TB treatment outcome as recorded in the NTP register during the one year follow up period. All variables were categorical, except for age which was analysed both as a continuous variable and categorised above and below the mean age of the study sample. Patients with any form of drug resistant TB represented a small proportion of the hospitalised TB patients (6.4%). We did not find any associations between TB drug resistance and continuity of care in the baseline study, and therefore did not analyse drug resistant TB patients separately in the outcome evaluation.

An estimated sample size of 163 patients per comparison group and 326 in total was required to measure an effect size of 15% improvement in the percentage of patients who continued care, with alpha of 0.05 and power of 80%. As these estimates are based on the assumption of randomisation to ensure comparability of two groups, we aimed for a minimum of 200 patients in each comparison group. Outcome data were extracted from the provincial Electronic TB Register (ETR.net) to assess whether patients arrived at NTP services. Previous studies had found gaps in the data between the ETR.net and facility based TB registers (170,177,178), We therefore hand checked PHC facility and district paper based TB registers for any patient and TB outcomes not found in the ETR.net. Missing patients and outcomes were also searched for in an integrated electronic provincial data system which linked the separate data sources in 2016. All data were captured and cleaned in an Excel database, and exported to Stata 15.0 for analysis (179). Advice on the analysis was obtained from a statistician.

Univariate analysis described the dependent (continued TB treatment and treatment outcomes) and all independent variables in the 2009/2010 'before', and 2013/14 'after' groups, as well as intervention and control groups in 2013/2014. Bivariate analysis and Chi^2 tests were used to compare before-after, and intervention-control groups. A binomial logistic regression was used to assess associations between the binary outcome and independent variables in 2013/2014. Significance was set at a p value <0.05.

Results

A total of 636 adult TB patients were admitted to wards at CAH during a six month period in 2009, and followed up after discharge. Their mean age was 36.9 years, 322 (50.6%) were women and most (542, 85.2%) lived in urban Cape Town, with 94 (14.8%) from rural areas **(Table 1)**.

In 2013 a total of 649 adult TB patients were admitted to the intervention and control wards. Of these 54 patients (8.3%) died in hospital, and 595 were followed up after discharge. Their mean age was 37.9 years (SD 13.1), with a median of 35 and interquartile range (IQR) of 16 to 74 years. Slightly more discharged TB patients were women (310, 52.1%) than men (285, 47.9%), and most (535, 89.9%) lived in urban Cape Town, with 60 (10.1%) from rural areas **(Table 1).**

Before- after comparison of all admitted adult TB patients in 2009/10 and 2013/14

The 595 discharged adult TB patients post intervention in 2013 were similar in age and gender, but included fewer rural patients (OR 0.7, p = 0.01) compared to the 636 adult TB patients before the intervention in 2009 **(Table 1)**. In hospital mortality was similar pre (10.7%) and post intervention (8.3%) (OR 0.77, p = 0.17), suggesting similar severity of illness.

In 2013 after implementation of the intervention most adult TB patients discharged from hospital continued TB treatment at a NTP facility (548, 92.1%), a statistically significant increase from 40.3% before the intervention (OR 17.3, p <0.001). In the 2013 post-intervention sample continuity of care was similar across gender, area of residence (urban versus rural), and notification status **(Table 2)**. However, older TB patients (p=0.05) were less likely to continue TB treatment at a NTP facility. TB patients discharged from internal medicine wards (93.4%) compared to other wards (85.7%) were more likely to continue TB treatment at an NTP facility (p=0.02).

A total of 364 (61.2%) of all discharged TB patients successfully completed TB treatment post-intervention. This was a significant increase from the successful treatment completion rate of 26.6% (OR 4.4, p <0.001) before the intervention. However, successful treatment completion rates in TB patients who arrived at NTP services did not differ between pre (169/256, 66.0%) and post intervention (364/548, 66.4%) patients.

Of the 2013 post intervention patients who arrived at NTP facilities, 52 (8.7%) defaulted, 19 (3.2%) transferred to another facility. Of concern was that 79 (13.3%) had no recorded NTP treatment outcome result post-intervention compared to before (7.2%) (p<0.001) (**Table 1**). In 2013, 81 (12.5%) patients died during the one year follow up period after discharge, in addition to the 54 adult TB patients who died in hospital prior to discharge, bringing the total deaths to 135 (20.8%) during the study period. Post vs pre intervention changes in risks of death after discharge (OR 1.4, p = 0.07), and in total deaths (OR 0.95, P=0.7) including those who died in hospital, were not significant.

Although only 138 (23.2%) patients were notified for TB in hospital in 2013, this was a significant increase from 14.2% before the intervention (OR 1.8, p <0.001).

Intervention- control comparison of adult TB patients admitted in 2013/14

Of the 595 post intervention TB patients, 329 (59%) were discharged from intervention and 266 (41%) from control wards **(Table 3)**. The intervention and control patients were similar in age and gender, but more control (13.9%) than intervention patients (7.0%) were from rural areas (p = 0.005).

More intervention (37.4%) versus control ward patients (5.6%) were notified (p <0.001), but continuation of TB treatment was similar in the intervention (92.9%) and control groups (89.9%) and not statistically significant in a bivariate analysis (p = 0.067). The difference in successful treatment outcomes between the intervention (61.1%) and control (59.0%) groups was also not significant (p < 0.263).

The binary regression to understand the effects of the independent variables on the main outcome indicated that younger age group (less than 38 years) (p = 0.02), and discharge from an internal medicine ward (p = 0.02) statistically significantly predicted continuity of care, but discharge from an intervention ward did not (p = 0.07) (**Table 4**). None of the other independent variables were associated with continuity of care in the model.

Discussion

Continuity of care and treatment outcomes for adult TB patients discharged from hospital improved significantly after a multifaceted evidence-informed intervention to improve TB patient discharge management and linkages in care was implemented under routine service conditions at an acute referral hospital in South Africa.

Similar effects were found in interventions to improve hospital linkages in South Africa and other high TB burden country studies (48,83,85,87). In South Africa improved coordination of TB patient discharges through a dedicated hospital TB Coordination Centre resulted in an increase from 50% to 93% in TB patients arriving at PHC clinics within two weeks of discharge (48). In India the integration of the NTP into hospitals and into the teaching of health professionals improved links to peripheral services with 74% of TB patients continuing care after discharge from hospital (83). In China, the NTP clinical guidelines, recording and reporting system, and standard TB referral forms were implemented in general hospitals. Staff were also trained in referral processes, and hospitals included in a national electronic TB

information system. This resulted in a significant increase to more than 80% of TB patients referred from general hospitals to NTP health facilities successfully continuing TB treatment (85). As large numbers of TB patients are admitted to acute care non NTP hospitals (19,31), often having multiple re-admissions (170), the growing evidence supports interventions such as adoption of NTP guidelines and forms, training of staff, improved referral systems and information linkages to improve continuity of care for TB patients. Strategies shown to be effective for other chronic diseases such as discharge planning, shared care, and disease management programmes should also be considered in interventions to improve continuity of care for TB patients (65,151,174).

Despite the CAH intervention ensuring that more discharged TB patients arrived at NTP services, once they arrived there was no additional improvement in TB treatment outcomes. The successful treatment outcomes of discharged TB patients, although much improved to 61.1%, remained below the 2014 national and provincial successful TB treatment rates of 77.2% and 81.8% respectively (14). The post discharge mortality (12.5%) of patients who arrived at NTP facilities also showed little improvement post intervention. These poor treatment outcomes suggest that further post discharge support within the community may be required, particularly for HIV co-infected and older TB patients, who had a higher mortality risk after discharge in our baseline study (170).

Risk factors for poorer continuity of care such as older age persisted after the intervention. In other South African studies a lack of formal education, being a non-South African, and alcohol or drug use increased the risk of poor continuity of TB care after hospital discharge; whilst older age, formal housing, and steady employment were protective (171,180,181). Discharged TB patients also reported not being informed about their illness and its treatment in hospital, not knowing they needed to continue treatment, not being asked about their concerns, being too weak or not having money or transport to get to the clinic, and having other responsibilities which needed their attention (36,37,182). They also indicated that prior negative experiences at clinics, particularly staff attitudes, and problems accessing facilities because of distance prevented them from continuing TB treatment.

Although TB is a mandatory notifiable disease in South Africa (5), hospitals do not prioritise TB notifications (36,37,57,170).The proportion of TB patients notified in this study increased

significantly after the intervention, but remained relatively low and was not associated with improved continuity of care. TB patients admitted to acute hospitals are required to be notified through a paper based notification system which is not linked to the NTP's electronic TB register (ETR.net) nor other routine health information systems. An electronic surveillance system for notifiable medical conditions was adopted in South Africa in 2018 but is yet to be implemented in hospitals or linked to the ETR.net (183).

Under-notification of TB is a global problem for which high TB burden countries are seeking solutions. China's national internet based disease reporting system integrated its vertical notification system, doubling TB notifications and facilitating follow ups of patients who had not arrived at NTP facilities to continue TB treatment (85). India's web-based TB surveillance system similarly increased TB case notifications. Mandatory reporting of TB patients using electronic information systems to improve the completeness and quality of TB information is now being advocated more widely (184).

The large number of missing treatment outcome results (13.3%) further contributed to the lower successful TB treatment outcomes. The records indicated that many CAH TB patients were discharged to district hospitals, rehabilitation facilities and prisons, none of which reported TB outcomes in the ETR.net. More integrated TB information systems across health services and links to other sectors, may reduce this further loss of patient information.

In this study, continuity of care for TB patients discharged from both intervention and control wards improved significantly from the baseline, with little difference between them. Our process evaluation found that control ward staff, particularly from internal medicine control wards attended training sessions, and managers and staff of intervention wards shared information and tools with control wards (185). This diffusion effect reduced the validity of the comparison of intervention and control wards in this study. In addition, the Hawthorne effect of the baseline observational study, focus groups and PAR with hospital staff may have resulted in wider adoption of behaviour changes than anticipated (186).

Strengths and limitations

The intervention was informed by research evidence on strategies for continuity of TB care. This was adapted for the context using PAR in collaboration with health service providers, which facilitated the adoption and implementation of the intervention.

This quasi-experimental study had high external validity as it was conducted under service conditions in the real world setting of a health system. However, the absence of random allocation of participants to the intervention and controls may have reduced the internal validity as a result of confounding. We attempted to manage this in the study design by having a before after historical comparison, and selecting similar patient groups for the intervention and controls. We also sought to identify and control for confounding in the analysis.

In addition, we conducted a mixed methods process evaluation to explore secular trends and understand the implementation of the intervention. This revealed that our observational study had prompted a provincial policy statement emphasising the importance of care pathways for TB patients discharged from hospital. This policy generated pressure for improvements at the hospital. Along with the use of participatory research methods this contributed to early diffusion of the intervention within the hospital and contamination between the control and intervention wards. It also stimulated parallel actions in the hospital to strengthen informational linkages and community based support for discharged TB patients which complemented the 'core' intervention package and may have had a broader impact on continuity of care. We were unable to separate the effects of the core components of the package and additional actions within the hospital.

Implications for practice

This study demonstrated the feasibility of implementation, and effects of an evidence informed intervention on continuity of care for TB patients discharged from hospital under service conditions. Given the size of the problem, the magnitude of the effect, and evidence of success of similar programmes elsewhere, such interventions to improve discharge management of TB patients and linkages in care to the NTP should be explored in acute hospitals in South Africa and similar settings.

Implications for research

More rigorous studies are needed of the effects of interventions to improve continuity of care for TB patients discharged from hospital, as well as studies to understand factors affecting the implementation and the costs of such interventions in complex hospital settings (124,187). Studies should also investigate linkages in TB information systems of all facilities which provide care for TB patients outside the NTP including rehabilitations services, private sector health services and prisons in South Africa (11).

Further research is needed on patient sociodemographic and health system factors contributing to poor continuity of TB care and TB treatment outcomes after hospital discharge.

Conclusion

A multifaceted evidence-informed intervention to improve discharge management and linkages between levels of care contributed to significantly improved continuity of care for discharged TB patients in a before after comparison. This is relevant to high TB burden settings where large numbers of TB patients are admitted to acute care hospitals and are lost to follow up after discharge. Failure to improve linkages in care has serious implications for TB patients' outcomes, and contributes to the development of drug resistant TB and ongoing transmission of TB in communities. Further rigorous research is required to evaluate the effects of interventions, to understand factors affecting their implementation and to describe the costs of interventions to improve continuity of care for TB patients discharged from hospitals in similar settings.

Declarations

- Ethics approval and consent to participate

Ethical approval was obtained from the Faculty of Medicine and Health Sciences, University of Stellenbosch (Ref: N09/05/149), and IRB exemption for data analysis from Harvard TH Chan School of Public Health (IRB17-0109). Permission for the study was obtained from the CAH, the Western Cape Government Health Department (WCGH) and the City of Cape Town.

- Availability of data and material

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

- Competing interests

The authors declare that they have no competing interests.

- Funding

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- Authors' contributions

LD conceptualized and designed the study; LD, RD, FKM, and FM made substantial contributions to acquisition, analysis and interpretation of data; LD drafted the manuscript, and all authors contributed to revising it critically for intellectual content.

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Table 1: Comparison of demographic characteristics and outcomes in the Pre- (2009/2010) and Post intervention (2013/2014) groups of adult TB patients discharged from hospital.

		After (2013/14) n (%)	Before (2009/10) n (%)	Odds Ratio (95% Confidence Interval)	Chi^2 P value
Adult TB patients N		595	636		
Age mean (95% CI)		37.9 (37.5-39.5)	36.9 (35.9 -38.0)	-	P=0.18
Sex	Female	310 (52.1%)	322 (50.6%)	1.1 (0.8-1.3)	P=0.61
	Male	285 (47.9%)	314 (49.4%)		
Residence	Rural	60 (10.1%	94 (14.8%)	0.7 (0.5-1.0)	P=0.01
	Urban	535 (89.9%)	542 (85.2%)		
Notified		138 (23.2%)	90 (14.2%)	1.8 (1.3-2.5)	P<0.001
Continued TB care		548 (92.1%)	256 (40.3%)	17.3 (12.2-24.7)	P<0.001
Successful Rx Outcome		364 (61.1%)	169 (26.6%)	4.4 (3.4-5.6)	P<0.001
Died		81 (13.6%)	64 (10.1%)	1.4 (1.0-2.0)	P=0.07
No Outcome		79 (13.3%)	46 (7.2%)	1.9 (1.3-2.9)	P<0.001
Total deaths		135 (20.8%)	150 (23.6%)	0.95 (0.7-1.3)	P=0.7

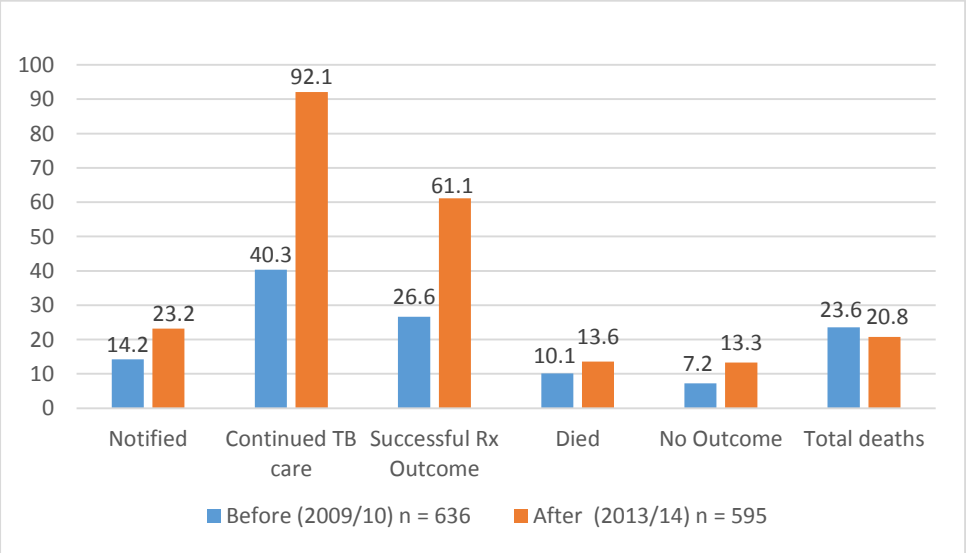

Figure 1: Comparison of outcomes in adult TB patients discharged from hospital before and after the intervention.

Table 2: Associations between continuity of TB care and independent variables in adult TB patients discharged from hospital in 2013/2014.

		Continued TB treatment at NTP facility n (row %)	Did not continue TB treatment at NTP facility n (row %)	Chi^2 P
Adult TB patients N = 595		548 (92.1%)	47 (7.9 %)	
Age (mean)		37.6 (CI 36.5 – 38.7)	41.5 (CI 37.2 – 45.9)	0.05
Sex	Female	285 (91.9%)	25	0.88
	Male	263 (92.3%)	22	
Residence	Metro	493 (92.1 %)	42	0.90
	Rural	55 (91.7 %)	5	
Notified	Yes	128 (92.8%)	10	0.75
	No	420 (91.9%)	37	
Discipline	Int Med	440 (93.4%)	31	0.02
	Other	108 (85.7%)	16	

Table 3: Comparison of the demographic characteristics and outcomes of the intervention and control groups of adult TB patients discharged from hospital in 2013/2014.

		All adult TB patients discharged, N	Intervention n (row %)	Control n (row %)	Odds Ratio (95% Confidence Interval)	Chi^2 P
Adult TB patients		595	329 (59%)	266 (41%)		
Age - mean (95% CI) Standard deviation		37.9 (36.8-38.9) SD 13.1	38.2 (36.8-39.6) SD 13.1	37.5 (35.9 – 39.0) SD 13.1		0.51
Sex	Female	310	169	141	0.94 (0.68 -1.29)	0.69
	Male	285	160	125		
Rural		60 (10.1%)	23 (7.0%)	37 (13.9%)	2.15 (1.2-3.7)	0.005
Notified		138 (23.2%)	123 (37.4%)	15 (5.6%)	19.4 (10.8-34.7)	<0.001
Continued TB care		548 (92.1%)	309 (92.9%)	239 (89.9%)	0.57 (0.31-1.05)	0.067
	Successful Rx Outcome	364 (61.1%)	194 (59.0%)	170 (63.9%)	0.81 (0.58-1.13)	<0.26
	Died	81 (13.6%)	54 (16.4%)	27 (10.2%)	0.57 (0.35-0.94)	0.03
	No Outcome	79 (13.3%)	41 (12.5%)	38 (14.3%)	0.85 (0.53-1.37)	0.51

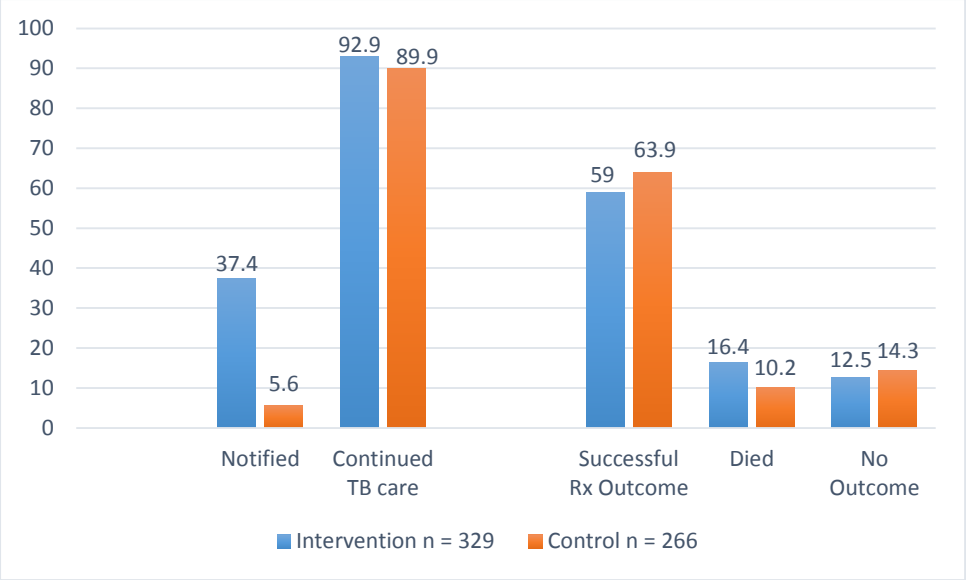

Figure 2: Comparison of outcomes in adult TB patients discharged from intervention and control wards of the hospital

Table 4: Binary regression of continuity of care, the intervention ward and other independent variables in adult TB patients discharged from hospital in 2013/2014.

	Relative Risk	**95% Confidence Interval**	**P value**
Age <= 38 years	-0.73	-1.34 to - 0.12	0.02
Intervention Ward	0.55	-0.05 – 1.16	0.07
Age <= 38 years	-0.75	-1.36 to - 0.14	0.02
Int Medicine Ward	0.76	0.12 – 1.4	0.02

Chapter 6: Understanding the implementation of an intervention to improve coordination of care for TB patients in South Africa: a process evaluation

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Abstract

Background

Poor coordination of care for TB patients discharged from acute hospitals results in many not continuing or completing TB treatment. A few interventions have improved continuity of care, but insufficient understanding of their implementation limits replication. This study investigated the implementation of a multifaceted intervention to improve continuity of care of TB patients discharged from a hospital in South Africa.

Methods

The study was undertaken at a 1300 bed tertiary academic hospital and primary health care services in a Province with a TB incidence of 681/100 000, where an intervention had improved continuity of care for discharged adult TB patients. We conducted a mixed methods process evaluation guided by an adapted Consolidated Framework for Implementation Research. A directed qualitative content analysis of documents, semi-structured key informant interviews and process monitoring data were triangulated to identify barriers and facilitators of implementation.

Results

Factors which enabled implementation, included the characteristics of the intervention, the people involved, the process of implementation and the external context. In a favourable policy environment, participatory action research facilitated the development of an appropriate and acceptable intervention which was readily adopted. Despite human resource constraints within the hospital, appropriate skills were sourced, roles clarified, and a sense of collective efficacy created in teams across levels of care. The implementation process included extensive engagement of organisational leaders and champions, joint planning, and periodic evaluations and reflection, creating co-ownership by service providers. Barriers to implementation included organisational fragmentation, hierarchical structures and human resource and information technology constraints. The loss of key staff and discontinuation of hospital coordinating meetings, resulted in the cessation of training and support for hospital activities. This was countered by strong community based support and information systems improvements which ensured management and information continuity in TB care between the hospital and PHC services.

Conclusion

A supportive external context, participatory action research and community resources contributed to the successful implementation of an intervention to improve coordination of TB care under routine service conditions in a resource constrained hospital and fragmented health system. To scale up and sustain interventions in similar complex hospital settings, additional support is needed to strengthen governance and leadership of change.

Introduction

South Africa has a TB prevalence in excess of 700/100 000, TB/HIV coinfection rates of 57%, and high levels of TB drug resistance (8). Acute care hospitals admit large numbers of TB patients who are not included in the National TB Control Programme (NTP). These 'missing' patients experience poor continuity of care with few completing TB treatment after hospital discharge (36,37,170), contribute to under-reporting of TB cases and deaths, and are not included in performance assessments of the NTP.

Interventions to improve continuity of TB care between acute care hospitals and NTP services (188,189) have been successfully implemented (48,86,173). However there is little explanation and understanding of how the interventions worked, and requirements for replication in other settings. Implementation, defined as 'the constellation of processes intended to get an intervention into use within an organisation'(190), of innovations in health organisations have often been poorly described (96). Medical research has prioritized the measurement of effects of interventions under ideal conditions, and failed to sufficiently elucidate mechanisms and contextual factors contributing to implementation under real world conditions (191,192). Interventions shown to be effective in particular contexts, often do not deliver the same results elsewhere for a variety of reasons which are poorly understood (193). This creates challenges in translating evidence of innovations into practice, and in scaling up interventions, particularly in Low and Middle Income Countries (LMIC's) (191).

Numerous theories, models and frameworks for implementation of innovations in practice environments (119,120,122) have been developed to guide implementation and evaluations of interventions (123,124). The Consolidated Framework for Implementation Research (CFIR) (122), a 'mega theory' developed by consensus from multiple theories of implementation, and Promoting Action on Research Implementation (PARIHS) (194), have been used extensively in high income settings but had little application in LMIC settings (126).

An intervention package to improve transitions in care of TB patients discharged from an acute care hospital in South Africa significantly improved continuity of care from 40.3% before to 92.1% of

discharged adult TB patients receiving treatment at NTP services after the intervention (195). The intervention exceeded expectations in the face of many challenges experienced during implementation. Little research has been conducted in South Africa and other LMIC's on interventions to improve care transitions, defined as 'a set of actions to improve coordination or continuity of health care as patients transfer between different locations or different levels of care within the same location' (125).

To understand what occurred during implementation and particularly why and how the intervention had succeeded, we used the CFIR, with adaptations from the 'Care Transitions Framework' (CTF) (196), to retrospectively guide a process evaluation of implementation of an intervention to improve TB continuity of care (120,197).

Methods

This study was undertaken at a 1300 bed central academic hospital (CAH) and primary health care (PHC) services in a Province with a TB incidence of 681/100 000 (14), where an intervention had been implemented to increase the proportion of discharged adult TB patients who continued TB treatment at NTP services. The intervention was informed by evidence from baseline observational and qualitative studies at CAH, other local studies and an overview of systematic reviews on continuity of care for chronic diseases (48,170,172). Participatory Action Research (PAR) was used to facilitate the development and implementation of the intervention (101).

The core components of a multicomponent package implemented in six adult internal medicine wards between January and December 2013 were:-

- A TB patient discharge management guideline and checklist;
- NTP patient referral forms and patient held cards which had previously not been used in the hospital;
- Information, education and counselling (IEC) tools for TB patients developed or adapted for use in the hospital;
- Training of ward staff in the NTP, TB notification and TB patient discharge management using the tools;
- Weekly supervisory visits to intervention wards to provide guidance and support;
- Weekly emailing of lists of discharged TB patients to PHC and Community Based Services (CBS) for follow up;

- A monthly coordinating committee meeting of hospital and PHC staff to improve internal and external communication, and provide oversight to the intervention.

The CFIR was adapted to include additional CTF constructs (196). A 'measurement of implementation' domain was added to assess outcomes of implementation (120). The final six domains were i. Core intervention characteristics, ii. External context, iii. Organisational characteristics, iv. Characteristics and roles of persons involved, v. Process of implementation, and vi. Measures of Implementation. Each domain contained several more detailed constructs (Table 1).

This adapted CFIR guided a mixed methods process evaluation consisting of three components, i) a directed qualitative content analysis of documents (198), ii) analysis of project monitoring data, and iii) key informant interviews with health care providers who had participated in the implementation of the intervention. We used the Miles and Huberman Framework for qualitative data analysis in i) and iii) for data reduction, data display and for drawing conclusions (199). The six CFIR domains were used as the first set of codes to guide all stages of analysis. More advanced analysis was conducted within each domain to explore the data and constructs in greater depth. We triangulated the different data to discover patterns within and across the data sources, and to identify any peculiar characteristics which may have affected implementation.

More than 40 documents from the periods before, during and after the intervention were sourced from the hospital, national and provincial health departments, key informants and the research team for the content analysis in 2016. These included national, provincial and hospital policies, guidelines and annual reports; two workshop reports (a pre intervention planning workshop, and a post intervention feedback workshop); intervention plans and tools; presentations at and minutes of provincial, district and hospital management meetings; hospital steering committee (HSC) meetings; research project meetings; email correspondence; progress reports to health services and funders; and conference posters and presentations (Annexure 5.1: List of documents).

The documents were organised by type, source and date of documents. Each document was read by the first author (LD) to identify content relevant to each of the CFIR domains. The text in the sections was reviewed and mapped against the relevant constructs in each domain (Table 1) to identify patterns and emerging themes within each domain and its' constructs. This information was synthesised and a draft narrative describing and interpreting the emerging themes reviewed by co-authors before finalisation.

Process monitoring data included training reports (numbers, dates and topics of training sessions; numbers, demographics, professional categories and wards of staff who participated; and

participants' feedback on the training sessions); assessments of the use of discharge management and patient education tools in intervention wards; patient chart reviews to assess completion of documents such as notification forms and referral letters; written feedback from ward supervisory visits; and feedback reports by PHC providers on communication and referrals from the hospital.

The study population for the semi-structured interviews included provincial, hospital and PHC staff including health managers, nurses, physicians, clerical staff, and community based staff who had participated in the implementation of the intervention (200). We purposively selected 20 key informants who represented different disciplines, levels of care and roles (201,202). Interviews were conducted rather than focus group discussions as we sought to obtain the perspectives of a cross section of individuals involved within and beyond the hospital. The key informants were contacted by the PI by email and provided with a formal letter of invitation describing the background to and purpose of the study. Follow up contact was made telephonically or in face to face meetings by the PI and a research assistant to arrange appointments for interviews which were held between July and December 2018. We looked for similarities and differences in participants' experiences and perspectives on the implementation of the intervention.

A brief interview guide based on the initial CFIR mapping of the document analysis provided prompts for the interviewer (Annexure 5.2). Written consent was provided by all participants and interviews were held in a private space in the workplace of each key informant. The interviews ranged between 45 and 90 minutes, and were conducted in English by an experienced qualitative research assistant who was independent from the implementation team but had worked in similar health service settings. He established trust with participants and created an interview environment which allowed participants to share their perspectives honestly. The interviews were audio recorded and transcribed by the research assistant. He was also fluent in Afrikaans and any responses in Afrikaans were translated into English in the transcriptions.

Of the informants, 17 were available for interviews, two were not in the country during the time of the interviews, and a third did not respond to invitations. The 17 who participated included 12 hospital personnel, three PHC staff, and two Provincial managers. Thirteen were female; 11 had a nursing background, three were medical doctors, two social workers and one administrative clerk.

The transcribed interviews were checked by the PI and any queries discussed with the research assistant and rechecked against the recordings for corrections. The interviews were analysed by the PI, an MD with two master's degrees in health systems and public health medicine, and more than 10 years' experience in health systems research. The co-author, FM, a PhD experienced in qualitative

research methods, independently reviewed the transcriptions and contributed to the analysis and interpretation. The draft manuscript was also reviewed by two other members of the intervention implementation team.

Data from each of the three components were mapped onto the six domains and constructs guided by CFIR tools (http:/CFIR.) (Table 1). All data were captured and organised in Microsoft Excel (version 2013) spreadsheet for analysis and interpretation. The data were analysed across the three main sources to identify patterns, sequences and emergent themes.

Ethical approval was obtained from the Faculty of Medicine and Health Sciences, University of Stellenbosch (Ref: N09/05/149). Permission for the study was obtained from the CAH, the Western Cape Government Health Department (WCGH) and the City of Cape Town.

Results

The three sources of data collectively covered all the CFIR domains, but clustered around different domains and constructs. The document content analysis provided most of the data on the intervention characteristics and external environment; the process monitoring data mostly on the process and outcomes of implementation, and the key informant interviews more broadly on the intervention characteristics, the internal setting, the people involved, and the process and outcomes. The data was triangulated to assess similarities and differences across the data sources in each domain and relevant constructs. The results are presented under the six CFIR domains, with their constructs in bold type within each domain. We provide selected verbatim quotes of key informants or from documents to illustrate the themes which emerged.

Intervention characteristics

The **source** and **adaptability** of the intervention were important constructs which positively influenced implementation. Health managers and staff felt that the source of the intervention was internal following research on continuity of care for TB patients at CAH. A workshop had tasked a team of health care providers and researchers with developing a 'TB Continuity of Care' intervention plan which was approved by the hospital management in June 2012.

> *'The purpose of the workshop was to invite researchers… to share research findings and experiences… with health service providers, in order to identify key interventions to improve continuity of care for TB and TB/HIV.' 'Feedback would be given to T Hospital management on*

recommendations emanating from the workshop, as part of the planning for the intervention study at T Hospital'. SANPAD Continuity of TB care workshop, 30 Sept 2011.

'Once we had the results, and we had a good look at the poor results, we had a workshop. What next…and what's the next step? Even before the workshop, we realised that the services, inside and outside the hospitals, were not clear, on referral pathways.' [#2, health manager (province)]

Hospital managers took ownership as they felt that the baseline study reflected poorly on the performance of the hospital.

'Firstly we had to acknowledge that we had a problem….and yes we acknowledged that. We agreed that if we have a problem, then we need to solve the problem. We had a few weeks, where we tried to pave the way forward. We looked at how we as management, could tackle this problem. We realised that it would need managerial input on many of the issues. We needed the clinical, nursing and clerical staff. In fact, we needed an entire team to be involved in this venture.' [#17, health manager (hospital)]

Ward nurses felt that the source was the hospital Unit for Infection Prevention and Control (UIPC), which played a key role in supporting the intervention in hospital wards.

'My manager Sister W asked us to help. She explained the IPC programme to us, along with Sister J (UIPC TB coordinator). I was the only one assisting Sister J, because when noticing the Sister, the rest of the staff ran away. I was always willing to help her. She asked questions around the TB patients, especially the ones in the single rooms. Sister W chose me because I was always willing to assist Sister J. Sister J suggested that I should go for the training.' [#14, nurse]

The **evidence** informing the intervention was seen as credible and included research at the hospital, systematic reviews, and local best practices which were disseminated and discussed at several workshops and meetings (170). A PAR process supported the development of the intervention and implementation plan which was approved by the CAH management.

'The intervention is grounded in the findings of a preceding study of the management and discharge of TB patients at CAH. This included a series of focus group consultations with hospital staff to identify barriers and enablers in the system'. Introduction in Intervention Plan adopted by CAH management on 25 June 2012.

'the researchers got together with management, to get the intervention approval. The researchers met with the clinical team. They explained what the research study was all about. The various components of the research were discussed. Doctors, nurses and the administration staff who played an exceptional role, were all involved' [#4, nurse]

'It wasn't an intervention where researchers would have a preconceived idea of going in, do things and running away. It was a participative approach' [#6, doctor].

The **adaptability** of the intervention was a recurring theme demonstrated by changes made to address challenges experienced during the planning and early implementation by service providers.

'Following a meeting with … (Pharmacy) and (nursing management)… it became evident that it was not appropriate to use TB ready packs in the initial phase of the TB CoC project since most patients are prescribed on multiple drugs in addition to TB treatment. It was proposed that nursing staff should ensure that a TTO (To take out) card with TB medication for 7 days is submitted to the pharmacy at least 24 hours before the patient is expected to be discharged from hospital'. Minutes of Hospital Steering Committee 30 July 2012.

'A few attendees raised concerns about the lack of time for application of both the TB flipchart and leaflet as part of a formal/structured educational session. This resulted in a group discussion…… some mentioned eagerness to apply the tools in a group format… Others were of the opinion that, depending on individual patient knowledge about TB, the tools are suitable for full or partial integration during the provision of routine nursing care to instil, expand or reinforce key messages toward continuity of care, treatment completion and cure.' Minutes of Nursing Unit Managers Meeting, 25 January 2013.

Trialability was incorporated in the plan, and the intervention was implemented and evaluated in selected wards.

'For the first 6 months these forms will be used only in the intervention wards and scaled up within the hospital after the intervention. The evaluations will assess the usefulness of the referral letter and patient card.' Minutes of Hospital Steering Committee, 28 May 2012.

'Initially they piloted in D10. Yes, we had a few headaches that needed to be addressed, but when they somehow got used to it, it wasn't that much of a problem.' [#4, IPC nurse].

'Originally when they started the continuation of TB care programme, they implemented it in D10. Along with that, they also implemented it in the different internal medicine wards as well.

The other wards were…… From D10, it expanded, and went to the other internal medicine wards, where TB patients were located.' [#10, nurse manager]

'We were focusing on specific areas, specific wards and a specific module. I thought that the results will be good, because we were focusing on something specific. The next step was to roll it out, to a bigger platform.' [#17, health manager (hospital)]

The **complexity** of implementing a multicomponent intervention in a resource constrained setting created numerous challenges. Service providers however identified the complexity as a **relative advantage**, as it recognised and responded to a multi-faceted and complex problem.

'For us, what matters, is the richness that comes from that intervention.' [#2, health manager].

'Their approach also helped. It was an approach that acknowledged the complexity of the issue. There wasn't only one problem that needed change, but multiple things that needed to change.' [#6, doctor]

'I do remember that we had so many changes that accompanied the continuation of TB care programme. We really needed lots of input and buy in from people, so that people could work together.' [#9, health manager]

The **design quality and packaging** was refined with service providers to respond to their needs. For example, a discharge checklist was suggested by nurses who, along with clinicians, contributed to the content development and packaging.

'TB Patient Discharge Checklist (with Guidelines on Patient Discharge for completion printed on reverse side): feedback on the final draft received from the Internal Medicine Module nurses and from Dr JT (who forwarded a copy to Prof M). The final guidelines should be printed on colour paper to avoid confusion with other discharge/management documentation used at ward level.' Minutes of Hospital Steering Committee, 30 July 2012.

'I think that the guidelines were clear. The research team compiled a form….I can't remember the name of the blue form. This form was usually completed by the nurses, when the patient was admitted. It was also completed by the admin clerk. It gave them a sense of direction, when the doctors spoke of the discharge. This form enabled them to ready the medication, so that the patient didn't wait too long for their medication, on discharge. It also guided their thoughts around notification and where these forms should go to. They were enthusiastic about the training package as it also enhanced their TB knowledge.' [#18, nurse (IPC)].

Ward nurses, while appreciating the design and packaging of the tools, also complained about the number of documents which they had to work with.

> *'We had a blue (discharge) checklist that we had to complete. Somehow this was a bit of a problem for some of the people in the ward. … We were extremely short staffed, and we didn't always get to all of this. It was very difficult, and that was one of the problems we had with the forms. If you were busy doing a pre-med, you couldn't run around filling in forms. … When we did get around to it, we completed the entire checklist. We used flipcharts as part of our patient education. It provided great TB information. How long the treatment should last. How long the lungs took to show results. We also used the different languages.' [#1, nurse].*

> *'It was the paperwork that I remember so clearly. We had lots of paperwork and forms that we had to fill in. I think some of the papers had to go back to UIPC'. [#15, nurse].*

A **history** of an earlier paediatric intervention to improve linkages in care generated support for the intervention.

> *'K did a special intervention, and hers was basically realising, that the kiddies….are discharged from TAH to Brooklyn Chest. ….where they complete their treatment, or die. Brooklyn Chest Hospital has never had an electronic register…or a manual register… So that intervention put a register in Brooklyn Chest, and then the number of linkages went up dramatically. I think it was eighty eight percent.' [#2, health manager].*

> *'.the paediatric internal medicine doctors. They have a very good system in place, in controlling TB in children. Remember that the National TB Control Programme was more geared to adult intervention, and not so much aimed at children. TAH along with Prof S had such an excellent programme going. Very often Mrs J, who I believe is now Deputy Director, would say "You guys can learn from paediatrics". That was very true as we could learn from Paediatrics.' [#18, nurse (IPC)].*

External Context

The external context was conducive and created a window of opportunity for implementation of the intervention. In terms of **population and patient needs,** TB was prioritised in national and provincial strategies because of its contribution to the burden of disease (56,203), and failure of acute hospitals to provide quality care for TB patients (36,37,170).

'I think that the study came at the right time, when we were still grappling with this problem, and looking at ways of how to address the TB problem. TB was a real and deep challenge.' [#17, health manager].

'The research was very well timed with the evolution of the department. It came in with a topic of continuity of care at the same time that the Province was building a vision of patient centred care. 2013 was still known as the Vision 2020. It has now become 2030. I think that the topic intervention legitimises a lot of the thinking that was happening in the Province. Province didn't have it in so many words. It gave a tangible case to look at continuity of care for TB. It made the conceptual thinking more concrete. Buy in was not challenging. It was a nice alignment….a policy window, and a nice alignment of priority.' [#6, doctor].

The project established **'external networks'** with the KNCV TB Foundation and Hospital DOTS Linkage (HDL), participating in a HDL workshop with partners from several countries (204). KNCV and two other South African TB projects participated in the intervention planning workshop, and KNCV collaborated on a funding proposal to support the intervention

External policies included a National Strategic Plan (NSP) which prioritised quality of health care, National Core Standards (NCS) and the establishment of a national Office of Health Standards Compliance (OHSC) to monitor the quality standards in health facilities (203,205). The Western Cape's Healthcare plan 2030 focused on patient centred care, and was supported by a Provincial Standard Operating Procedure (SOP) for TB Care Pathways, referencing the baseline study at CAH (56,206).

'The approach to 2020 focuses on a "care pathway" across the various levels of the health service' and 'The patient flow between acute hospitals, TB hospitals, CBS and PHC needs to more efficiently managed'.. 2020 The future of health care in the Western Cape, Department of Health, Western Cape Government, November 2011. (56)

'At that stage, health care 2030 (WCGH Strategy) was being developed. They immediately linked that with this particular intervention, to plan the way forward.' [#2, health manager]

'This circular services to inform the Health Care Services of the development of a SOP in the management of referrals of TB patients between the various levels of care. A recent study at CAH has shown that only 22% of patients discharged from the hospital access appropriate care following discharge. Based on this and with the adoption of the Vision 2020 population and health outcomes approaches, along with the Clinical Governance Policy, it became evident that

an SOP be developed to ensure an integrated pathway for TB patients across all service platforms.' Circular H 18/2013, Department of Health, Western Cape Government (206).

Patient centredness was a recurring theme, from national and provincial policies, to hospital management and staff.

'*The driving force behind 2020 is the need for a stronger patient centred approach that focuses on improving the patient experience and the technical quality of care' 2020 The future of health care in the Western Cape*, *Department of Health, Western Cape Government, November 2011.*

'An intervention plan for adult patients needed to be effected … taking cognisance of a) 2020 (strategic plan),….*and d) liaison with patients;' Hospital Executive Committee Meeting minutes, 24 Jan 2012.*

'In terms of the patient education, they also kept a record of the education given to the patients. They also engaged with the family members visiting the patient, and explained the nature of the disease, and more importantly, the importance of treatment. Education on how the family members could assist in the completion of the TB treatment was given.' [#4, nurse (IPC)].

'We also created a safe environment for patients to ask the necessary questions. That freedom and space was created by us. All visitors received TB education as well, to help them understand the disease better. This was done in all the official languages, namely English, Afrikaans and Xhosa. We also used the flipcharts, and that was kept in the treatment room. It was an exceptional tool, in providing family education. All the visitors benefited from this education.' [#15, nurse].

'What happens if they are bedridden at home? There's another thing that we did. We linked, not just the facility, but we linked with the NPO's that we funded in the area, so that they could also follow up.' [#3, PHC staff].

The project involved **community resources** through PHC, Community Based Services (CBS), Non Profit Organisation's (NPO's) and Community Health Workers (CHW's) who followed up discharged TB patients.

'I met with Mrs TQ (Provincial Manager of CBS), and a team of 6 CBS coordinators … today. They are keen to be involved and have apparently been trying to improve referrals between

CAH and their services for the past few years.' Email correspondence of project team, 31 January 2013.

'We had the support of the Provincial office. I think, and in my opinion, the link between the local authorities is of the utmost importance, and in my opinion should be strengthened even more. Eventually we got them on board. That was the home based carers as well as the TB coordinators, especially from the Metro region.' [#18, nurse (IPC)].

'We linked, not just the facility, but we linked with the NPO's that we funded in the area, so that they could also follow up.' [#3, PHC staff].

Organisational Characteristics

This domain presented numerous challenges for implementation. The **structural characteristics** of this academic referral hospital and its referral services reflected a complex pattern of relationships within a historically fragmented health system.

'In terms of history, the district health services operated in three components. We had a district hospital. Then we have the PHC facility, we have a community based service platform, where we contract our home based care services to non-profit organisations. …..We had a communication gap between the people in the hospital, operations teams and the clinicians. They didn't know how to connect with us, to ensure that information and communication gets to us. At that stage we had three (provincial) sub directorates. We had HAST, community based services and meetings to ensure continuity of care. At that stage, health care 2030 was being developed. They immediately linked that with this particular intervention, to plan the way forward.' [#3, PHC staff].

'Our major external problem is with the City of Cape Town. Remember that the City of Cape Town does TB. As a department, we do all the other illnesses. We are reliant on the City, and they in turn are reliant on the community based carers, to do the work outside in the community.' [#5, PHC staff].

'That expectation was orbiting us, and it was a struggle to get the NPO and the facility to speak to each other. It was a problem to get a coordinated structure, at facility level.' [#3, PHC staff].

'It took them fifteen years to realise that we have don't have a link to our community anymore.' [#2, health manager].

Disciplinary and clinical silos further contributed to the fragmentation of care.

> *'I think that in provincial and organisational culture, people tend to work in silos. People are insulated in their outlook. We have a culture that says…this is the job that I get paid for…and this is what I do. People are not open to suggestions' [#3, PHC staff].*

> *'linkage was haphazard…as you had to link up with a specific team…in the form of surgery or medicine. CAH itself operates in a silo. With each medical component, you have to meet with the surgical head and his team.' 'We made many attempts in hospital. Let me use the example of the IDC (Infectious Diseases Clinic). In one day, my HAST counterpart and I, had to meet with paediatric TB and adult TB. We also had to meet with paediatric HIV and adult HIV, because of the sub specialities. That's the complexities in CAH.' [#3, PHC staff].*

> *'Carers think in silos and find it difficult to think integratedly.' [#5, PHC staff].*

A number of **teams, networks and communication** channels within and across organisations and levels of care participated in the intervention. The provincial and hospital management approved the intervention, and delegated coordination to a multidisciplinary Hospital Steering Committee (HSC) of hospital managers, clinical staff, PHC staff, and researchers.

> *'A working committee needs to be established to manage the more detailed aspects. The members should be:*
>
> *Nursing: Ms D and Ms H (hospital nursing managers)*
>
> *HAST: 3 members to be recommended by Dr D (Provincial and PHC services)*
>
> *Internal Medicine: Dr T (infectious diseases specialist)*
>
> *Hospital Management: Dr M*
>
> *UIPC: Sr M '*
>
> *Minutes of a meeting of hospital managers and researchers, 17 April 2012.*

> *'After we engaged the provincial office, the agreement was that CAH would have a co-ordinating committee, focusing primarily on this intervention. Then we got the buy in from managemen.t' [#3, PHC staff].*

'Prof D met us at Naughton House through our Provincial office. This was facilitated through Mrs TK. The people present at this meeting were Prof D, our Manager DF and the CBS coordinators. She explained the programme to us, the way forward, and the gap between hospital, community and support for TB adherence, regarding the client. We had more meetings at our main offices at KB. After that we were invited to the monthly meetings at CAH. CBS and HAST were also invited to that meetings.' 'We had regular meetings with Prof, and the CEO of Tygerberg. From a CBS perspective, we would give feedback about the referrals that we received from Tygerberg.' [#5, PHC CBS staff].

'The point I'm trying to make is that it took the input of many people, and networking that aided our quest, in getting the patient to the correct clinic, when discharged from our wards.' [#10, health manager].

'I felt that it was supported, from the top to the bottom, and that includes the nursing staff, right down to the household staff. Every time a PTB patient was discharged, I could say to any household worker' 'The other plus to that was, the workload was shared, and not all of the responsibility was on the shoulders of the Staff Nurse.' [#16, nurse].

Additional coordinating meetings were established within the PHC services to strengthen links between the HAST programme, PHC facilities and NPO's.

'We had monthly meetings with representatives from Health Impact Assessment (Provincial Unit) as Dr D came from the provincial office…..for monitoring purposes. Our manager or director felt that we should involve our HAST colleagues, as they were not at the initial provincial meeting.' [#3, PHC staff].

'I have a monthly meeting with the (CBS) coordinators. All the minutes of the meetings will be handed over to them. At the monthly meetings I will speak through the agenda point, which deals specifically with TB/HIV. This is discussed on a monthly basis. All the TAH information will be discussed at the coordinators meeting. I have six NPO's that I manage. We have project managers, coordinators and supervisors, which collectively form part of that meeting. From that point, they are supposed to hand over to the carers, and we monitor their monthly meetings with the carers, checking on the information they hand over to the carers.' [#5, PHC staff].

The teams used formal and informal networks to facilitate communication within and across organisations.

'When you're an old cat, and you've learnt to manoeuvre, you draw strength from other things. Your networking, picking up the phone, your relationship management, plays a big role.' [#3, PHC staff].

'She (hospital coordinator) also went to workshops Sr E (PHC nurse) invited her to. That helped and kept her informed on the latest. That enabled her to strengthen her networks with the PHC workers.' [#4, nurse (IPC)].

'If the patients were from the rural region….because of our networking, we could just send the forms to them. I simply cannot stress the point more, between the referral hospital, and a dedicated person in local authority…. The two of us had an excellent working relationship. Coming back to the link with the local authority….CAH, or any other referral hospital, must also have that Link person in the hospital.' [#18, nurse (IPC)].

The **implementation climate** was supportive with a **tension for change** following wide dissemination of the baseline study, and perceived **compatibility** of the intervention with principles of patient centred care and efficiency advocated in policies.

'The realisation that we were already fighting, and trying to find a solution when this came, made it easier to get the necessary buy in, and the cooperation needed for this study. This was the second part when we realised the dangers. We were in the process, and struggling to find ways …and looking at ways to address the problem. It really came at the right time, when we as an institution were trying to find solutions to the problem.' [#17, health manager].

'At the time HIV/TB was very high on the agenda in all the wards, especially in PPE (Personal Protective Equipment). I must say that everybody was on board…in all the wards…for the continuation of care TB programme. The training and the PPE, for all the nursing, was very high on the agenda. In D10, the doctors also received training. I think the new interns or medical students, received their training at Stellenbosch University, as part of their orientation.' [#10, nurse].

'The community health workers…… The 2013 project coincided with us, having integrated TB and HIV adherence support. Improving the overall communication, the NGO and the facility assisted us.' [#5, PHC staff].

Active **communication of goals and feedback** was perceived as important, as summarised in the post intervention workshop report.

'Factors that facilitated improved continuity of care for TB patients in the project included i) Good communication between stakeholders, and ii) Regular feedback from researchers.' Continuity of TB Care workshop, 29 August 2014.

This was confirmed by HSC members, but ward nurses felt they received insufficient communication and should have been included more.

'You must remember that a lot of ground work was done before implementation. It was well advertised. People were definitely informed as to what we intend doing.' [#18, nurse (IPC)].

"When meetings are called only those in higher positions are called to sit in and participate' 'As I said, we were the juniors. It was only the hierarchy going to the meetings. What was discussed we don't know. We only got the tail end of the story.' 'We had to follow their instructions.' [#12, nurse].

'In the beginning, I think the new staff felt intimidated by the unknown. I think more lectures, or information should be given to the staff, so that a sense of belonging can develop, or about the implementation. Don't hide the information.' [#15, nurse].

Despite this the intervention wards were receptive if not entirely **ready for implementation**. Extensive **leadership engagement** at different levels, and active support of hospital management was reflected in meeting minutes, and confirmed by informants.

'The slideshow was – amongst others…presented at a Senior Management team meeting and District Health Services EXCO meeting. Henceforth, it was to be presented at the upcoming Divisional EXCO meeting,' Hospital Executive Committee Meeting minutes, 24 Jan 2012

'The intervention also involved sensitising management, meetings with management; I think that at CAH, the intervention was well implemented. There was good buy in from local management. The governance structure was set up.' [#6, doctor].

'It was your clinicians, student interns, Unit Managers, Nursing Staff and the administrative ward clerks. The buy in was great. However the programme was better implemented in some wards, than in others, especially where your Unit Managers were quite optimistic to implement, and see that things are working.' [#18, nurse (IPC)].

The **commitment** of health service staff to implement the intervention was also reflected in meeting minutes and by informants.

'The majority of attendees expressed excitement about the implementation of the project.' Nursing Unit Managers Meeting minutes, January 25 2013.

'Yes, listening to people and knowing that there was buy in throughout the platform…..provincial, district, hospital ….that there was a commitment.' [#6, doctor].

'Yes…everybody….from the ward clerk to everybody else. It truly became the talk of the town, and was on everybody's lips. Collectively people decided that the forms must be completed and that we couldn't send refer the patients without the necessary documentation. That also coincided with our fight with the pharmacy, because it was important. That letter must come through…and we want the seven day treatment….and we need to give the patient everything….because we couldn't send them without the forms….saying that we do, when in reality we don't.' [#10, nurse].

'I was very excited about the programme, because I'm a talkative person. Educating the patients and their families was good for me. Once the families came, they knew that I will provide family education; I took them to the treatment room, and showed them the board, and how it works from A to Z. I encouraged them that once the patient returns home; they must see that they adhere to their medication.' [#14, nurse].

'We also had the positive attitude of the nursing staff, which augured well for the intervention. We also had the positive attitude of the administrative staff. We had wonderful admin clerks in Wards D8 and D9.They were on the ball. Even before the intervention, they would call the doctors, if notification or referral forms were not completed. That was a real feather in our cap. We had two extremely diligent admin clerks.' [#18, nurse (IPC)].

Despite the improvements in interdisciplinary team functioning, there were concerns that doctors were not as committed to support continuity of care for TB patients. Doctor's communication with patients was also a concern to nurses.

'Nurses are concerned about doctors not completing the documentation.' Ward supervision visit notes, 6 May 2013.

'I can tell you that initially we had a battle getting the doctors to complete the paperwork. The nurses had to run after them. The doctors would say they're coming back, never to return. They usually completed it the following day. … in the beginning we struggled with the doctors. As time went on, we got to know each other. They knew who they could mess around. I didn't

take that nonsense. They knew that once I requested the forms, they had to complete it. It was their attitude once we requested, that really got to me.' [*#15, nurse].*

'I think that sometimes the doctors didn't have the communication skills to speak to the PTB patients. There were times when we had to move the patient from a particular ward, to a single room. The doctors didn't tell the patients that they had PTB. That became our responsibility ….the nursing staff. We have become the bad guys.' [#16, nurse].

'Doctors do their rounds, along with all the other internal medicine wards. Whilst doing their morning rounds, they might say to the patient "We are discharging you today". The problem lies in the fact that they do not explain the process of discharge.' [#14, nurse].

'Some of the patients, after being in hospital for five days, would take out their cards. They told me that they showed their cards to the doctors….must be the SI… but the doctors expressed no interest.' [#18, nurse (IPC)].

Stigma and fear of infection also affected implementation with some staff expressing anxiety about working with TB patients.

'I can say that it was scary, because you were not sure if you were also affected, or in danger of picking up the disease. Our job involved physical contact with TB patients for one or two weeks. When the diagnosis was confirmed, your fear amplified, thinking that you might have the disease as well.' [#14, nurse].

'From the start of your nursing career, you are taught about TB and infectious diseases. We didn't have enough staff, and at the time of the implementation, we were only a few. Everybody was coming here, the stigma around TB was very rife, and they were not sending us any students. Everybody was scared.' [#12, nurse].

'Many of our patients complain about the fact, that the doctor didn't see him. You look into the notes and it's written down that he's seen the patient. You tell the doctor that the patient said that he didn't see him. Are they scared to go in?' [#12, nurse].

Available resources were constrained. The hospital management indicated that no additional staff or resources were available, and activities had to be integrated into existing staff functions. The UIPC added training, supervision visits, and data management and information transfer to existing UIPC staff functions. A clerical intern was however allocated to assist with the data management and information transfer.

'There had been further communication with Infection Control re training… Prof M (Director of UIPC) indicated they would concentrate on training of nurses, doctors in Internal medicine.' 'Nursing training will be incorporated into the nurses' in-service training block.' Hospital managers and research team meeting minutes, 17 April 2012.

'There were people who said that that was not how far the role of the IPC Practitioner within the hospital should go. There was nobody else to take on that role. I know that they spoke of employing an administrative person, or another nurse. You would understand that it would have been very difficult to employ another nurse, in an administrative role, because of the shortage of nurses. What the TB Research team, IPC Unit and Dr agreed upon at the time, was that I would become more involved in the training of the staff, of the identified wards….on the TB Continuation of Care Initiative.' [#18, nurse (IPC)].

'This was when Dr M placed a data-capturer intern with us. Her duties include doing the rounds, and collecting the forms from the different wards. If she found incomplete forms for the next day's rounds, she usually addressed it immediately. She will highlight the incomplete part on the particular form. Then she called the OPM and the admin clerk.' [#4, IPC nurse]

Informants inside and outside the hospital highlighted the many competing priorities, and shortage of staff, resources and support which made implementation difficult.

'There are many things happening' 'there are many things with the clinicians that are often like that. There wasn't always the support…depending on personnel availability…I think if you were tasked, and you still had lots of other things….I think to have full commitment, may have been a bit of a challenge.' [#1, doctor].

'From my side, it was a lot of work. At the time, I felt extremely overburdened. Remember that I was seen as the rogue. I was constantly fighting with everybody.' 'I was also bringing in extra admin work that they had to complete, within their own time constraints. There were times when they would just say "You want it, you can complete it".' 'Yes staff things. The ward clerk at the time also felt that it was not part of her job description, to collect things. I wanted her to collect the things, but in the end, we had her buy in.' [#10, nurse].

'We are still waiting on this and that. We must do everything and we only had one Sister on duty. They have never ever heard our complaints. It's a very good programme, but we just didn't have the capacity and the hands to do it.' [#15, nurse].

'I don't think that it was all smooth sailing from the start, but it became better. Human resources remained a challenge. ….Their response was that there was just no money available, for a post of that nature, at that time. There was absolutely nothing that we could do other than motivate.' [#4, IPC nurse].

'Once the patient was discharged, we had to do all that work. You had to provide patient education, whilst the other patients were waiting. We needed extra hours to complete the work.' [#14, nurse].

'The programme in itself was great. We enjoyed it. The problems were that we were understaffed. That was our main problem and that hindered the programme. In the execution of the programme, my thoughts were constantly on my other daily duties.' [#15, nurse].

'In terms of the implementation, we would get referrals, and in the beginning it didn't work so well. How. What …where…and when? TAH did not have a dedicated or a designated person responsible for ensuring that we get the referrals.' [#3, PHC staff].

'I think that in the beginning, we were passionate about the intervention. We did things to the best of our ability and our knowledge. The lack of staff hampered the effectiveness of our programme. You really wanted to do it, but if you only have three or four nurses for the day, and only one Sister, it's a tough job to do. You also have your daily workload to complete.' [#16, nurse].

'Access to Information, training and education' was an important intervention component, but time constraints of clinical staff resulted in most training occurring during short breaks or afterhours. The UIPC established a team of trainers from its own staff, clinicians, researchers, PHC and NPO staff who trained more than 150 hospital staff in a series of 20 small group workshops.

'Nursing managers: proposed 2 hour once-off training for day and night staff.' Hospital Executive Committee Meeting minutes, 28 May 2012.

'Night staff to be offered session 1 only due to shortage of staff.' Hospital Executive Committee Meeting minutes, 25 June 2012.

Nurses and medical interns were trained separately with limited opportunity for interdisciplinary team learning or to reinforce learning with practice. Nurse and clerical staff training was complemented by weekly supervision visits to the wards.

> *''This (sic) will be followed up with more information, supervision by Nursing Unit/Ward Managers, senior clinicians, and by patient education and support trainers.' Final Intervention Plan, 26 June 2012.*

> *'What I can say is that Dr J was the clinician who attended the meetings. He was responsible for the training of the interns. That didn't go too well. The training of the nursing staff went well, as we did the day and night staff, in different time slots.' [#18, nurse (IPC)]*

> *'Because you had a rotation of medical interns every three months, the clinicians however…it was difficult to keep up the training of that group. The intervention went very well, but because of the aforementioned fact, the intervention did not go as well as we expected it to go.' [#18, nurse (IPC)].*

The *'Health information Technology (HIT) and Information systems'* were problems, with poor integration of health information systems in the hospital and between levels of care. The intervention plan identified the need for improved electronic information systems to identify and track TB patients in the hospital and to notify PHC services of discharged TB patients.

> *'Electronic database. This is important for improving continuity of patient care. A data capturer has been identified. This system will feed into a provincial database.' Hospital management and research team meeting, 17 April 2012.*

> *'They didn't know how to connect with us, to ensure that information and communication gets to us. Processes were in place in terms of the paper. As I said, historically referrals were in triplicate for all TB clients….so those things were there. The problem is, we were still paper based. The technology was there, but we didn't use it optimally. From a gap perspective, we needed the optimal utilisation of technology and for us as a system not shifting, and improving the linkages.' [#3, PHC staff].*

Information linkages were improved initially by using a researcher and clerical intern to collate and email lists of discharged patients to HAST and CBS coordinators. This was subsequently replaced by an electronic Continuity of Care Record (eCCR) developed by a member of the research team which was piloted at CAH in 2014.

> *'I had linkage with some of the staff members. I think he's name was A. He usually sent me the referral letters, although the patient received the transfer letter from CAH. He usually sent me the copies of the transfer letters. That enabled me to follow up, and check whether the patient*

arrived at the clinic. I in turn, could tell A exactly which patients arrived at the clinic. After that, we would do a home visit, to establish where the patient is.' [#8, PHC nurse].

'LM, the clerk from the IPC Unit, also took on a massive responsibility. I don't know if she's still doing that. She was capturing the notification forms, and sending it to the appropriate clinics. When they spoke of the Electronic Notification System….communicable disease control…we also discovered that the notification system at TAH was not performing optimally.'[(#18, nurse (IPC)].

'At CAH, and at the ward level, they identified one individual who would communicate with us. The referral was scanned, sent to us by email, and then we would distribute to the relevant facilities. Yes…the referral was emailed to us and then we would scan. That made us the connecting link between the facilities.' [#3, CBS].

'Then we linked the contact person with all the HAST coordinators in the Department of Health, and all the community based services. That was the sub structure coordinators. That afforded us…meaning the system….the opportunity to improve this very low cure rate. This we achieved by purely communicating.'

'It didn't really change it, but enhanced it…..especially the technology. Now, I'm not the only one that receives the email, she sends it to everyone'. [*#3, CBS].*

Participants of the August 2014 workshop confirmed that the lack of appropriate HIT and Information systems was a barrier to the intervention, and that the use of Information Communication Technology (ICT) by the intervention improved communication and coordination of TB care.

Characteristics and Roles of Providers

The critical contribution of the persons involved emerged through five of the seven constructs. Their **knowledge and beliefs about the intervention** developed over the course of the project from not seeing the need for an intervention to taking responsibility for supporting ongoing practices.

'Essentially it required a mind-shift. Sometimes the facility will report that Patient X hasn't been seen for a week. Carers would report that they couldn't find the patient. When we investigated we found that there was a little bit of resistance. They will lament the fact that they have too many homebased clients and their paper work was astronomical.' [#5, PHC staff].

> *'In the beginning we felt a bit threatened by the new programme. You felt that all of this was unnecessary. As the programme progressed, we understood a bit more. … I think that once we got into the flow of things, and gained a better understanding, things became better.' [#15, nurse].*

> *'Personally I think that I learnt a lot, by being part of it. As physicians, we're not usually involved in improving…even though we should be … in this kind of exercise. I have learnt a lot and it helps me with my students as well, as I explained to them, the importance of all of this.' [#1, doctor].*

The HSC did not have specific **skills and competencies** in implementing 'continuity of care' interventions, but drew on a wide range of persons internally and externally to support implementation.

> *'We used the NPO's and they rolled out the intervention. This was achieved with the support of the City, the Department and the TB coordinators.' 'SA did all of the TB/HIV Integrated Training. That was her portfolio. She did all the training and visited all the different clinic sites.' 'From our side we had the HAST component, who was JM, who also offered support when we needed it. S taught us how the stationary worked. J made sure the information was filtered down to the NPO's within our area.' [#5, CBS].*

The HSC represented a multidisciplinary team including nurses, physicians, hospital managers, UIPC staff, HAST and CBS's coordinators, and researchers which defined and delegated **roles** to teams and individuals. A senior hospital manager took responsibility for overall coordination. Nursing management and UIPC were tasked with training and integrating activities into nursing practices; an infectious diseases physician secured other physicians' support and time for the training of medical interns; and PHC staff followed up discharged TB patients. Research team members provided technical guidance, undertook process and outcome evaluations, and regularly updated health service providers.

> *'Clarified roles and responsibilities'* improved continuity of care, but *'staff set on roles and job descriptions – inflexible roles' and 'professional silos'* were challenges. *Continuity of TB Care workshop report, 29 August 2014.*

> *'At the time, I happened to be the manager in charge of IPC, and I was automatically appointed as the coordinator of this project. In other words, whatever intervention was implemented, I had to see to it…on the side of the hospital….that these interventions were carried forward. If*

any equipment or consumables were needed, I had to ensure that these things were done accordingly. I involved all the clinicians and all of that. In a nutshell, my role was to coordinate this new Continuation of TB Care Project, in order to improve our outputs…what we have…in terms of increasing and making sure that, once the patients were treated at Tygerberg, they were not lost.' [#17, health manager (hospital)].

'We called on Dr JT, the head of Infectious Diseases Clinic, and directly involved in TB. I left it up to him, and he was responsible for ensuring that the recommendations were met.' [#17, health manager].

The records and interviews reflected a **collective efficacy** to improve coordination of care despite the numerous challenges, partly facilitated by the **self-efficacy** and the resilience of **champions** such as UIPC staff and nurse managers who motivated ward staff.

'The operational managers were in my opinion, the real drivers of this intervention. Here I'm talking about the nurses in charge of the wards. The nurses put reminders in place, reminding the doctors to complete the notifications…and the absolute need to complete it.' [#9, health manager].

'That's why we feel that we constantly have to develop ourselves, and learn. We are a small team, but we are part of a bigger and comprehensive health care.' [#3, PHC staff].

'It also brought with it, a feeling of teamwork. We had the doctors, clinicians, admin clerks, nurses, the UIPC and our colleagues in the PHC setting.' [#4, IPC nurse].

Process of Implementation

Clear patterns emerged around the process constructs, although **planning**, **process ownership**, and **engagement** overlapped. **The planning** began at a workshop with health service providers, and was followed by a series of engagements with health managers to produce an intervention plan with clear goals, activities, roles and timelines. The extensive planning period and multiple consultations allowed inclusion of various information sources and stakeholders.

'We got into the executive meetings. At the time there was a meeting called DEXCO, which was the District Executive Committee, and we requested an agenda to present the findings. I and another investigator FM went along and presented the results. We requested presenting at an operational level. There was a divisional meeting for central hospitals, regional hospitals and EMS, and all of them presented at that forum. We reused our slides over and over. We

presented and went to the districts. Then we received invitations to workshops as well….like the patient centred experience workshop at Lentegeur. They had people from across the Province. We were asked to talk about continuity of care and these findings.' [#6, doctor].

Process ownership by health managers ensured the legitimacy of the intervention and authorised its implementation.

'That aside, Dr D and her team then came to speak to management, to present the results. We embarked on several meetings, and looked at how best to approach this problem. Firstly we had to acknowledge that we had a problem...and yes we acknowledged that. We agreed that if we have a problem, then we need to solve the problem.' [#17, health manager].

'Absolutely and it's minuted in a meeting, where senior management, at deputy director general level, stated that this is the first time that we have research results have been presented to us like this, with this action participative approach.' [#6, doctor].

'I was the assistant manager in nursing, overseeing the internal medicine component or module. My role was to attend the TB continuity of care programme meetings on a regular basis. Included in my role was to see that the implementation takes place, and also to see that the decisions that were taken, were being executed.' [#9, health manager].

The **engagements** secured *'organisational leaders'* support, and the establishment of the HSC to coordinate implementation. *'Opinion leaders and champions'* particularly the UIPC, nursing managers and an infectious diseases physician championed implementation amongst hospital staff, and a research team member (RD) based in the provincial department ensured ongoing support from provincial managers. Although no dedicated *'formal appointments of internal implementation leaders'* were made, a hospital manager chaired the HSC, and nursing managers and the UIPC managed the training and implementation in the wards and links with PHC services in addition to their ongoing responsibilities.

'The development of the tools with the unit for infection prevention and control, UIPC…there was lots of enthusiasm. The training numbers were good. I'm comparing that to other projects that were happening in that hospital, and in the province. This was really one of the more successful research projects. It was also very successful in empowering the system, in ownership being with management and staff, and generating that enthusiasm among the staff.' [#6, doctor].

> *'She was a clinical programme coordinator as well. She usually sat with the intern and requested the week's notifications. Daily we received a lab report that contained the TB results. She will check and compare her work against that,...she will personally go the ward. Her job was to only do that (TB IPC). She didn't have any other tasks assigned to her, so she had the time to do it.' [#4, IPC nurse].*

Other *'key stakeholders'* included HAST and CBS coordinators who provided links to PHC services and patients in the community.

> *'From our team we had LA and LS. They helped with the roll out of the intervention. We also had the facility managers, and people within the facility. EC from the City also helped and guided us through the intervention. These are the role players that guided us.' [#5, PHC staff].*

In **executing** the intervention, decisions were made at monthly HSC meetings between June 2012 and December 2014. The intervention was implemented in stages, with the development of tools and staff training occurring in 2012, and activities in intervention wards commencing in late January 2013.

Activities were monitored during 2012 and 2013, ensuring **reflection and evaluation** through progress reports to health service providers. Evaluations of training found that of 86 (92.5%) of 93 day shift ward nurses targeted were trained in counselling TB patients; and 68 (68.7%) of 99 targeted nurses and clerks participated in training in the NTP and discharge management in six workshops between August and November 2012 (Table 2). The feedback resulted in scheduling of further training for day staff and after-hours training for night staff during 2013. The evaluations also documented that 34 staff from non-intervention wards attended the NTP training and 33 attended the TB patient counselling training.

Table 2: Number of TB Continuity of Care training sessions and participants.

	Target	**Date: Dec 2012**		**Date: June 2013**	
		No. of sessions	**Total trained**	**No. of sessions**	**Total trained**
Nurses & Clerks: NTP	99	6	68 (68.7%)	7	74 (75%)
Nurses: Patient counselling and IEC	93	6	86 (92.5%)	7	91 (98%)

Night staff				5	34
Interns	40	3		4	28 (70%)

Participants completed evaluation forms at the end of each session. More than 80% of nursing and clerical staff trainees felt that the training was 'outstanding' or 'very useful'. Nurses were particularly interested in the TB patient counselling and education sessions with many requesting further counselling training and opportunities for practice. Medical interns were harder to reach, with 28/40 (70%) trained in four NTP session. They also indicated that the content was relevant, improved their knowledge, and could be applied in practice. Trainee feedback on the tools contributed to adaptations of the tools.

Nursing managers distributed tools to wards, and the UIPC conducted weekly supervisory visits. The ward visits, patient folder audits and patient interviews however found that discharge checklists and referral forms were not properly completed, health promotion tools were inaccessible, and patient education was not provided as planned

> *'The following challenges were noted:*
>
> - *Completion of discharge documentation remains a challenge and constant reminders need to be given to both nursing staff and doctors.*
> - *It was also noted that patient education is not taking place based on the patient interviews done thus far, even though the TB leaflets and training flipcharts are available in the ward. ACTION: Sr H to address this challenge when conducting her ward visits.*
>
> *.' Hospital Steering Committee Minutes, 17 July 2013.*

Further discussions with nursing staff reinforced the need for supervisory visits, for refresher training and simplification of health promotion tools for use by ward staff. Adaptions made appeared to improve the uptake and use of the tools. Establishing a reliable system of sharing discharged patient information with PHC services also required ongoing attention before it functioned adequately.

Measures of Implementation

The post intervention workshop in August 2014 elicited perspectives of health service providers on the implementation outcomes. Workshop participants felt that 'management buy in and support' and extensive participation of health service providers during planning contributed to an intervention

which was **acceptable** to service providers at all levels, and **adopted** with health service managers' taking responsibility for its implementation.

The baseline assessments, and ongoing engagements by researchers with service providers ensured that the interventions were **appropriate** to the problems and the context. However, ensuring **fidelity** to the planned intervention and study design was challenging in a busy hospital with limited resources, and complex organisational structures and relationships. Despite the challenges, intervention tools were finalised as planned, and most of the target groups trained prior to or early in implementation (Table 2).

> *'I got the impression that everything happened. The forms were there. The training went as planned, most of the time. There wasn't always the support…depending on personnel availability…and so on….if I can remember correctly. I can't remember that well. My impression was that it was reasonably well implemented. I can't remember the transfer of data to the community based areas…whether that went well. Overall I thought it was well implemented.' 'What stands out for me was getting the training done for everybody. That was a bit of an issue, and getting everybody involved with their schedules.' 'Everything happened.' [#1, doctor].*
>
> *'After they received the training and understanding, and the basic understanding of the intervention, it became part of their daily tasks. Going through the intervention, I was often surprised at the things that I didn't pick up.' [#4, IPC nurse].*
>
> *'Remember that we had to take them out of their wards, for a specific time, so human resources played a vital role. We overcame that and produced a good amount of upskilled staff members. All of them went for the staff training that was done on the premises.' [#9, health manager].*

The project did not incur additional **costs** except for materials and employment of a data clerk. No additional health professionals were employed and activities were integrated into functions of existing staff.

> *'In fact, the study actually tried to do that. Ideally the study aimed at making that an integral part of our being. You didn't have to think about it. It's what you had to do. Some of the things we did were somehow incorporated into the daily duties of the nurses. That's why I'm saying that some of them are still maintained. They were slotted into their daily duties, and in turn,*

became an integral part of their daily duties, in the running of the ward'. [*#17, health manager].*

Documents reflected that the hospital extended and **sustained** activities throughout 2014 and 2015. In particular, decisions were recorded in HSC minutes in 2014 to extend the intervention training to all relevant hospital staff, disseminate the tools to all wards, and for the HSC to continue meeting periodically. The August 2014 workshop also proposed scaling up the intervention within the province, and established a provincial task team to lead this.

Although informants confirmed that the activities had **penetrated** beyond the intervention ward in the hospital, they felt that opportunities for scaling up or improving continuity of care for patients with other diseases had not been fully exploited.

'Well I've seen this now, and it works well…..and I don't think that it's too complicated. I would recommend similar interventions for all. I'm specifically thinking about diabetes and HIV patients.' [#1, doctor].

'They should have up-scaled it in the hospital, given the sheer numbers that they have. Linkage to care, and continuity of care, from this big brother perspective, is a challenge. We know that given the sheer numbers that they have. If this one thing worked so well, why not replicate it in the ….as a good lesson learnt. It increased and improved the cure rate. It might also improve the revolving doors that are coming back, if you do a similar linkage.' [#2, health manager].

'Yes, and also expand into all their pockets. If you look at the first thousand days…referral and linkage to discharge…similar to what we've done…that would be a winner. That's an immediate game changer. They are the referring hospital; similar to what the TB has done….' [#3, PHC staff].

'At provincial level, what happened to the plans to roll out the continuation of care to all other chronic illnesses after discharge? There was a plan to redirect them to the proper place, where they should be. These plans applied to all hypertension, diabetic and other chronic illnesses. There were talks about that as well.' [#18, nurse (IPC)].

Informants also indicated that important activities such as the hospital training, use of tools and the coordinating committee had not been sustained.

'there are aspects of it that are being sustained' The training has not been sustained.' [#6, doctor].

> '*When we started the programme, we had four flipcharts. It stood in the nursing station, and that's where we advertised it. We used it quite often. Currently I only have two. One is here, and one is inside. The flipcharts are not being used. Forms are not being filled in. I don't have them anymore, and it's been years. We did not continue with it, and it slowly phased out. As new people came along…Mrs E was still around….it just stopped. In the end we only had one or two people using them, and continuing with it. In the end they also stopped. They felt that if the rest of us were not using it, why should they.' [#11, health manager].*

> *'Definitely not. I don't think that it has been sustained, and definitely not as vigorously as in the past. Once a patient has been newly diagnosed, most of them are moved to ... We don't use the forms anymore (in particular ward). … The green card is missing as well. We still have the flipcharts. The green card should be implemented again, as that's the one we need to tick off. I think that some of the things are still in place. I think it's the forms that are missing.' [#16, nurse].*

> *'In many ways they tried their utmost to sustain the implementation tools, and carry on with it. Perhaps on reflection, I would say that some of the vigour was missing. I truly think that the implementation tools will continue, because of the TB awareness created by this programme.' [#18, nurse (IPC)].*

The information linkages between the hospital and PHC services were sustained and improved. The manual TB patient database and sharing of discharged TB patient discharge information across levels of care was labour intensive, and was subsequently replaced by a pilot of the electronic Continuity of Care Record (eCCR) before being scaled up in the Province (207).

> *'Making use of standard discharge stationery. That is being sustained because of the electronic platform to which it has been migrated. That process which started on paper, has been migrated to the electronic platform, and has been sustained and scaled.' [#6, doctor].*

> *'At that time the doctors started doing the continuation of TB care programme on the computers. They used the eCCR along with the different forms, and focused primarily on, where the patient was going to be referred to.' [#11, health manager].*

The community linkages were also sustained and extended to support other facilities in the province.

> *'I can speak to the outside practices. In the proposal of the Care Pathway Policy that went out….our community based platform was brought into the fold. What happens is that the sister*

will put that referral letter in the basket. She will have somebody in the body of the community health worker, to take that referral letter and ask "Can you please check if this person is still alive. Is he still living here and is he still on treatment or not". Before the intervention, that community platform was not used.' [#2, health manager].

'Referring to us, it's still happening. Referring to us …referring out….ensuring that there's a follow up, it's still happening. It's definitely sustainable. It has been sustained.' [#3, PHC staff].

'At the moment the referral system is working very well. They send the referrals directly to me, and we send it to the NPO in the community, to go and do the follow up. If the patient is linked to the facility….. '[#5, PHC staff].

'We have a very good relationship with them (ipid CBS). We also fill in home based care forms. We decided not to go through the Social Worker. We usually complete that form. We do not fill out home based forms for any medication.' [#11, health manager].

Hospital informants felt that staff turnover and shortages undermined the intervention's sustainability within the hospital.

'The other problem occurs when the old staff members are leaving, and new members have to be trained. The well trained UIPC staff seems to be leaving, or some of them are transferred to other hospitals. Remember that new staff must be trained from scratch.' [#16, nurse].

'People were completing the forms. They were so aware and enthused to do this. Later on it became a burden for some, because we had a change of staff, especially the Unit Managers and your Ward Clerks. The stationery became a white elephant…in a sense. The training was not done, as it should have been done. They said that they didn't have time. The flipcharts were also too big to handle. They said that it was too much information. We advised them to stagger the information over the entire period of admission. There was no need to do everything immediately. They didn't manage to do that. So we asked them to focus on the continuation of the medication. Everybody knew that the medication should be used for five or six months. You desperately needed to tell the patients, that the local authority would be following up, to check their adherence.' 'I still think that the success, or whatever we started, it had to be continued. I believe that.' [#18, nurse (IPC)].

'We have turnover in wards...we have new interns…and if you don't continue with those components identified, the continuative care, it will not be that good, going forward.' [#1, doctor].

Even the UIPC indicated that they struggled to scale up and sustain the intervention despite their key role in implementing the intervention.

'We couldn't implement it (sic throughout the hospital) from the IPC unit per se, simply because of our workload. Remember that I was the third IPC Nurse responsible for TB Control. Before I came, it was Mr S and R V. You must remember that along with that, we still had our other areas of responsibilities as well.' [#18, nurse (IPC)].

Suggestions by informants to sustain the intervention included re-establishing a governance structure, appointing a coordinator, an interdisciplinary approach, providing more staff and ongoing training for all team members.

'The plan in our final meetings….because that was the question, was the sustainability of the entire programme. One of the strategies was to schedule the meetings in the beginnings, and monthly….and see if things are stabilising. After that, we were looking at three monthly, and then six monthly meetings. That ideally was the plan. What I'm saying is that we could have those things, if we maintained it. We could be monitoring and evaluating it.' [#17, health manager].

'My advice would be, that firstly, get your structures in order. Unfortunately staffing is a problem. I think that even though the hospital would have to spend time and money, on the appointment of someone responsible for TB management, for me it would be worthwhile in the end.' [#4, IPC nurse].

'I think the committee, and the meetings we had. …and obviously it's the driving force behind it…I think that's important…..somebody that's committed to making sure that these things happen…and that there's an agenda every time….and that there's timelines. I think that's the most important part of it. The components added to it, is basically….those were well planned components….but without a team to implement and to continuously do it. That was one of my issues with it. How is it sustainable without that specific, continuous...looking for stuff?'[#1, doctor].

'My advice would be to get the nursing staff on board. Get the group together. That must include the social worker. Originally the social workers were not involved in this intervention. It was only when we went to the wards for implementation, that I from my side, involved the social worker. We made sure that they collected the correct addresses, follow up, and provide the outside family support. From the start, I would suggest that the social worker, the hospital's IT people, management of the targeted ward for implementation, and the correct SOP's are all in place, before implementation. We also need the doctors buy in, and more importantly, they must be informed beforehand.' [#10, health manager].

'Keep everything about the intervention programme, but please give us more staff.' [#16, nurse].

'I feel that programmes can work but more attention must be paid to the shortage of staff. That is our main problem in this hospital and we need extra hands.' [#15, nurse].

'I also think that we need more staff TB training. ……I also feel that staff needs more training, in talking to patients.' [#14, nurse].

'We should have more lectures. We should start at the bottom. Share the information with everyone. Even though I'm an Assistant Nurse, we care for the patients. It doesn't matter if I don't work with medication. In our wards, the Assistant Nurses are very clever. Don't forget the hospital uses moonlight Sisters. They know nothing. We should be teaching the moonlight staff about our programmes. Tell them about the forms, and show them how to complete it.' [#15, nurse].

Discussion

The different sources of data provided a range of perspectives on the implementation of the intervention at CAH. The document content analysis provided most data on external context, the planning and the early implementation stage. The perspectives were often those of policy makers, senior managers and researchers, which were both optimistic and pragmatic around the goals and plans for improving continuity of TB care. The process monitoring data provided perspectives of middle managers and staff at the 'coal face' in the hospital wards and community, and highlighted challenges experienced during implementation. The key informant interviews provided a retrospective view from a cross-section of implementers, reflecting differences in their experiences, ranging from appreciation and regret by managers who recognised the value of the intervention but were unable to sustain it; ward nurses who welcomed the intervention, but complained about

inadequate staffing, support and communication; and community services who remained steadfastly committed to continuing the intervention despite constraints experienced with their hospital partners.

Key findings

Important factors emerged in this study that either facilitated or limited implementation of the TB CoC intervention. The **intervention's characteristics** were seen as favourable, in that it was developed internally, was informed by evidence, it was piloted, the design and packaging responded to local needs, and it was adaptable.

The importance of adapting evidence informed interventions for local needs, resources, and priorities in LMIC's has been recognised (76,208). This intervention package included several evidence based components which had improved continuity of care for chronic disease patients discharged from hospital in HIC settings such as a patient held NTP 'green card' TB treatment record (138), nurse driven discharge planning and support (65,141), and inter-active communication between hospital and PHC staff (140). .

The main adaptations to evidence informed interventions related to the health professionals involved. In our setting nurses replaced doctors in some hospital activities, and lay health workers replaced social workers and nurses in providing follow up support to discharged TB patients. This task shifting made it feasible to implement the activities despite shortages of doctors and nurses (164,209). Although the importance of adapting evidence for implementation is recognised, it raises new challenges in understanding different types of adaptations, and assessing the effects on fidelity and outcomes (210,211).

The **external context,** including new policies for TB control and quality of health care (212), supported by external networks and pressure, created an environment which was conducive to change. Local decision makers were receptive to testing innovations to improve linkages in TB care and received the support of top health management in the Province (213).

Organisational characteristics such as fragmentation, hierarchies and professional silos created obstacles to transitions in care which frustrated implementers. They overcame them by using informal and formal networks to communicate and establish interdisciplinary teams across levels of care. Extensive leadership engagement, staff commitment and access to information and training contributed to a readiness for implementation. However, extreme resource constraints in staffing and information systems made implementation challenging.

Public hospitals in South Africa are under-resourced, have limited management capacity, and many barriers to interdisciplinary team functioning (214–217). The strong influence of external context and organisational constraints were also described in implementing child health interventions in hospitals in Kenya and Ghana (218). A greater awareness and detailed assessments of contexts to inform implementation of interventions in hospitals is required in such settings. Additional systems strengthening activities in response to the context should be planned and undertaken within or complementary to core interventions (192).

The persons involved clarified and allocated roles, accessed a mix of skills and competencies, improved interdisciplinary team work, and created a sense of collective efficacy across levels of care**.** Although no formal appointments of implementation leaders were made, the engagements with leaders at multiple levels created ownership through an inclusive planning **process.** Opinion leaders and champions, and a governance structure for decision-making supported execution of the intervention across levels of care. Nurses were seen as the main drivers of the intervention, with perceptions of less commitment by medical doctors in this setting (172). This differed from the response of the academic medical profession in India, where doctors successfully implemented strategies to improve the clinical management of TB in hospitals and linkages with other levels of care (83).

The use of PAR in this study to actively engage service providers at all stages of the planning and implementation, ensured alignment to the local context, facilitated adoption and strengthened human capacity and relationships (219,220). These relationships, feedback loops, and the ability of participants to self-organise strengthened implementation of the intervention in a complex system (221).

Similar processes of joint leadership by hospital management, implementing team and facilitators, and the integration of intervention activities into the roles of key individuals, were also essential to the successful implementation of interventions in Kenyan hospitals (222). In Kenya, effective organisational leadership and management systems mitigated the effects of resource limitations in hospitals (223), and motivated hospital managers supported by facilitators were able to overcome resource constraints to implement interventions (224).

The **measures of outcomes** indicated that the intervention was acceptable, appropriate and feasible, and was formally adopted in the hospital, PHC and community services. Successful implementation did not however translate fully into sustainability. The cessation of the HSC meetings led to a loss of accountability, coordination and support for staff. Intervention roles were not formalised into existing

hospital job descriptions, and no resources were allocated to sustain the functions. Staff turnover, decreased supervision, support and supplies undermined staff efforts to sustain hospital activities. Implementers felt that a functioning governance structure, adequate staffing, more supervision and ongoing training could have better sustained the intervention.

Although sociocultural approaches such as PAR methods assisted in facilitating organisational change in the short term, leadership characteristics and organisational culture contributed to an inertia or 'path dependency' within the hospital which undermined efforts to sustain the intervention (225). This reflected findings on implementing innovations and providing leadership for change in hospitals in similar settings, and the unpredictability of hospitals as Complex Adaptive Systems (CAS) (226).

The importance of improving health management, leadership and organisational capacities to strengthen health systems and improve the quality of health care, particularly in the context of CAS is strongly emphasised in the literature (225,227,228). The limitations to sustainability in this hospital may have been addressed by parallel interventions to strengthen management and leadership (229). However, there is little evidence on how to effect such leadership and organisational changes in the health literature, and more multidisciplinary research is needed to inform interventions in similar hospital settings in LMIC's (225,230,231).

In contrast to the hospital, community based activities and linkages in information systems were maintained and strengthened. Five years post intervention the PHC and community services had sustained and strengthened support for care transitions for TB patients. PHC managers established coordinating structures to ensure accountability for TB CoC, maintained personal networks and actively used the electronic information linkages to support continuity of care of TB patients (35). This drew on evidence that LHW's improve treatment adherence for TB patients and care for chronic disease patients in PHC settings (163,164), and that 'transition counsellors' or 'case managers' improve continuity of care for chronic disease patients discharged from hospital. The role of LHW's in improving linkages in care for TB or other chronic disease patients discharged from hospitals warrants further research in similar settings.

The sustained improvements in informational continuity suggests that adoption of information, technology and communication (ICT) can contribute to improving continuity of care for patients discharged from hospital. In China improvements in continuity of care for discharged TB patients were partly attributed to inclusion of hospitals in NTP electronic information systems and were advocated for adoption in other countries (85,184). However, although there is extensive innovation in the use

of eHealth in the health sector, the research evidence on the effects of ICT on quality and continuity of care remains weak particularly in LMIC's (232).

Limitations and strengths

The CFIR, with the CTF adaptations, provided a validated tool which included appropriate constructs to evaluate an intervention to improve care transitions. An independent qualitative researcher established trust with participants, and created an environment and facilitated interviews which allowed participants to share their perspectives honestly. A few staff were no longer available and there may have been some recall bias in interviews because of delays between the implementation period and interviews. Similarly, relevant policies and reports for the document content analysis may have been missed because of the delay in compiling the information. Possible subjectivity in the analysis and interpretation by the PI was limited by the involvement of the research assistant, another researcher and implementers who reviewed and discussed the results.

The use of mixed methods, and the triangulation of three different data sources provided rich data at different stages of implementation, and reflected the perspectives of a range of stakeholders over time. This provided breadth and depth in understanding the context, mechanisms and actors which enabled or impeded implementation of a multifaceted intervention to improve continuity of care for TB patients in a complex hospital setting. However, the findings may not be generalizable to other settings as the interviews and the document analysis were context specific.

Implications for practice and research

The study confirmed that the core intervention package was appropriate, and that adaptability to the context was important. It also demonstrated that mechanisms such as PAR improved adoption and strengthened organisational capacity to implement the intervention. Greater use of PAR in implementation science can enhance adaptation and uptake of innovations in the complex reality of health services in LMIC's (219).

The CFIR, CTF and frameworks such as the Ideal Transitions Framework (233), provide useful guides for planning and evaluating similar interventions. However, their application has mostly occurred in high income settings and further experience in LMIC's would be valuable in adapting them to the specific needs in these settings (126). Given the importance of context in LMIC's, more emphasis on health systems components, such as governance, leadership, financing, human resources and information systems should be strengthened in these tools for use in such settings.

Further research should also explore governance, leadership, inter-professional team functioning and organisational change in strengthening linkages and continuity of care for TB patients in similar settings. The valuable role in this study of CBS and innovations in ICT to support continuity of care for TB patients warrants further exploration for TB and other chronic disease patients discharged from hospital in resource constrained environments.

Conclusion

A complex package of evidence informed activities to improve coordination of TB care was successfully implemented under routine service conditions in a resource constrained and fragmented health system. Implementers overcame organisational constraints to develop an appropriate and acceptable intervention and processes to implement it. A supportive external context and PAR contributed to achieving the implementation outcomes. Community and ICT components of the intervention were sustained and strengthened, but hospital activities diminished without external facilitation and support. Similar interventions to improve continuity of care for TB patients in resource constrained hospital settings should consider strengthening governance, leadership and management, and human resources in addition to core intervention components.

DECLARATIONS

Ethics approval

Ethics approval for the study was provided by the University of Stellenbosch, and an ethics exemption from the Harvard Chan School of Public Health (HSPH) for the data analysis and writing of manuscripts undertaken by the PI while a fellow at HSPH.

Data availability

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

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Authors' contributions

LD conceptualized and designed the study, LD, RD, FM made substantial contributions to acquisition, analysis and interpretation of data; LD drafted the manuscript, and all authors contributed to revising it critically for intellectual content.

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Conflict Of Interest

The authors declare that they have no competing interests.

Table 1. The Care Transitions Framework (CTF) adaptation of the Consolidated Framework for Implementation Research (CFIR)

CTF adaptation of the CFIR		
	CFIR Construct	**Short Description**
I. INTERVENTION CHARACTERISTICS		
A	Intervention Source	Perception of key stakeholders about whether the intervention is externally or internally developed.
B	Evidence Strength & Quality	Stakeholders' perceptions of the quality and validity of evidence supporting the belief that the intervention will have desired outcomes.
C	Relative advantage	Stakeholders' perception of the advantage of implementing the intervention versus an alternative solution.
D	Adaptability	The degree to which an intervention can be adapted, tailored, refined, or reinvented to meet local needs.
E	Trialability	The ability to test the intervention on a small scale in the organization [8], and to be able to reverse course (undo implementation) if warranted.
F	Complexity	Perceived difficulty of implementation, reflected by duration, scope, radicalness, disruptiveness, centrality, and intricacy and number of steps required to implement
G	Design Quality and Packaging	Perceived excellence in how the intervention is bundled, presented, and assembled
II. OUTER SETTING (External Context)		
A	Population & Patient Needs & Resources	The extent to which population and patient needs, as well as barriers and facilitators to meet those needs are accurately known and prioritized by the organization. E.g. prevalence of disease, community determinants
B	External Networks	Involvement with organisations, systems, and partnerships that support and promote care transitions
C	External Pressure	Pressure emanating from outside the organisation to implement the intervention e.g. key peer or competing organisations have implemented care transitions
D	External Policy & Incentives	A broad construct that includes external strategies to spread interventions including policy and regulations (governmental or other central entity), external mandates, recommendations and guidelines, pay-for-performance, collaboratives, and public or benchmark reporting.
E	Community Resources	Availability and access of service providers, and multiple levels of community services and supports not directly involved in the intervention
III. INNER SETTING (Organisational Characteristics)		
A	Structural Characteristics	The social architecture, age, maturity, size and composition of an organization.
B	Team and network characteristics	Influence, breadths, depth, and role diversity of the teams and networks engaged in the intervention

	Teams, Networks & Communications	The nature and quality of teams and social networks and the nature and quality of formal and informal communications within an organization.
	Team and network self organisation	Capacity to arrange and organise for a defined purpose without external pressure or mandate
C	Culture	Norms, values, and basic assumptions of a given unit or organization that affect views of the intervention and its implementation
D	Implementation Climate	The absorptive capacity for change, shared receptivity of involved individuals to an intervention and the extent to which use of that intervention will be rewarded, supported, and expected within their organization.
1	Tension for Change	The degree to which stakeholders perceive the current situation as intolerable or needing change.
2	Compatibility	The degree of tangible fit between meaning and values attached to the intervention by involved individuals, how those align with individuals' own norms, values, and perceived risks and needs, and how the intervention fits with existing workflows and systems.
3	Relative Priority	Individuals' shared perception of the importance of the implementation within the organization.
4	Organizational Incentives & Rewards	Extrinsic incentives such as goal-sharing awards, performance reviews, promotions, and raises in salary and less tangible incentives such as increased stature or respect.
5	Goals and Feedback	The degree to which goals are clearly communicated, acted upon, and fed back to staff and alignment of that feedback with goals.
6	Learning Climate	Organisations willingness to promote trial and error, test new methods and innovate
E	Readiness for Implementation	Tangible and immediate indicators of organizational commitment to its decision to implement an intervention.
1	Leadership Engagement	Degree of commitment, involvement, and accountability of leaders and managers to high quality care transitions, and specifically to intervention components.
	Staff Commitment	The degree of physicians, nursing, clerical, and community care, and other staff involvement in transition planning
2	Available Resources	The level of resources dedicated for implementation and on-going operations including money, training, education, physical space, IT infrastructure and systems, and time.
	Staff time	Staff time dedicated to implement the intervention
	HIT	Electronic information management infrastructure in place to support electronic information management, including IT that crosses all organisations
	IT systems	Technological systems and capabilities to support care transitions
	Other resources	Resources for implementation and ongoing operations to support change and innovation, including grant or other funding specific to care transitions
3	Access to information, training and education	Ease of access to digestible, applicable information about the intervention and how to incorporate it into work tasks. Resources dedicated to training and education available within the organisation

F	Continuity	Information continuity (exchange of information) and relationship continuity, both with providers and patients/caregivers across organisations
G	Patient/caregiver-centredness	Extent to which the organisation(s) knows and prioritizes patient and caregiver goals, needs and preferences, and has the resources and services to meet them.
IV. CHARACTERISTICS AND ROLES OF PROVIDERS, PATIENTS AND CAREGIVERS (Persons involved)		
A	Knowledge & Beliefs about the Intervention	Individuals' and team's attitudes toward and value placed on the intervention as well as familiarity with facts, truths, and principles related to the intervention.
B	Skills and competencies	Degree of relevant subject matter expertise, skills and competencies within the implementing team, unit and organisation
C	Role	Individuals' role and responsibility for the intervention. The degree of multiple and shared roles
D	Self-and collective efficacy	Individual belief in their own capabilities to execute courses of action to achieve implementation goals.
		Conviction of individuals and teams involved that the intervention can be carried out in cooperation with each other
E	Individual Stage of Change	Characterization of the phase an individual is in, as he or she progresses toward skilled, enthusiastic, and sustained use of the intervention.
F	Individual Identification with Organization	How individuals perceive the implementing organization and their relationship and degree of commitment with that organization.
G	Other Personal Attributes	A broad construct to include other personal traits such as tolerance of ambiguity, intellectual ability, motivation, values, competence, capacity, and learning style.
V. PROCESS		
A	Planning	The degree to which a scheme or method of behaviour and tasks for implementing an intervention are developed in advance and the quality of those schemes or methods.
1	Assessing	Formal assessment of care transition issues; the needs of users; barriers to change; the timing of these activities relative to implementation
2	Goal Setting	Written goals, objectives, benchmarks, and timeline activities and their feasibility and adequacy
B	Process Ownership and Roles	The diversity of transition roles involved in the process of implementation; authority and accountability for these activities.
C	Engaging (&transition roles)	Attracting and involving appropriate individuals in the implementation and use of the intervention
1	Organisational leaders	Managers and others with authority to dedicate resources and make decisions to adopt, maintain or abandon the implementation
2	Opinion Leaders	Individuals in an organization who have formal or informal influence on the attitudes and beliefs of their colleagues with respect to implementing the intervention

3	Champions	Individuals who dedicate themselves to galvanising and maintaining support for the intervention and overcoming indifference or resistance
4	Formally appointed internal implementation leaders	Individuals from within the organization who have been formally appointed with responsibility for implementing an intervention as coordinator, project manager, team leader, or other similar role.
5	External Change Agents	Individuals who are affiliated with an outside entity who formally influence or facilitate intervention decisions in a desirable direction.
6	Key stakeholders including staff	Key individuals within the organization who are essential to get buy-in and use the innovation
7	Patients/Customers	The ultimate beneficiary of the innovation; in healthcare organizations, it is often patients
C	Executing	Carrying out or accomplishing the implementation according to plan.
1	Decision making	Frequency, duration, and timing of the activities involved in making decisions. The directionality of these activities.
2	Staging and iteration	Degree to which the care transition is carried out in iterative, incremental steps or implemented in its entirety within a specified period.
D	Reflecting & Evaluating	Quantitative and qualitative feedback about the progress and quality of implementation accompanied with regular personal and team debriefing about progress and experience.
VI. OUTCOMES (from Proctor 2011)		
A	Acceptability	Degree to which intervention goals, strategies, tactics and specific activities are agreeable, palatable or satisfactory
B	Adoption	Intention, initial decision, or action to employ or cease the intervention
C	Appropriateness	Suitability of the intervention to the specific transition issues or problems to be addressed
D	Feasibility	
E	Fidelity	Degree to which the intervention was implemented as originally designed by those who developed and/or introduced it to the organisation
F	Cost	
G	Penetration	Depth of integration of the intervention within the organisation involved in the intervention and its subsystems
H	Sustainability	Extent to which changes resulting from the intervention are maintained or institutionalised within the organisation(s) ongoing stable operations

Chapter 7: Policy brief on continuity of care for TB patients discharged from hospital in South Africa

This policy brief aims to answer the following questions from the perspective of provincial, TB programme, hospital, and primary health care (PHC) service managers:-

- Do TB patients continue and complete TB treatment after discharge from acute care hospitals in South Africa?
- What health systems factors contribute to poor continuity of care for TB patients after discharge from hospital?
- Which interventions could be implemented to improve continuity of care for TB patients discharged from acute care hospitals in South Africa?

Current knowledge about continuity of care for TB patients in South Africa.

Large numbers of TB patients are admitted to public acute care hospitals in South Africa (19). Such hospitals generally do not link to the ETR.net, the electronic TB registration system used by the national TB programme (NTP). We therefore do not know if TB patients continue and complete TB treatment after discharge. A study at a hospital in the Western Cape found that 36% of discharged TB patients continued TB treatment after discharge (Study 1). Similar studies at hospitals in Gauteng and Kwazulu-Natal found that 50% and 29% of discharged TB patients respectively continued TB treatment after discharge (36,37).

Key actions for improving continuity of care for TB patients discharged from hospital.

We conducted several studies to identify factors that contributed to continuity of TB care, to assess evidence on strategies to improve continuity of care, and to evaluate an evidence informed intervention implemented in the Western Cape. The key actions identified from these studies are listed below, and further detail provided about each study on the next pages.

Health systems level actions

- Implement multicomponent strategies which include context appropriate combinations of discharge planning, provider and patient education, information linkages, structures to facilitate communication and coordination of care between hospital and PHC providers, and telephonic and/or lay health worker follow up and support of discharged TB patients;
- Strengthen infection, prevention and control in hospitals to create a safe environment for staff and patients to interact;
- Strengthen governance of continuity of TB care by defining roles and responsibilities at health facility and district level;
- Develop policies with guidance on strategies for improving continuity of care for TB patients;
- Invest adequate finances in strategies to improve continuity of care for TB patients;
- Monitor and evaluate continuity of TB care to assess and manage performance.

Health workforce level actions

- Provide pre-clinical and in-service training of doctors and nurses in the clinical management of TB patients based on NTP guidelines, patient centred care, interdisciplinary collaboration and discharge planning;
- Train and deploy lay counsellors in hospital settings to provide appropriate education and counselling for TB patients before discharge and follow up support after discharge;
- Strengthen middle management competencies to support and sustain change and innovation.

Health systems factors affecting continuity of care for TB patients discharged from hospital

Study 1: Status of continuity of care for TB patients discharged from a referral hospital.

We conducted an observational study of continuity of care in a cohort of 788 TB patients admitted to a referral hospital in the Western Cape, and assessed risk factors for poor continuity of TB care.

Key findings:-

- TB patients were young (32 years), urban (83%) with high HIV co-infection rates (32%);
- 74% had a bacteriological TB test, and 25% were tested for HIV in hospital;
- 13% were notified for TB;
- 48% received TB medication in hospital;
- 36% continued TB treatment after discharge,
- 33% were re-admitted to hospital during a 6 month period;
- 24% had a successful TB treatment outcome, and 21% died;
- Better continuity of care was associated with adults, urban residence, bacteriological TB tests in hospital and TB medication on discharge;
- Fragmented hospital TB data systems did not provide continuity with PHC information systems.

Discussion: Good clinical management was a strong predictor of continuity of TB care in this study. This confirmed findings of associations between bacteriology and continuity of care for paediatric TB patients at TAH (178). Patients without a discharge letter or with incomplete information in the letter had an increased risk of not linking to TB care after discharge (171).

Citation: Dudley L, Mukinda F, Dyers R, Marais F, Sissolak D. Mind the gap! Risk factors for poor continuity of care of TB patients discharged from a hospital in the Western Cape, South Africa. PLoS One. 2018;13(1): 1-11. http://dx.doi.org/10.1371/journal.pone.0190258

Study 2: Perceptions and experiences of hospital staff about continuity of care for TB patients.

We conducted focus group discussions with 60 hospital staff to identify factors which impacted on continuity of care for TB patients.

Hospital staff's concerns and recommendations to improve the clinical management and referral processes for TB patients were:-

- Strengthen infection prevention and control to address staff fears of occupational exposure to TB, particularly MDR, which affects care of TB patients;
- Provide training on the NTP, the clinical management and counselling of TB patients for all disciplines to improve hospital staff knowledge and competencies;
- Improve clinical documentation on the TB patients, and improve communication about TB patients in hospital and with PHC services;
- Develop discharge planning tools, and adopt a patient centred approach by including the patient and carers in making discharge arrangements;
- Strengthen interdisciplinary team work;
- Provide time and resources (e.g. counsellors) for patient education and counselling in hospital.

Discussion: The lack of patient centred care was also emphasised by TB patients who generally felt they were not informed about their disease and its treatment while in hospital, were not always aware that they needed to continue treatment, and were not included in decisions about discharge arrangements (182). PHC staff also felt that more culturally and linguistically appropriate education and counselling (by trained counsellors) should be provided for TB patients in hospital (182).

Citation: Marais F, Kallon I, Dudley L. Continuity of care for TB patients at a South African hospital: A qualitative participatory study of the experiences of hospital staff. PLoS One. 2019:14(9):1-22. https://doi.org/10.1371/journal.pone.022242

Evidence on strategies to improve continuity of care for TB patients

We searched the literature but found no systematic reviews or experimental studies of interventions to improve continuity of care for TB patients discharged from hospital. In the absence of direct evidence, we conducted an overview of continuity of care for chronic diseases to identify strategies for other chronic diseases which might be applicable to TB. We also tested and evaluated an evidence informed intervention at a referral hospital.

Study 3: Strategies to improve continuity of care for chronic disease patients discharged from hospital.

We conducted an overview of systematic reviews using the Cochrane methodology (132). We included 13 systematic reviews and 3 overviews of continuity of care for chronic diseases which reported on four main strategies:-

Information and communication strategies included patient held records which increased patient involvement in and satisfaction with care, but had little effect on health care utilisation or clinical outcomes; telephone follow-ups of discharged patients which improved patient compliance with primary care appointments; and interactive communication between specialists and primary care physicians which improved patient clinical outcomes.

Discharge planning *(development of individualised discharge plans for the patient prior to leaving hospital)* on its own, with post-discharge support or as part of a multicomponent intervention reduced hospital re-admissions and improved patient satisfaction.

Shared care *(joint participation of primary and speciality care physicians in patient care plans)* improved selected clinical outcomes, patient's attendance at visits, patient satisfaction, and reduced patient defaulting.

Multicomponent strategies included disease management programmes *(a systematic approach to chronic care which employs multiple ways of influencing patients, providers and the organisation of care)* and integration of care *(multidisciplinary interventions at different stages of the care process in two or more institutional areas)*. These reduced re-admissions to hospital, improved clinical outcomes, patient satisfaction and quality of life. For selected diseases, including HIV, it improved uptake and adherence to treatment, and retention in care.

Citation: Dudley L, Wiysonge C. Overview of strategies to improve continuity of care for chronic diseases between hospitals and primary care services. 2019. Unpublished.

Study 4: Effects of an intervention to improve continuity of care for TB patients discharged from hospital

We conducted an outcome evaluation using a before after control quasi experimental study design to compare continuity of care for adult TB patients discharged from hospital to assess the effects of a multicomponent intervention package implemented at a referral hospital. The package included discharge planning, hospital staff and patient education, information linkages and coordination with PHC services, and community based follow up of discharged TB patients.

Key findings:

- The continuity of care outcomes of 636 adult TB patients admitted to hospital before the intervention were compared to outcomes of 595 adult TB patients admitted after implementation of the intervention;
- The percentage of adult TB patients who continued TB treatment after discharge from hospital improved significantly from 40.1%% before to 92.1% after implementation of the intervention ($p< 0.001$).

Discussion: The effects were significant and demonstrated that it is feasible to implement a complex intervention to improve continuity of care for TB patients discharged from hospital in the local context. Similar effects were found in an earlier South African study which established a hospital TB coordinating centre as part of a multicomponent strategy to improve continuity of care for discharged TB patients (48).

Citation: Dudley L, Dyers R, Mukinda FK, Marais F. Discharge planning and support to improve continuity of care for TB patients discharged from hospital: an outcome evaluation. Submitted to BMC Health Services Research.

Study 5: What factors affected the implementation of an intervention to improve continuity of care?

We conducted a process evaluation guided by the Consolidated Framework for Implementation Research (CFIR) to understand factors which affected implementation of the intervention. We triangulated data from activity monitoring collected during implementation, a document content analysis, and interviews with 17 hospital and PHC staff and managers after implementation.

Key findings:

- Factors which favoured implementation included the characteristics of the intervention (evidence informed, multicomponent and adaptable in the context); the people involved (champions who helped create collective efficacy); a participatory process of implementation, and the external context, particularly the prioritisation of TB control and patient centred care in provincial policy.
- Several organisational characteristics were unfavourable. Fragmentation and hierarchies across levels of care frustrated implementers. In the hospital, financial and human resource constraints, limited use of informational technology, and professional silos were barriers to implementation.
- Hospital activities were not embedded, staff training stopped and ward activities decreased following the loss of key staff. Responsibility to sustain the intervention in the hospital was unclear.
- Information linkages through the electronic Continuity of Care Record (eCCR) and community based TB patient follow up were sustained.

Discussion: To successfully implement and sustain similar interventions in resource constrained hospitals, support for governance, management, finances and human resources is needed in addition to the core intervention components.

Citation: Dudley L. Understanding the implementation of a complex intervention to improve continuity of care for TB patients discharged from hospital: a process evaluation. 2019. Unpublished.

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Full report: Policy brief on continuity of care for TB patients discharged from hospital in South Africa

Background

South Africa is a high tuberculosis (TB) burden country which appears on the three WHO priority lists for high TB incidence (781/100 000) (2016), MDR TB and TB/HIV incidence (8). Most TB patients in South Africa were treated through the National TB Control Programme (NTP) at public sector primary health care (PHC) clinics and specialized TB hospitals. In addition, large numbers of TB patients were admitted to acute care hospitals, with TB patients accounting for 17% of all admissions to public acute hospitals in Cape Town and were the main cause of hospitalisation of HIV infected persons (19,21).

Hospitalised TB patients were usually provided with a week of TB treatment on discharge and referred to PHC services or specialized TB hospitals to continue the appropriate TB treatment regimens. Hospital clinicians raised concerns that many discharged TB patients were re-admitted and may have discontinued TB treatment. Most hospitalised TB patients were also not notified (37,57), and were therefore not followed up by public health services after discharge.

National strategies to improve the quality of health care included a focus on continuity of care, as did provincial plans (56,234). The Western Cape provincial TB programme had also developed referral and hospital admission guidelines for TB patients, but did not provide strategies to improve continuity of care for TB patients discharged from hospitals (206).

Studies had found poor continuity of care for TB patients discharged from hospitals in South Africa (36,37), and one hospital reported improvements after implementation of an intervention (48). Other high TB burden countries also highlighted problems in the engagement of hospitals in TB control and developed strategies to improve linkages in care for TB patients (189). This policy brief therefore responded to the need for evidence to inform strategies to improve continuity of care for TB patients discharged from acute care hospitals in South Africa.

Purpose of the policy brief

The policy brief on strategies for continuity of care for TB patients discharged from hospital aimed to facilitate the transfer of knowledge in an accessible format for health decision makers and service providers.

Health policies are influenced by a variety of factors:-values and beliefs, stakeholder power, institutional constraints, and available financial resources, among others. Research evidence is essential for well-informed health policies (137), but is not sufficient on its own to inform policy (110). Policy development needs to take account of the context, decision makers and the process of decision making (110,235). Engagement with policy makers is therefore important to clarify their needs, and to assess the appropriateness of the evidence to their context, and barriers which may affect the uptake and implementation of evidence informed policy options.

More importantly research undertaken in one population and setting may not be directly transferrable to a different population and context. Policy briefs therefore should include evidence from implementation research which tests the feasibility of implementation, explores the factors that affect implementation, and assesses the effects of implementing evidence informed interventions in different contexts.

This policy brief included the best available evidence from research including systematic reviews and primary research in the local context, interpreted the research evidence in relationship to the specific context, engaged with stakeholders to identify and address barriers to implementation of research evidence, and assessed implementation of evidence informed strategies to improve continuity of care for TB patients discharged from hospital in South Africa.

Methods

The policy brief summarised and synthesised the findings of five studies on continuity of care for TB patients including:-i) an observational study of continuity of care for TB patients discharged from a referral hospital in the Western Cape; ii) a qualitative study of the perceptions of hospital staff of continuity of care for TB patients; iii) an overview of systematic reviews on continuity of care for chronic diseases; iv) an outcome evaluation of an intervention to improve continuity of care for TB

patients at a referral hospital in the Western Cape; and v) a process evaluation to understand the implementation of the intervention at a referral hospital in the Western Cape.

The observational and qualitative studies assisted in clarifying the problem of poor continuity of care for TB patients discharged from hospital, identifying health systems factors which contributed to the problem and obtained the perspectives of hospital staff on the problems and possible solutions. The studies were complemented by findings of other local research studies, some linked to the main study at the referral hospital, and discussed with service providers in a workshop.

The overview of systematic reviews identified options to address the problems. Policy dialogues of this evidence assessed the appropriateness of the evidence to the context, and barriers to implementation.

The outcome evaluation assessed the effects of a multicomponent intervention which was informed by the evidence and implemented using participatory action research (PAR) at a local referral hospital. The process evaluation assessed factors which facilitated or impeded implementation, and contextual issues which were important to sustain the intervention.

A process of engagement with stakeholders was integrated throughout all stages of the research and in each sub-study. This involved using policy dialogues, workshops and PAR to engage service providers and decision makers in clarifying the problem, defining the research questions, planning the research, interpreting the findings and making recommendations which are incorporated in the policy brief.

The policy brief presents the findings in an accessible and user friendly format for decision makers. We used the 1:3:25 format for policy briefs, which includes a one page of 'take home' messages; a three page executive summary; and a 25 page synthesis (236). The one and three pager provides sufficient information on the key findings and policy options to inform decision makers. The 25 pages includes more detailed content, to be used by decision makers or health service staff involved in developing policies and guidelines, or who would like to scrutinise the supporting evidence more thoroughly in making decisions on continuity of care for TB patients.

Framing of the problem

The failure of TB patients to continue treatment after discharge from hospitals is approached from a health systems perspective. Although TB is curable, it has features of a chronic disease because of the

long duration of illness and drug treatment particularly for 'retreatment' and drug resistant TB disease, and because many TB patients remain chronically infected and experience disease relapses across their lifetime (59). The extensive co-morbidities of TB with HIV and other chronic diseases such as diabetes and chronic obstructive pulmonary disease further contribute to the importance of providing integrated management of care for TB and other chronic diseases (18,62). Chronic disease patients require multiple interactions with health services, involving numerous service providers and levels of care, over their lifetime. The linkages between providers and levels of care within the health system for chronic diseases are therefore critically important to ensure continuity of care, optimise health outcomes and ensure efficient utilisation of scarce health care resources.

Poor continuity of care is a problem of coordination and communication within and between organisations within complex health systems. The design of health systems and organisations with various components which function in isolation or are not coordinated results in fragmentation rather than harmonization of the delivery of health care. Health care has also been organized to provide episodic management of acute illnesses in response the burden of disease of earlier centuries (127). With increased life expectancies and the epidemiological transitions to a higher burden of chronic diseases, the design of health systems in low and middle income countries (LMIC's) has responded poorly to the need for continuity of care over time and health care providers (58).

In South Africa where poor linkages and a lack of coordination of care between levels undermine access to and the quality of care for TB patients, little research has been undertaken to describe and understand the problems or to test interventions to improve continuity of care for TB (18,19).

Size of the problem

Several studies have found that TB patients admitted to public acute care hospitals in South Africa experienced poor continuity of care after discharge from hospital (36,37,176). At Chris Hani Baragwaneth Hospital in Gauteng, 31% of admitted TB patients were not notified, and only 50% reached PHC services on discharge to continue TB treatment. At Edendale Hospital in Kwazulu Natal 42% of laboratory confirmed pulmonary TB patients were started on TB treatment in hospital, 29% reached a PHC clinic after discharge and 18% eventually completed treatment. At Tygerberg Hospital in the Western Cape only 13% of TB patients were notified, 36% continued TB treatment after discharge, 24% successfully completed treatment, and 32.7% were re-admitted at least once to Tygerberg within a six month period (176).

In 2016 the South African NTP detected 69% of all TB cases, and achieved an 81.7% successful treatment outcome rate for patients commenced on treatment (14). Many of the 'undetected' TB patients may have presented at acute care hospitals which were not part of the NTP. For South Africa to achieve the WHO End TB Strategy goals of screening 90% of vulnerable groups, diagnosing and commencing 90% of these on TB treatment, and achieving 90% successful TB treatment outcomes by 2022 (30), the NTP should identify and ensure that TB patients discharged from acute hospitals continue and complete TB treatment.

Poor continuity of TB care results in treatment interruptions and poor patient clinical outcomes, increased drug resistance, chronic infection and ongoing spread of TB in communities. This ultimately results in increased health service costs due to repeat visits, more complex treatments and re-admissions to hospital. The costs to patients and families for health care, loss of income, absence of caregivers and avoidable disability result in high societal costs (45).

Health systems factors underlying the problem

We conducted an observational and a qualitative study to identify health systems factors underlying continuity of care in the local setting.

Observational study (176)

Methods

This retrospective observational study used routine information to describe hospitalised TB patients, their clinical management, and whether they continued TB treatment after discharge from hospital. We also assessed associations between patient factors, the clinical management and continuity of care.

Key findings

788 hospitalized TB patients were identified in 6 months. Their median age was 32 years, 400 (51%) were male, and 653 (83%) were urban. A bacteriological TB test was performed for 74%, 25% were tested for HIV in hospital, and 32% of all TB patients had documented evidence of HIV co-infection. Few (13%) were notified for TB; 375 (48%) received TB medication; 284 (36%) continued TB treatment after discharge; 91 (24%) had a successful TB treatment outcome, and 166 (21%) died. Better continuity of care was associated with adults, urban residence, bacteriological TB tests in hospital and

provision of TB medication on discharge. Fragmented hospital TB data systems did not provide continuity with PHC information systems.

Conclusion

Discharged TB patients experienced poor continuity of care, with children, rural patients, those not tested for TB in hospital or discharged without TB medication at greatest risk. Suboptimal quality of hospital TB care and a fragmented hospital information system without linkages to other levels underpinned poor continuity of care.

Qualitative study (172)

This study sought to understand factors from the perspectives of hospital staff that influenced the clinical management and discharge of TB patients, and to elicit recommendations to improve continuity of care for TB patients.

Methods

PAR was used to engage hospital staff working with TB patients admitted to a central academic hospital in the Western Cape Province, South Africa. Data were collected through eight focus group discussions with nurses, junior doctors and ward administrators. Data analysis was done using Miles and Huberman's framework to identify emerging patterns and to develop categories with themes and sub-themes. The participants influenced all phases of the research process to inform better practices in TB clinical management and discharge planning at the hospital.

Key findings

The emerging themes and sub-themes were categorized into two overall sections: The clinical care management process and the discharge and referral process. Nurses expressed a fear of exposure to TB and MDR-TB due to challenges in clinical and infection-prevention and control (IPC). Clinical hierarchies, poor interdisciplinary teamwork, limited task shifting and poor communication interfered with effective clinical and discharge processes. A high workload, staff shortages and inadequate skills resulted in insufficient information and health education for TB patients and their caregivers. Despite awareness of the patients' socioeconomic challenges, some aspects of care were not patient centred, and caregivers were not included in discharge planning. Communication between the hospital and referral points was inefficient and poorly supported by information systems. Hospital staff recommended improved IPC practices and interdisciplinary teamwork in the hospital, that TB education for patients be integrated with hospital staff functions, with more patient centred discharge

planning, and improved communication across hospitals and PHC levels.

Conclusions

Interdisciplinary teamwork, more patient centred care, and better communication within the hospital and with PHC services are needed for improved continuity of care for TB patients. Further studies on factors contributing to, and interventions to improve, continuity of TB care in similar hospital settings are needed.

Discussion

Two local studies found that appropriate TB clinical management in hospital, particularly TB bacteriology testing and provision of TB medication on discharge, was strongly associated with better continuity of care and patient outcomes in (171,176). Hospital staff also identified shortcomings in the clinical management, discharge and referral of TB patients which they felt contributed to poor continuity of care (172). Staff factors included fear of TB infection due to insufficient protection from occupational exposure to TB; lack of knowledge and competencies in TB clinical management including patient education and counselling; and unclear roles and responsibility with regard to patient education, clinical management and the discharge of TB patients. At an organisational level a lack of guidelines for discharge management of TB patients, workload and staff shortages, and an organizational culture which entrenched disciplinary silos and hierarchies impeded effective interdisciplinary communication and care of patients.

The observational study at TAH also found shortcomings in health information systems including poor documentation of patients' diagnosis and treatment in hospital patient records and referrals, and the absence of a reliable, integrated hospital TB information system (176). The hospital and PHC information systems were not linked, and this along with low TB notification rates and incomplete information in referral forms, impeded follow up of patients and communication between levels of care. The hospital staff also felt that poor documentation, inadequate clinical information systems and insufficient use of information technology to support communication within the hospital and with other levels of care contributed to poor continuity of care (172).

Other local studies found that patient and socioeconomic factors such as low education levels, lack of access to food, frequent relocation, being a non-South African, and alcohol and drug use contributed to poor continuity of care of hospital discharged TB patients (171,180,181). This was echoed by TAH staff who felt that low literacy levels and language barriers limited communication with patients prior to discharge; and that poor socioeconomic conditions and lack of community based support presented

challenges for patients in continuing TB treatment after discharge (172). TB patients discharged from hospital in the Western Cape were distressed by the lack of information about their disease and treatment while in hospital, and that they were not asked about their circumstances or about arrangements to continue TB treatment after discharge (182).

A workshop in 2010 attended by hospital, PHC and NGO managers and staff discussed the studies on continuity of care for TB patients at South African hospitals, evidence on continuity of care for chronic diseases from systematic reviews, and experiences and recommendations from other high TB burden countries from KNCV (189). Additional factors identified in this workshop were that hospital staff were unfamiliar with and did not regard themselves as being part of the NTP, had little knowledge of or links with community health services, and felt they were too busy to create links with other levels of care. They felt that poor patient knowledge, migration for health care, high levels of HIV co-infection and the lack of integration of TB-HIV care, and poor links in information systems also contributed to poor continuity of TB care (Unpublished TB Continuity of care workshop report, Stellenbosch University, September 2010).

Evidence of strategies to improve continuity of care for TB patients

Overview of strategies to improve continuity of care for chronic diseases between hospitals and primary care services

We searched the literature for systematic reviews and experimental studies on continuity of care for TB patients discharged from hospital, but found none. In the absence of any such direct evidence, we conducted an overview of continuity of care for chronic disease patients discharged from hospital, to identify potential strategies which might be applicable to TB patients.

Methods

We were guided by the approach to conducting an overview of reviews as described by Becker and Oxman in the Cochrane Handbook for Systematic Reviews (132). We conducted electronic searchers of the Cochrane Database of Systematic Reviews, the Effective Practice and Organisation of Care Group (EPOC) specialised register, the McMaster Health Forum for Health Systems Evidence (www.healthsystemsevidence.org), the SUPPORT database of summaries of systematic reviews (www.supportsummaries.org) and MEDLINE, and checked reference lists of included studies. We extracted the key findings of each review, assessed the quality of the evidence, and summarised important information regarding the interventions, participants, settings and outcomes. The quality

of the evidence was assessed based on the GRADE approach and the key findings were expressed consistently as to reflect the quality of the evidence. Considerations of applicability and the need for monitoring and evaluation were informed by policy dialogues with decision makers.

Potential barriers to implementing the policy options were identified by brainstorming using a detailed checklist of potential barriers to implementing health policies; through primary research conducted locally and through engagements with local service providers and decision makers. Systematic reviews of relevant implementation strategies to address the barriers were identified using the databases listed above.

Key findings

The included reviews were grouped into four options:-1) information or communication strategies; 2) discharge planning and support; 3) shared care or care pathways, and 4) disease management programmes and integrated care. No reviews of education or incentives were found. We describe the key findings of the included systematic reviews for these four options, and the advantages, disadvantages and acceptability of each based on the policy dialogues. The costs and cost-effectiveness of all four options is uncertain.

The overall assessment of applicability for all four options, suggests that while there may be significant potential benefits, the quality of studies and settings where the studies were conducted (all in high-income countries) limit the ability to draw firm conclusions about whether any of them lead to improved patient health outcomes (and if so, at what cost) in TB patients in LMIC's.

Information, education and communication strategies

Definition**:** Interventions to improve information transfer and communication between hospitals or specialist care, primary care providers and patients to improve continuity of care and patient outcomes.

Three systematic reviews assessed the evidence on information or communication strategies for improving continuity of care for chronic diseases. These included patient-held records (PHR's) (138), telephone follow up (TFU) post hospital discharge (139), and interactive communication between primary care physicians and specialists in the management of patients (140).

They found that:-

- The use of PHR's may improve patients knowledge, preparedness for appointments and ability to monitor their own health, but may not improve patient satisfaction or health outcomes;
- The use of TFU's of discharged patients may improve adherence with keeping PHC appointments, but it is uncertain whether it has any effects on patient psychosocial or physical outcomes, or hospital re-admissions;
- Interactive communication between collaborating primary care physicians and specialists probably improves clinical outcomes in patients with depression, and may improve clinical outcomes in diabetic patients. The effects may be enhanced by interventions to improve the quality of information exchange.

Applicability of findings

Advantages:

- Information and communication strategies provide additional mechanisms of communication between hospitals, PHC providers and patients which are not routinely used;
- Advances in technology and access to it in South Africa, including in the public sector, make it possible to introduce these additional components;
- PHR's also increase patients control over the management of their disease, and contributes to patients empowerment;
- Can contribute to improving continuity of care, either individually or in combination.

Disadvantages:

- Require support and involvement of health care providers;
- Assumes that patients are literate, motivated and able to understand and use information;
- PHRs may be lost by patients, so duplicate systems may be needed to ensure that records are maintained**;**
- May increase health professionals workload without any clear benefit**;**
- TFU's are labour intensive, and depend on all patients having telephones;
- TFU has been superseded by newer telephone technology, such as mobile phones and use of SMS's for communication with patients and health providers;
- Confidentiality of patient information if calls are taken by other household members, or if SMS's are sent to shared mobile phones.

Acceptability:

- Overall the interventions were seen as acceptable to health care providers and patients;

- Health professionals may be resistant to patients having their own records, and the additional workload this may place on health service staff in completing these records;
- Cost implications may reduce acceptability in an environment with limited financial resources.

Discharge planning and support

Definition: Discharge planning is the development of individualised discharge plans for the patient prior to leaving hospital, with the aim of improving patient outcomes, improving coordination of services, and containing costs. This may be complemented with pre- and/or post discharge support activities such as patient education and follow up in the community.

We identified 3 systematic reviews and 1 overview which found that discharge planning and support (65,141,142,150):-

- Probably reduces the hospital length of stay and re-admissions for patients with a medical diagnosis;
- May improve use of primary care services, adherence to medication and improve patient and provider satisfaction;
- It is uncertain whether it has any effects on costs.

Applicability of findings

Advantages:

- Discharge planning provides tools and processes to guide and support hospital staff in managing the discharge of patients;
- Assists in clarifying roles and responsibilities of different categories of staff within the hospital and at other levels of care in the discharge process;
- Promotes interdisciplinary collaboration in managing the discharge process;
- Potentially promotes a more patient centred approach.

Disadvantages:

- May involve additional work (including paperwork) for busy hospital ward staff;
- Hospital staff may not have the competencies to provide patient education and counselling as part of the discharge process;
- Requires commitment of different health professionals within the hospital to take responsibility for specific actions and to collaborate across disciplines;

- May require a dedicated person, time and resources for the hospital to involve PHC health professionals which may not be available.

Acceptability:

- Very acceptable to health care providers, particularly hospital nurses;
- Health professionals may be resistant to adopting new tasks without additional capacity being provided to support discharge planning;
- This may have cost implications in resource limited environments.

Shared care and clinical care pathways

Definition**:** Shared care and clinical pathways involve the joint participation of primary care and speciality care physicians in the planned delivery of care, informed by an enhanced information exchange over and above routine discharge and referral notices.

We identified three systematic reviews on the effects of shared care and care pathways (143–145). They found that:-

- Shared care may improve clinical outcomes, and has mixed effects on patient reported outcome measures, medication prescribing and use, and participation in shared care services;
- Integrated multidisciplinary care across the primary and secondary care interface may improve patient satisfaction, patient attendance of visits, and reduce defaulting from treatment. It is uncertain whether it improves clinical outcomes;
- Clinical pathways may improve documentation, and reduce in-hospital complications. It is uncertain whether clinical pathways reduce length of hospital stay, in-hospital mortality, hospital re-admissions or hospital costs.

Applicability of findings

Advantages:

- Ensures that primary care providers are informed about the hospital management of the patient;
- Enables primary care providers to be involved in planning the patients care after discharge;
- Potentially ensures that treatment decisions are appropriate for the patients context and strengthens links to community based resources;
- Provides easier access to specialists for consultations or referrals back to hospital.

Disadvantages:

- Needs time and active involvement of specialists from hospitals, which is not always available;
- Often hospital specialists see their role only as ''seeing more complex patients'' in a PHC setting, as opposed to supporting and mentoring PHC colleagues;
- Requires skilled ''case manager" (e.g. psychiatric nurses) to coordinate the link between hospital specialists, PHC services and to follow patients up. These skills may be scarce or expensive and different models of case management need to be considered and evaluated in resource constrained contexts.

Acceptability:

- Very acceptable and is being advocated in a few programmes, particularly mental health;
- Acceptability is dependent on resource availability, particularly finances and human resources for case management and to free up hospital specialists time to participate in shared care.

Disease management programmes and Integrated care

Definitions:
Disease Management: Programmes (DMP's) are designed to prevent or manage chronic conditions using a systematic approach to care and potentially employing multiple ways of influencing patients, providers or the organization of care (153).
Integration: Provision of multidisciplinary interventions at different stages of the care process in two or more institutional areas (76,151).

We included four systematic reviews (146–149) and two overviews (151,152) on the effects of DMP's and integrated care. They found that DMP's and integrated care reduced hospital re-admissions and emergency department visits for a range of chronic medical conditions. For specific diseases:-

- DMP's for HIV/AIDS which included case managers may improve drug management, and increase entry to and continuity on medical care.
- DMP's for heart failure which included case management probably reduce mortality and hospital readmissions;
- DMP's for diabetic patients probably improve glycaemic control, adherence to treatment guidelines, patient satisfaction, and quality of life,

- DMP's for COPD probably improve patient satisfaction, adherence to treatment guidelines, and length of stay in hospital
- DMP's for asthma patients probably improve adherence to treatment guidelines.

Applicability of Findings

Advantages:

- Supports adopting a combination of strategies in a complementary way to improve quality and continuity of care and patient outcomes;
- Promotes multidisciplinary team work in patient care;
- Encourages patient centred care with greater involvement of patients in their own care;
- Can be adapted to the context with different combinations of interventions in DMP packages.

Disadvantages:

- Requires capacity and commitment from different health professionals to collaborate in managing care;
- Patients may require a higher level of health literacy to participate actively in care planning and management;
- The policy environment and organisational culture may not support more integrated strategies of care within and across institutions and levels of care in different settings;
- There is no conclusive evidence on the cost-effectiveness of disease management programmes, nor on direct cost implications in LMIC settings with constrained resources.

Acceptability:

- DMP were considered acceptable by health service providers;
- Concerns were however expressed about the leadership, organisational culture and resource requirements to support DMP and integrated approaches to care in fragmented and hierarchical health systems.

Implementation considerations

A policy dialogue workshop with relevant managers at the Department of Health of the Provincial Government of the Western Cape discussed the evidence from systematic reviews of continuity of care for chronic diseases, and identified potential barriers to implementation. These were further tested in workshops with hospital and PHC staff, and in the evaluation of the intervention at TAH.

We categorised the main barriers into those related to patients, health professionals and the health system. Patient related barriers included patients' knowledge and care seeking behaviours, literacy levels, language barriers, poor treatment adherence and utilisation of PHC services. Health professionals' barriers included their knowledge and competencies; health worker motivation; high workloads and staff shortages within the hospital and poor communication with patients and insufficient patient centred care. Health systems barriers included organisational culture particularly hierarchical structures and bureaucracy; inadequate interdisciplinary team functioning; inadequate access to and use of information communication technology (ICT), lack of community based support for discharged patients, and governance to sustain interventions.

We checked previous policy briefs, SUPPORT Summaries (http://www.support-collaboration.org), and the Health Systems Evidence database (http://www.healthsystemsevidence.org) for systematic reviews on potential strategies for each barrier with particular reference to continuity of care between levels (i.e. hospital to PHC services); which we summarised in the table below.

Summary table of implementation strategies

Barriers	Strategies	Evidence
Implementation strategies to address barriers linked to patients		
Patients' knowledge and care seeking behaviours	Patient education materials and health literacy	There is some evidence that health literacy interventions which used mixed strategies, and patient education or interventions can improve adherence to treatment and use of health care (Grimshaw 2004, Berkman 2011, M'
	Pharmacy related services	Additional pharmacist provided services may reduce hospital admissions and improve some clinical outcor interventions to improve patient adherence to medication e.g. dose dispensing units, counselling, use of differer services, are uncertain (Nieuwlaat 2014).
	Mobile text messages and Reminders	Mobile phone text messaging to patients probably improve adherence to ART treatment (Mbuagbaw 2013), ar adherence to TB treatment (Nglazi 2013). Pre-appointment reminders for TB patients may increase clinic atter 2014).
	Incentives, cash transfers, vouchers	There is low-to-moderate certainty evidence that cash incentives, non-cash incentives, conditional cash transfe and use of voucher schemes affect utilization of health services (Wiysonge 2016, Lutge 2015, Haynes 2008, Lag
		Community mobilisation probably increases demand for health services. More intensive and participatory r effective (Lee 2009).

Community based support for patients	Community mobilization Lay health workers in community health care	Lay health workers probably improve child health care uptake, infant breastfeeding practices and improve pulm high risk behaviours and improve treatment adherence in HIV patients in PHC settings (Lewin 2010, Petersen 2
Implementation strategies to address barriers linked to health workers		
Health workers' knowledge and competency	Printed educational materials, educational meetings, inter-professional education, audit and feedback, reminders and patient-mediated interventions, Tailored interventions	Printed educational materials alone may slightly improve professional practice, including referral practices (Gig Moderate to high quality evidence shows that educational meetings (Forsetlund 2009), and inter-professiona professional performance and patient outcomes. Interventions that included audit and feedback (Ivers 2012), manual paper reminders (Pantoja 2014) and comp 2009) lead to improvements in professional performance and patient outcomes. Patient mediated interventions probably improve health care professionals adherence to recommended clinica Tailored interventions are probably effective in addressing specific barriers to change in health professional be
Health worker motivation	Local opinion leaders Adequate payment, pay for performance, non-financial incentives	Local opinion leaders, acting alone or in concert with other interventions, probably improve health professio (Flodgren 2011). Low-quality evidence that adequate payment, pay for performance, and non-financial incentives improve perfo 2012, Mathes 2019)

Poor interdisciplinary team functioning Communication with patients	Inter-professional collaboration Interventions to promote patient centred care in clinical consultations	Externally facilitated inter-professional activities or inter-professional meetings may slightly improve recommended practices and use of healthcare resources. It is uncertain if IPC interventions improve patient a care, or collaborative working (Reeves 2017). Patient centred care interventions for providers may improve the provider-patient consultation process, may and behaviour e.g. attendance and follow up consultation and patient health status (Dwamena 2012).
Implementation strategies to address barriers linked to health system		
Organisational culture Hospital Staffing Lack of access to and use of ICT Governance and Leadership	Strategies to change organisational culture; Hospital nurse staffing models, and nurses as substitutes for doctors. Information systems and ICT Governance arrangements	The effectiveness of strategies to change organisational culture is uncertain (Parmelli 2011). Task shifting from doctors to nurses in PHC probably generates similar or better health outcomes for a range of if different nurse staffing models have any effect on patient or staff outcomes in hospitals (Laurant 2018, Butle The effectiveness of interventions to promote the use of ICT adoption in healthcare settings is uncertain (Gagn No relevant studies on hospital governance relevant to continuity of care (Herrera 2017).

Outcome Evaluation

An intervention to improve TB patient discharge management and linkages between levels of care was implemented at an acute referral hospital in the Western Cape, South Africa. This study aimed to evaluate the effects of the intervention on continuity of care for TB patients discharged from hospital under routine service conditions.

Methods

The outcome evaluation used a before after controlled 'quasi experimental' study design. We compared continuity of care for discharged adult TB patients before and after implementation of an intervention by assessing TB patient registration and outcomes captured in routine health information systems. We also compared intervention to control ward patients. All adult hospital admissions with a primary or secondary TB diagnosis during each period were included. Patient data from routine health information systems were analysed in STATA 15.0. We compared before-after and intervention-control groups using bivariate analysis and Chi^2 tests; and conducted a binary regression to assess associations.

Key findings

Significantly more discharged adult TB patients continued TB treatment after (548/595, 92.1%) compared to before (256/636, 40.3%) the intervention (OR 17.3, p <0.001). A total of 364 (61.2%) of all discharged TB patients successfully completed TB treatment post-intervention. This was a significant increase from the successful treatment completion rate of 26.6% (OR 4.4, p <0.001) before the intervention. However, successful treatment completion rates in TB patients who arrived at NTP services did not differ between pre (169/256, 66.0%) and post intervention (364/548, 66.4%) patients.

In the post-intervention sample continuity of care was similar across gender, area of residence (urban versus rural), and notification status. However, older TB patients (p=0.05) were less likely to continue TB treatment at a NTP facility. TB patients discharged from internal medicine wards (93.4%) compared to other wards (85.7%) were more likely to continue TB treatment at an NTP facility (p=0.02).

Conclusion

A multifaceted evidence-informed intervention to improve discharge management and linkages between levels of care contributed to significantly improved continuity of care for discharged TB patients in a before-after comparison. Contamination as a result of diffusion effects reduced the validity of comparisons across intervention and controls wards. Further research is required to evaluate interventions to improve continuity of care for TB patients discharged from hospitals in similar settings.

Process Evaluation

A few interventions have improved continuity of care for TB patients discharged from hospital. Implementation, defined as 'the constellation of processes intended to get an intervention into use within an organisation'(190), has been poorly described, and we have insufficient understanding of their implementation to replicate the interventions in different settings. This study investigated the implementation of a multifaceted intervention to improve continuity of care of TB patients discharged from a hospital in South Africa.

Methods

The study was undertaken at a 1300 bed tertiary academic hospital and PHC services in a Province with a TB incidence of 681/100 000, where an intervention had improved continuity of care for discharged adult TB patients. We conducted a mixed methods evaluation guided by an adapted Consolidated Framework for Implementation Research. A directed qualitative content analysis of documents, semi-structured key informant interviews and process monitoring data were triangulated to identify barriers and facilitators of implementation.

Key findings

Factors which enabled implementation, included the characteristics of the intervention, the people involved, the process of implementation and the external context. In a favourable policy environment, PAR facilitated the development of an appropriate and acceptable intervention which was readily adopted. Despite human resource constraints within the hospital, appropriate skills were sourced, roles clarified, and a sense of collective efficacy created in teams across levels of care. The implementation process included extensive engagement of organisational leaders and champions, joint planning, and periodic evaluations and reflection, creating co-ownership by service providers. Barriers to implementation included organisational fragmentation, hierarchical structures and human resource and information technology constraints. The loss of key staff and discontinuation of hospital coordinating meetings resulted in the cessation of training and support for hospital activities. This was countered by strong community based support and information systems improvements which ensured relational and information continuity in TB care between the hospital and PHC services.

Conclusion

A supportive external context, PAR and community resources contributed to the successful implementation of an intervention to improve coordination of TB care under routine service conditions in a resource constrained hospital and fragmented health system. To scale up and sustain interventions in similar complex hospital settings, additional support is needed to strengthen governance and leadership of change.

Chapter 8: Discussion

This chapter discusses whether the study achieved its aims and objectives, the key findings, strengths and weaknesses and implications of each sub-study.

The thesis set out to study the problem of poor continuity of care for TB patients discharged from hospitals to PHC services, with many patients not completing TB treatment and experiencing poor treatment outcomes. In particular it aimed to describe the problem, identify risk factors for poor continuity of care, synthesize evidence to inform the development of an intervention, to implement and evaluate such an intervention, and to develop a policy brief to translate the findings into policy and practice in the Western Cape, South Africa.

I described and identified risk factors for poor continuity of TB care, firstly through a literature review which included studies in South Africa and other LMIC's (Chapter 2). An observational study at TAH measured continuity of care in a cohort of discharged TB patients, and identified socio-demographic and clinical management risk factors for poor continuity of care (Chapter 3).

We complemented this with a study which explored factors influencing the clinical management and discharge of hospitalised TB patients from the perspectives of healthcare staff at TAH to better understand the problem, the context and the people involved, and their recommendations to address problems experienced (Appendix 6). This 'embedded' knowledge assisted in clarifying health system and provider factors which contributed to poor continuity of TB care, and the type of interventions which would be most appropriate at TAH.

An overview of continuity of care for chronic disease patients provided evidence on the effects of strategies on patient and health system outcomes (chapter 4). Although I did not find systematic reviews of strategies to improve continuity of care for TB or HIV patients discharged from hospital in South Africa or other LMIC's, I assessed the applicability of the studies on chronic diseases from HIC to the local context to assist in identifying appropriate strategies. The overview, along with the findings from chapters 2,3 and 4 informed the co-design of a multicomponent discharge planning and support intervention to improve continuity of care for TB patients discharged from TAH.

An outcome evaluation assessed the effects of the intervention on patient outcomes (chapter 5), and a mixed methods process evaluation provided an understanding of factors that facilitated or impeded implementation and the achievement of the outcomes of the intervention (Chapter 6).

Finally, a policy brief summarised strategy options from the overview, assessed their applicability in the local context, described barriers to implementation and strategies to address these barriers (Chapter 7). It incorporated findings from the other studies in this thesis, and input of health service providers which informed the applicability of the policy options

and assessment of barriers to implementation.

Two articles have been published, a third has been submitted for publication, and two more are being drafted for publication.

1. **Dudley L**, Mukinda F, Dyers R, Marais F, Sissolak D. Mind the gap! Risk factors for poor continuity of care of TB patients discharged from a hospital in the Western Cape, South Africa. PloS one. 2018 Jan 25;13(1):e0190258.
2. Marais F, Kallon II, **Dudley LD** (2019). Continuity of care for TB patients at a South African hospital: A qualitative participatory study of the experiences of hospital staff. PLoS ONE 14(9):e0222421.

The key findings, strengths and weaknesses, and implications of each of the studies are discussed further.

Introduction and literature review

TB remains a major contributor to the burden of disease in South Africa, with the country ranking in the top 30 countries for high TB incidence, TB/HIV co-infection, and drug resistant TB. The absolute numbers and severity of disease in TB, TB/HIV co-infected and drug resistant TB patients, as well as co-morbidities with other chronic diseases, has resulted in substantial increases in acute hospital admission rates for TB patients in South Africa (19–21).

Despite the extensive hospitalisation of TB patients, acute public hospitals have not participated in the historically vertical National TB Control Programme (NTP) in South Africa. TB patients admitted to such hospitals have been sub-optimally managed, and experienced poor continuity of care after discharge. Less than half of TB patients continued treatment and less than one fifth completed TB treatment after discharge from hospitals in South Africa (36,37). These TB patients were also not documented in the NTP, contributing to the large number of TB patients 'not detected' by the NTP.

The shifts in global TB strategies to include hospitals in NTP's and the local prioritisation of TB control and quality of care, created a context in which research was needed to both quantify and understand continuity of care for TB patients discharged from hospital, and to identify and test effective strategies to improve continuity of care for TB patients to inform policy and practice in the Western Cape.

Local studies had described the problem but provided little evidence of interventions to improve continuity of care for TB patients. Other high TB burden countries had implemented several strategies to include hospitals in NTP's but conducted very limited evaluations of these strategies. In contrast an extensive literature was available on models and evidence on continuity of care for chronic diseases in HIC's which could inform strategies in LMIC's.

Theory and framing of the problem and research methods

This research adopted the perspective that TB is a chronic disease, for which patients require multiple contacts with different health service providers at different levels over an extended period of time. Health systems were however designed as multiple separate components organised in hierarchical structures to cater largely for the management of acute health episodes. Chronic disease patients therefore experienced many barriers to continuity of care in such fragmented health systems.

After reviewing a wide range of definitions and interpretations of continuity of care in the literature, the following definition was most appropriate in this study:-

'Continuity of care is the provision of coordinated care and services over time, and across levels and disciplines, which is coherent with the patient's health needs and personal circumstances' (2).

I used the framing of health systems as a CAS to understand the problems of poor continuity of care, potential interventions, their implementation and evaluation. In CAS's the implementation of interventions or innovations are dependent on a range of factors related to the unpredictability of people and their interactions within and outside the organisation, and characteristics of the organisation and broader context. I reviewed a range of conceptual models which sought to guide the planning and evaluation of implementation of interventions in complex health systems. These models recognised the importance of the context (internal and external), the people involved (actors), and methods of implementation, in addition to the characteristics of interventions, and the ways these influenced implementation. I drew on these to assist in assessing the problem, interpreting and applying evidence from systematic reviews, and in co-designing, implementing and evaluating an intervention with service providers.

Implementation science methods also informed the approach to the evaluation of the intervention, with the use of a mixed methods process evaluation guided by the Care Transitions Framework (CTF) adapted from the CFIR (122). I complemented this with an outcome evaluation using a quantitative study design to assess the effects of the intervention.

The policy brief was based on evidence and a process of active engagement with health care providers and policy makers to assess the applicability within the local context, and to provide guidance on strategies to assist implementation.

Observational study

The observational study described a cohort of 788 TB patients discharged from TAH as young, urban, unemployed, and a third HIV co-infected. Many (74.4%) had TB bacteriology tests in hospital, 65.1% had a confirmed bacteriological diagnosis, but less than half (47.6%) were issued with TB medication. Only 36% continued TB treatment after discharge, and 24% successfully completed TB treatment. An important finding was that good clinical management, including

bacteriological diagnosis and dispensing of TB medication in hospital, improved continuity of care and reduced TB patient deaths.

The TB patients were similar to those in other hospitals in South Africa, except for lower HIV co-infection rates at TAH. Previous studies also described suboptimal TB clinical management (36,38,171), but few assessed the relationship between this and continuity of TB care and outcomes after hospital discharge. An evaluation of an integrated TB/HIV focal point at Helen Joseph Hospital found that the absence of a discharge letter increased the risk of not linking to TB care; and that a lack of information about HIV status or CD4 in the referral and not having ART initiated in hospital increased the risk of failed linkage to HIV care after discharge (171).

Other studies had found relationships between patient factors and failure to continue TB treatment after discharge. These included a lack of formal education, being a non-South African, no fixed address, lack of steady employment or formal housing, and alcohol or drug use (171,237). TB patients traced after discharge also reported not knowing they needed to continue treatment, being too weak to get to the clinic, and having other responsibilities which needed their attention (36,37). A qualitative study also found that patients were not informed about their diagnosis and treatment in hospital, were not consulted on arrangements to continue treatment, and left the hospital with feelings of hopelessness (182).

My study also documented shortcomings in information systems within the hospital, and poor informational linkages between the hospital and PHC services. This confirmed findings of other hospital and TB information systems studies, and the limited use of technology in health facilities in South Africa (37,57,177,238).

Strengths and weaknesses

The study depended on the availability and quality of data in fragmented routine information systems. Data collection required accessing and integrating data from multiple sources in and outside the hospital, and extensive data verification. Through this process we managed to obtain reliable data on the key patient, clinical management and outcome indicators. However, the data on patients' socioeconomic circumstances was incomplete, limiting assessment of these as risk factors for poor continuity of care.

We were unable to assess the effects of migration for treatment on continuity of care as virtually all hospital TB patients had Western Cape addresses in the hospital records. Earlier studies had reported that a fifth (21%) of patients lived at addresses other than those provided in hospital records and that a similar proportion (17.4%) of TB and HIV patients were not South African nationals (37,171).

Implications for practice and research

Poor continuity of care for TB patients discharged from hospital appears to be a common experience with it now being documented in at least three major public hospitals in different Provinces in South Africa. The large proportion of hospitalised patients with TB, and high levels of TB patients 'undetected' by the NTP, provides grounds for stronger links between hospitals and the NTP.

The suboptimal clinical management of TB patients in hospital, and association between bacteriological TB diagnosis and provision of TB treatment in hospital and better outcomes is further motivation for adoption by hospitals of evidence based NTP clinical guidelines. The pre-clinical training of doctors and nurses should include management of TB patients according to the NTP clinical guidelines, as was successfully demonstrated by India's medical schools (83). Further research is needed on interventions to improve the clinical and discharge management of TB patients in hospital in South Africa. Integration of TB patient information within the hospital and across levels of care could strengthen linkages in care for TB patients. Research on innovative use of technology to support information linkages is warranted.

Published study reference:

Dudley L, Mukinda F, Dyers R, Marais F, Sissolak D. Mind the gap! Risk factors for poor continuity of care of TB patients discharged from a hospital in the Western Cape, South Africa. PloS one. 2018 Jan 25;13(1):e0190258. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0190258

Outcome Evaluation

A before after comparison in the outcome evaluation found that a multicomponent evidence-informed intervention to improve discharge management and linkages between levels of care contributed to significant improvements in continuity of care for adult TB patients discharged from hospital. Younger age and discharge from internal medicine (mostly intervention wards) predicted better continuity of care for adult TB patients in a binary regression. These findings confirmed earlier ecological or observational studies of similar packages of interventions which substantially improved linkages in care for TB patients discharged from hospital in South Africa and other high TB burden countries (48,83,85). However, none of the earlier published studies were experimental and our quasi-experimental study found very little difference in outcomes in the intervention and control ward patients.

For discharged patients who arrived at PHC services, improved discharge management did not further improve treatment outcomes, and further post discharge support may be needed by TB patients at home or in the community. TB patient factors mentioned earlier, along with health systems barriers including clinic staff attitudes, distance to facilities and stock-outs of medication need to be explored further in this context (36,182,237).

A systematic review of discharge planning found that multicomponent interventions which included post-discharge support such as TFU's home visits or a 'transition coach' were more effective (142). Quality evidence also exists of interventions to improve TB treatment adherence in ambulatory care such as mobile phone text messages, pre-appointment reminders, patient incentives, and lay health workers (164,239–241).

Some patients from TAH for whom no outcomes were reported were discharged to prisons and rehabilitation services which were not part of the NTP. Along with acute public sector hospitals, private sector health services, prisons and intermediary care facilities such as rehabilitation centres should also be linked to the NTP (11,28,32,33).

Strengths and weaknesses

Quasi-experimental studies have high external validity as they are conducted in the real world settings of health systems, and are recognised as valuable for implementation research in the health sector. However, they do not adequately control for confounding and their internal validity may be weak. We attempted to manage confounding in the study design by using similar groups for the intervention and controls, and by identifying and controlling for confounding in the analysis.

In addition, we conducted a mixed methods process evaluation which sought to explore secular trends and understand the implementation of the intervention. This revealed that our baseline descriptive study had stimulated a provincial policy statement emphasising the importance of care pathways for TB patients discharged from hospital. The provincial department were therefore keen to learn from the 'pilot' TAH intervention to inform strategies to improve continuity of TB care. The external pressure through the policy statement and senior provincial managers and the use of participatory research methods contributed to early diffusion of the intervention within the hospital and contamination between the control and intervention wards. It also stimulated parallel actions in the hospital to strengthen informational linkages and community based support for discharged TB patient which complemented the 'core' intervention package and may have had a broader impact on continuity of care. We were unable to separate the effects of the components of the package and additional actions within the hospital.

Implications for practice and research

The findings from this study of an intervention implemented under routine service conditions builds on a body of evidence from systematic reviews and case studies in South Africa and other LMIC's. More experimental research of effects of interventions to improve continuity of care for TB patients is needed in LMIC settings. This should be complemented with implementation research to adopt or adapt evidence from HIC's to South Africa and other LMIC's. However, the evidence to date supports implementing improved discharge management practices and linkages in care, while continuing to carefully monitor the processes and evaluate the effects (242).

Additional research on discharged TB patient needs and health systems barriers to continuity of care to inform post discharge support is needed in the South African context. Economic evaluations of such interventions would assist in decision making.

Process Evaluation

The use of the CFIR and triangulation of data sources provided a rich analysis of factors that affected the implementation of the TB CoC intervention. Key findings were that the characteristics of the intervention were favourable, particularly the adaptability of an evidence informed intervention package in the local setting. The external context was conducive and included the support of the provincial top management. PAR facilitated a process of implementation which ensured the commitment of leaders and staff at all levels, provided capacity development of staff, and built relationships in hospital teams and networks across levels of care.

The internal context within the hospital was unfavourable with resource constraints and an organisational culture which frustrated implementation and undermined sustainability. The persons involved overcame barriers by using formal and informal networks and created a sense of collective efficacy and accountability. These contributed to the achievement of the intervention outcomes. However, hospital managers and staff were unable to fully sustain the discharge planning activities, while community based follow up and support of TB patients, and provincially led use of ICT to improve information linkages were strengthened subsequently.

Other hospitals in LMIC's faced similar challenges with extreme resource constraints and organisational cultures which resisted innovation and change (243). Leadership and management in such settings struggled to initiate and manage change, but with external support and facilitation were able to overcome the challenges. In the TAH study, without the ongoing external support or provision of resources to sustain 'new' activities, the 'path dependence' of the hospital led to a reversion to previous practices (225).

The sustained CBS follow up and support of TB patients in this study, and prior evidence of the success of lay health workers (LHWs) in TB treatment and chronic disease care, suggest that it is feasible for LHW's to support transitions in care for TB patients discharged from hospital (163,164). The use of ICT to facilitate exchange of patient information also provided opportunities to overcome organisational constraints in hospitals.

Strengths and weaknesses

The CFIR and CTF provided a validated framework and tools to assess implementation. Mixed methods illuminated perspectives from several sources at different stages of implementation of the intervention, and allowed triangulation of the data. The interviews and document analysis provided an in-depth understanding of complex phenomena within

the context of an acute care hospital in South Africa. An experienced qualitative researcher who was independent from the implementation team established trust with participants and created an interview environment which allowed participants to share their perspectives honestly. However, the findings may not be generalizable to other settings as the interviews and the document analysis were context specific. A few staff were also no longer available and there may have been some recall bias in interviews because of delays between the implementation period and interviews. Possible subjectivity in the analysis and interpretation by the PI was limited by the involvement of a team of researchers who reviewed and discussed the results.

Implications for practice and research

Implementation of innovations in resource constrained hospitals requires an understanding of the health care providers and organisational context in order to address systems challenges. Further research is needed to explore what works to strengthen leadership and facilitate organisational change in similar hospitals to improve the quality and continuity of care for TB patients. Rigorous research on LHW's providing pre and post discharge support for TB patients, and the contribution of ICT to improving continuity of care for TB patients in resource constrained environments is also needed.

Overview

The overview included 13 systematic reviews and three overviews of strategies to improve continuity of care for chronic diseases patients discharged from hospital. They were grouped into four main strategies, i) Information and communication; ii) Discharge planning and support; iii) Shared care and care pathways and, iv) Disease management programmes and integrated care. No systematic reviews were found of standalone interventions providing patient or provider education or incentives.

Of the information and communication strategies, one systematic review found that patient held records (PHR's) may improve chronic disease patient's knowledge, preparedness for appointments and ability to monitor their own health, but may not improve patient satisfaction or health outcomes. A systematic review of telephone follow up (TFU) from hospitals to patients found that TFU's may improve adherence with keeping PHC appointments, but it was uncertain if had any effects on patient psychosocial or physical outcomes. The effects of inter-active communication between collaborating primary care physicians and specialists probably improved clinical outcomes for specific chronic diseases.

Three systematic reviews and one overview of discharge planning and post discharge support for patients with chronic diseases were included. They found that discharge planning and post discharge support may improve the use of primary care services, adherence to medication, and probably reduced hospital re-admissions. Multicomponent interventions which included TFU and other activities such as patient education, home visits or a transition coach appeared to be more effective than single component interventions in one review.

Three systematic reviews provided evidence that shared care and care pathways involving primary and secondary care practitioners probably improves clinical outcomes for some chronic diseases; may improve documentation, patient attendance, and patient satisfaction; and may reduce defaulting from treatment and in-hospital complications.

Four systematic reviews and two overviews provided evidence of the effects of disease management programmes (DMP's) and integration of care. DMP's and integrated care for patients with chronic diseases may improve receipt of medication, hasten initiation of recommended treatment, improve adherence to treatment guidelines and continuity in appropriate medical care, may improve patient satisfaction, and probably reduce hospital re-admissions and mortality. Multicomponent strategies were more likely to be effective than single component strategies in one review.

It is uncertain whether any of the strategies to improve continuity of care for chronic diseases reduces health service or patients costs.

Strengths and weaknesses

The overview followed the Cochrane methodology for conducting overviews. However overview methods are still developing and have some inherent weaknesses. We may therefore have missed or excluded relevant studies, or over- or underestimated benefits. No systematic reviews were found on interventions to improve continuity of care for TB patients, and the included reviews were almost exclusively from HIC's on older patients with chronic non communicable diseases.

Implications for practice and research in LMIC's

The updated evidence from this overview can be considered by decision makers wanting to improve continuity of care for chronic diseases in LMIC's. However the settings and target populations may differ from those in the reviews from HIC's. Chronic communicable diseases patients in LMIC's are younger, poorer, and less educated, and the health systems are not as well-resourced and may be organised differently to those in HIC's. The direct relevance and application of the evidence needs to be considered carefully with such differences. The effects of the interventions on affordability and equity in LMIC's should also be monitored.

Good quality experimental studies on continuity of care for TB and other chronic disease patients are needed in LMIC to assess new strategies or adaptations of existing strategies from HIC to develop a body of evidence in the context of LMIC's. In addition, more implementation research on strategies under the real world conditions of health systems in LMIC's is needed to understand how to adapt and implement strategies from HIC's. Economic evaluations of such strategies are needed to inform decision making.

Policy Brief

The policy brief aimed to facilitate the transfer of knowledge on strategies for continuity of care for TB patients discharged from hospital in an accessible format for health decision makers and service providers. It included the best available evidence from research including systematic reviews and primary research in the local context, interpreted the research evidence in relationship to the specific context, engaged with stakeholders to identify and address barriers to implementation of research evidence, and assessed implementation of evidence-informed strategies to improve continuity of care for TB patients discharged from hospital in South Africa.

We used the 1:3:25 format for policy briefs which includes a one page of 'take home' messages; a three page executive summary; and a 20-25 page synthesis (236).

Strengths and weaknesses

The problem was relevant to policy makers who were keen to find appropriate policy options to improve continuity of care for TB patients in South Africa. The wide range of studies and methods assisted in describing and understanding the problem, provided evidence from systematic reviews, and translated these into practice in the local by co-designing, implementing and evaluating an intervention adapted for the local context. The process of ongoing 'knowledge exchange' with service providers in the Western Cape ensured rapid translation of the evidence into local policies and practice. The policy brief would therefore serve to further strengthen policy and practice in the Western Cape, and to promote adoption of policies to improve continuity of care by other Provinces and the National Department of Health.

A weakness was the absence of systematic reviews on continuity of TB care, and that the reviews in the overview were mainly on chronic non communicable diseases in HIC's. The policy brief addressed this by engaging with health care providers to assess the applicability of the options, and to identify considerations for implementing any strategies in the local context.

Implications for practice and research in LMIC's

Strategies to improve continuity of care have been developed, implemented and evaluated in well-resourced health systems which may differ substantially from those in South Africa or other LMIC's. Implementation in less resourced settings may require adaptations of the interventions to ensure feasibility and appropriateness for the local context. This could fundamentally change the intervention by diluting activities and reducing its effects. Monitoring and evaluating the implementation in the different settings, and especially if adaptations are made, is important.

The core intervention activities may also need to be complemented with activities to overcome organisational barriers to implementation and sustainability. Although the policy brief provides considerations for implementation, this needs to be supplemented with implementation research to translate evidence used for policy into practice in LMIC settings. Further development of implementation research methods, and guidance on approaches to use to address different implementation questions is needed.

Chapter 9: Conclusions and future direction

This chapter discusses the overall contribution of the study to the knowledge and practice of continuity of care for TB patients discharged from hospital in South Africa. It identifies gaps in current knowledge and new research questions which emerged to inform further research and practice to improve continuity of care for TB patients discharged from hospital in South Africa.

The thesis included a comprehensive set of studies on continuity of care for TB patients discharged from hospital in South Africa. The management of TB was approached as having similar requirements for continuity of care as chronic diseases, and a health systems framing applied in the research. A range of research methods was used to describe and understand the problem, to identify the best available evidence of strategies to address the problem, to evaluate the process and effects of implementing an appropriate intervention in the local context, and to translate this evidence into policy.

Contribution to knowledge

The thesis contributed to knowledge about continuity of care for TB patients discharged from hospital in several ways:-

- By applying a chronic disease management lens to continuity of care for TB patients in South Africa, it applied a different approach to understanding problems underlying the management of TB patients. Although many previous authors recognised that the management of chronic communicable diseases such as TB, HIV and malaria have much in common with chronic non communicable diseases, none had applied this to studies of continuity of care for TB patients in South Africa;
- Similarly, a few researchers had previously identified particular health care delivery challenges but none had used a health systems perspective to understand the inability of fragmented health care to ensure continuity of care for TB patients. This study provided a framework to understand the problems and identify solutions at a systems level to improve continuity of care for TB patients;
- The study was one of two in South Africa to test and find associations between the clinical management of TB patients in hospital, continuity of care and clinical outcomes; with implications for the training and competencies of doctors and nurses;
- The overview was the first to specifically search for systematic reviews of interventions to improve continuity of care for TB patients discharged from hospital. Although we found no such systematic reviews, by identifying this important gap it will hopefully motivate further primary studies on continuity of care for TB and other communicable chronic diseases in LMIC's;

- The study demonstrated the perceived value of using PAR to engage providers in translating evidence into practice and to support implementation of interventions in complex and resource constrained hospital settings;
- The outcome evaluation confirmed the beneficial effects of a multicomponent discharge planning and support intervention implemented using a PAR approach. However, it also demonstrated the challenges in conducting an outcome evaluation using a quasi-experimental design under routine service conditions;
- The policy brief was the first to identify policy options for continuity of TB care, and to advise on their applicability and strategies to address barriers to implementation in the South African context;
- The study in its entirety demonstrated successful knowledge translation in practice by involving health decision makers iteratively throughout the research process. Health decision makers and care providers' active participation at all stages resulted in buy-in to the research, commitment to implementation of the intervention and rapid uptake of findings in policy.

Overall limitations

The thesis faced numerous challenges in the research process. Most of the studies were conducted in a complex, fragmented and under-resourced health service environment. Challenges included engaging with and obtaining approval for the various studies from several health authorities and levels of care, the data had to be requested from multiple sources, was often inaccessible and of poor quality, and staff availability to participate in intervention activities such as training was constrained because of work-demands and understaffing. Attempts to use quasi-experimental study designs to conduct a rigorous evaluation of an intervention were not successful because of the limited control the study had of the implementers and environment. Despite these challenges, the hospital and PHC services bought into the research, participated actively in workshops, meetings and implementation activities, and sufficient data was obtained, extensively cleaned and validated for the different sub-studies.

The absence of experimental studies or systematic reviews of continuity of care for TB patients discharged from hospital in any settings presented a substantial gap in the evidence to inform policy and an intervention to be tested locally. The alternative of using evidence from an overview of systematic reviews of continuity of care for chronic diseases was not ideal but provided useful approaches for policy makers to consider. We attempted to address questions of applicability in the context by engaging with health service providers and by testing an intervention in the local context.

Contribution to practice

The study demonstrated that it was feasible to implement a multicomponent discharge planning and support intervention, and that the intervention improved continuity of care for TB patients under routine service conditions. The use of a participatory action approach was perceived as important in facilitating change, building capacity of staff, and

strengthening relationships within and across levels of care to facilitate change in a fragmented and resource constrained environment.

Adaptations such as task shifting to nurses and LHW's to use available and more affordable health personnel did not impede the effectiveness of the intervention in this setting. This is an important consideration in environments with limited human resource capacity and constrained budgets.

Although the hospital discharge planning activities were implemented successfully, without external facilitation or additional resources they were not sustained. In contrast, the information linkages and community based follow up of patients after implementation received ongoing support from provincial managers (from a planning unit, TB and CBS programmes) and were sustained after the research was completed.

South Africa has recently adopted quality improvement initiatives to address shortcomings in the TB cascade, and to identify the missing 'TB' patients and improve their management (Pal M, 2018). In translating evidence into practice to better integrate acute care hospitals with the NTP, the findings of this study suggest that not only is an awareness and responsiveness to the local context important, but that much more is needed to effect and sustain change in resource constrained and complex hospital settings. Change needs to be embedded as part of organisational learning, requiring a deliberate commitment to ongoing improvement, facilitative leadership and investment in staff capacity in organisations. As change is the result of the accumulation of small shifts in behaviour and practices, effective and ongoing leadership to facilitate and support change processes in such a hospital over the long haul is needed (225).

> 'Long-term commitment to new learning and new philosophy is required of any management that seeks transformation. The timid and the fainthearted, and people that expect quick results, are doomed to disappointment.' W. Deming

In poorly performing and under-resourced health systems, the challenges of leadership and resource capacity may be barriers to such organisational learning. Thus sustaining similar interventions may require activities to facilitate leadership development, to develop a learning organisational culture and to strengthen governance in under-resourced hospitals and health systems in LMIC's (244).

Health care providers considered strategies such as DMP and integrated care un-implementable in the local context. The requirements for broad multidisciplinary team collaboration, shared care across levels of the health system, and case management required extensive resources and organisational changes which appeared to exceed the available capacity. They however also rejected single component strategies such as information linkages on its own, and felt it was important to address multiple underlying problems contributing to poor continuity of care. Interventions which met this

brief and were considered feasible such as discharge planning and support, nevertheless also required adaptation to the context which may have changed the intervention in important ways.

The discharge planning and support intervention was applied to a very different chronic disease population who were young, less educated, unemployed, lived in poor socioeconomic conditions and included many migrants compared to chronic disease patients in HIC's. Despite these differences, the system changes managed to improve the outcomes for these patients. However, aspects of patient centred care which hospital staff felt were important, were the most difficult for hospital staff to implement. They felt that they did not have the time or competencies to provide patient counselling and education.

Contribution to teaching and learning

The study was used in teaching students in a master's programme on health systems and services research, and generated new research questions which other postgraduate students were able to use for their research.

A research assistant, Dr Idriss Kallon, completed his doctoral study in 2018 on 'Influences on the continuity of care for patients with mycobacterial tuberculosis referred from tertiary and district hospitals'. This qualitative study explored continuity of care from the perspective of TB patients discharged from hospital, their family, LHWs', PHC and district hospital staff. The findings complemented my research by providing an understanding of TB patients' and their families' experiences, and the perspective of PHC providers (182).

In response to the findings of poor quality data and information linkages in the TAH observational study, Dr Robin Dyers a public health medicine registrar, completed his MMed thesis on ICD misclassification at TAH (245). He worked with the provincial department of health to develop an integrated electronic continuity of care record (eCCR) to improve ICD coding, the quality of referral letters by hospital clinicians and access to the referral letters by primary care clinicians (245). The web-based eCCR was piloted at TAH and scaled up to all hospitals in the Province to improve informational linkages across levels of care (207). This has assisted in improving continuity of care for all patients discharged from hospital who require ongoing care in the province.

A MPhil HSSR student, Dr Theresa Mann from the Department of Orthopaedic Surgery at TAH, completed her masters research in 2018 under Dr Dyers supervision on 'Loss to follow up of spinal TB patients at TAH', assessing whether spinal TB patients attended follow up visits and completed treatment, and identifying factors which contributed to attendance of visits and treatment completion.

Implications for research

This thesis identified several gaps in our knowledge and opportunities for further research on continuity of care for TB patients discharged from hospital in South Africa and similar settings.

Very few studies on continuity of TB care explored the embedded knowledge of health care providers, or the experiences of TB patients and their carers. More qualitative studies could provide a better understanding of the patient, provider and health system factors which contribute to poor continuity of TB care to ensure that interventions respond to patients' and providers' needs and are appropriate in the context.

The few continuity of TB care intervention studies in South Africa and other high income countries were observational studies which could not fully attribute effects to specific interventions. Although systematic reviews provided more rigorous evidence on strategies to improve continuity of care for chronic diseases, very few of the primary studies in these reviews were conducted in LMIC's. More rigorous experimental studies are therefore needed to evaluate interventions to improve continuity of care for TB patients in South Africa and similar settings.

Such studies should test innovative solutions which have not been used in HIC's or adapt interventions which have worked in HIC's for the local context. Particular gaps noted in this thesis were the absence of studies of interventions targeting hospital doctors to improve the clinical management and continuity of care of TB patients; and the paucity of good quality research on ICT's in improving continuity of care for chronic diseases. Lay health workers providing patient education, counselling, follow up and support of discharged TB patients discharged from hospital also remains untested in South Africa.

Patient centred care emerged as an important issue for health care providers, and was supported by the study of TB patients' experiences (182). A systematic review provided evidence of the benefits of interventions to promote patient centred care in clinical consultations (246). However, none of the primary studies in the review were conducted in LMIC's. Rigorous research is needed on interventions to promote patient centred care and its effects on continuity of care for TB patients in South Africa.

Further studies on the translation of evidence into practice are needed. The assumptions that evidence on integrated care for chronic diseases from HIC's can simply be applied to LMIC's has not been adequately tested (76). Many of these strategies may not be implementable or may require adaptations in LMIC settings with different populations, resources, and health system characteristics. Additional health system strengthening activities may be needed to support implementation and sustainability of such interventions in hospitals in LMIC's.

Policy brief frameworks have incorporated considerations of applicability and implementation strategies (247). However these remain theoretical, and more implementation research in local contexts is needed to inform the continuum of

evidence to policy and practice (248). Policy briefs could be much enhanced by more evidence from local implementation research.

More transdisciplinary approaches in particular are needed to understand problems, develop and implement context appropriate and sustainable strategies for integrated care in resource constrained health systems (249,250). In the health sector the evidence on organisational change is limited, and theoretical approaches which use organisational learning in approaching integration of health care have not been tested empirically (230,244). The use of PAR methods to facilitate leadership, better governance and promote organisational learning should be further tested in hospitals in resource constrained hospital settings.

Lastly, more rigorous economic evaluations of interventions to improve continuity of TB care are needed in all settings, and particularly in LMIC's.

Conclusion

This set of studies sought to i) describe and understand continuity of care for TB patients discharged from hospital; ii) to use a range of sources of evidence to inform the co-design of an intervention; iii) to evaluate the process of implementation and effects of the intervention; and iv) to produce an evidence informed policy brief on continuity of care for TB patients in South Africa.

The study found that TB patients discharged from hospital experienced poor continuity of care, and that better clinical management in hospital was associated with improved continuity of care for TB patients. Hospital staff felt that inadequate IPC, poor communication and limited interdisciplinary team work, along with insufficient patient centred care underpinned clinical management and referral processes which did not support continuity of care for TB patients.

We found evidence on several strategies to improve continuity of care for chronic disease patients in HIC's, but none on TB patients in LMIC's. Using PAR and drawing on the available evidence a multicomponent discharge planning and support intervention was co-designed and implemented at TAH.

A before after evaluation found that continuity of care for TB patients improved significantly after implementing the intervention. A process evaluation found that the characteristics of the intervention, the external context, the persons involved and the methods of implementation favourably affected implementation. The inner context of the hospital was unfavourable and presented challenges to the implementation and sustainability of the intervention. Discharge planning activities in the hospital were not sustained, but informational linkages and community based follow up and support of TB patients continued several years after the intervention.

The available evidence on strategies to improve continuity of care for chronic disease patients in HIC's may not be directly applicable to TB and other chronic disease patients in LMIC settings. More rigorous studies of interventions to improve continuity of care for TB patients discharged from hospital in LMIC's is required; alongside implementation research to understand and respond to health systems challenges in resource constrained hospital settings. Both types of research are needed to close the gaps in the translation of evidence into practice in the real world health systems of LMIC's.

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Annexures

Annexure 1: Protocol Report for Registration for a PhD in Public Health

Title: Health systems research to assess and improve continuity of care for Tuberculosis patients discharged from hospitals to primary health care services in the Western Cape, South Africa.

Candidate:

Assoc Prof Lilian Dudley

Principal Specialist

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1. EXECUTIVE SUMMARY

Theme: Continuity of care for tuberculosis (TB) patients between hospitals and primary health care (PHC) services.

Main Research Questions: Do TB patients discharged from hospital reach PHC services to continue TB treatment? Does improving the discharge management systems improve continuity of care between the hospital and PHC services for TB patients?

Scope: This PhD by publication consists of four study components which will be conducted sequentially to build the evidence on the theme. Different study designs are used in each sub-study to answer each research question, to demonstrate competence in and contribute to developing health systems research methods.

1.1 Observational study

A cross sectional study, including descriptive and analytic components, of continuity of care for TB patients discharged from Tygerberg Academic Hospital (TAH) to PHC services in the Western Cape. This study will describe the current status of coordination of TB care between the hospital and PHC services, and provide baseline data for the evaluation of an intervention.

1.2 *Research synthesis*

An overview of systematic reviews of strategies to improve continuity of care between hospital and primary care services for chronic diseases, both non communicable and communicable, will be undertaken. The overview will assess the extent of prior research on the subject and seek to identify appropriate strategies which could be applied locally to improve continuity of care for TB patients.

1.3 Intervention study

Participatory action research (PAR) methods will be used to develop, implement and evaluate an intervention to improve continuity of TB care with active involvement of health service providers. The evaluation method will use a quasi-experimental design to assess the effects of a complex intervention under routine health service conditions.

1.4 Knowledge Translation

The study results will be synthesized into a policy brief to communicate in an accessible format to decision makers. The development of the policy brief will include the synthesis of the ''evidence'' from the research, as well as engagements with decision makers to ensure relevance and applicability of the research in the local context. The process of the development of such a policy brief will be described.

Through these four components this study will generate new knowledge on continuity of care for TB and other chronic diseases, to inform the development of strategies to improve health care delivery for TB patients and contribute to health policy and planning for continuity of care for all chronic diseases in South Africa. At least 4-5 publications will be produced by 2015.

Proposed place of research: The primary research (2, 3) will be undertaken at TAH and in PHC services in the Western Cape. The knowledge translation study (4) will take place in the Western Cape.

Time period: The studies contributing to this PhD commenced in 2010, and will be completed by the end of 2014 (annexure 1), and all publications will be submitted by 2015 so that graduation can occur by the end of 2015. Registration was scheduled for 2011, but for personal reasons this was delayed.

Budget: Sufficient grant funding has been secured to cover the costs of the research.

2. GLOSSARY

AIDS	Acquired Immunodeficiency syndrome
CBS	Community Based Services
CHBH	Chris Hani Baragwaneth Hospital
DOTS	Directly Observed Treatment Short course
EPOC	Effective Practice and Organisation of Care
ETR.Net	Electronic TB Register
FMHS	Faculty of Medicine and Health Sciences
HDL	Hospital DOTS Linkage project
HIV	Human Immunodeficiency Virus
HSR	Health Systems Research
ICD	International Classification of Diseases
KAP	Knowledge, Attitudes and Practice
LMIC	Low and middle income countries
MDR	Multi-Drug Resistant TB
MRC	Medical Research Council

NDOH	National Department of Health
NHLS	National Health Laboratory Services
NTP	National TB Control Programme
PAR	Participatory Action Research
PHC	Primary Health Care
PTB	Pulmonary Tuberculosis
SANPAD	The South Africa Netherlands research Programme on Alternatives in Development
SU	Stellenbosch University
SUPPORT	SUPporting POlicy relevant Reviews and Trials
SURE	Supporting the Use of Research Evidence
TAH	Tygerberg Academic Hospital
WHO	World Health Organisation
XDR	Extensively Drug Resistant Tuberculosis

3. BACKGROUND

3.1 Hospitals in TB control

South Africa is one of 22 high TB burden countries, with high levels of TB/HIV co-infection, and the 3rd highest numbers of drug resistant TB patients globally[1, 2, 3]. Despite a recent worldwide decline in TB incidence and mortality, the TB epidemic in South Africa continues to grow unabated[3]. The absolute numbers and severity of disease in TB, TB/HIV co-infected and drug resistant TB patients have resulted in substantial increases in acute and chronic hospital admission rates for TB[4, 5]. Despite this increase in admissions and impact on hospitals of the TB epidemic, little attention has been paid to the quality of care and continuity of care for hospitalized TB patients.

The new National TB Control Programme (NTP) first implemented the 'DOTS' programme in South Africa in 1996, focusing on delivery through the district health system[2]. Hospitals were not included in the initial implementation of the NTP, and are still not required to comply with national treatment guidelines or to use the national reporting and recording system for TB patients. Routine data is therefore not available to assess the quality of hospital TB care, or contribution of hospitals to TB control in South Africa.

Recent studies indicate that TB patients admitted to secondary and tertiary hospitals in South Africa are managed sub-optimally and referral to primary health care (PHC) facilities is problematic[6, 7, 8]. At Chris Hani Baragwanath Hospital

(CHBH), 46% of TB patients presented directly to the hospital, suggesting that many admissions for TB may not be appropriate or are potentially avoidable. Of those admitted, 31% were not notified, and only 50% reached primary health services on discharge to continue TB treatment[6]. The HIV co-infection rate in this setting was high with 80% of PTB patients testing positive for HIV.

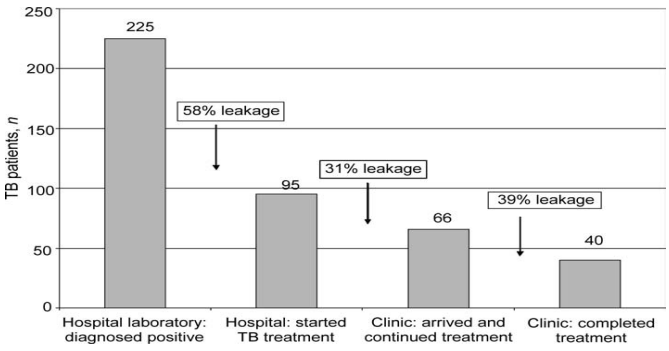

Figure 1: Leakages of TB patients, Edendale Hospital, Kwazulu Natal.

At Edendale Hospital in Kwazulu Natal, only 17% of TB patients had a bacteriological diagnosis, with most patients diagnosed on chest x-ray alone (45%). Of those with laboratory confirmed pulmonary TB, 42% were started on TB treatment in hospital, 29% reached a PHC clinic after discharge and 18% eventually completed treatment (Figure 1). The failure to involve hospitals in TB control has contributed to the development of MDR and outbreaks of XDR in South Africa[8, 9].

Evidence of insurmountable barriers in negotiating the transition between levels of care for patients in Cape Town[10], and poor notification of hospital TB patients with only 13% notified[11], suggests that continuity of care for hospital TB patients in the Western Cape may have similar problems.

3.2 Interventions to improve continuity of care for TB patients

A complex intervention at CHBH, including the establishment of a dedicated TB Centre, resulted in a dramatic improvement in successful TB patient referrals to PHC from 50% to 93%[12,13]. However, the intervention required substantial resources and has not been replicated elsewhere. The PhD candidate visited the Centre in 2011 to gain more insight into the intervention. It was clear that many of the activities had not been maintained, and that the TB centre functioned as a vertical unit dependent on external funding. Systems were duplicated with AIDS patients on anti-retroviral treatment (ART) also having to be discharged through a separated ART centre, and continuity of care for other chronic diseases such as diabetes were not managed by the TB Centre. With high levels of co-morbidity, such a vertical centre focusing on TB care alone, is inefficient and does not provide comprehensive 'patient- centred' care.

GF Jooste Hospital, a district hospital in the Cape Metropole also successfully improved continuity of care for TB patients through the use of trained lay health workers (LHW's) who provided education and support for TB patients, and actively followed up patients discharged to PHC services[14.] I visited this site in 2011 and met with the clinicians and LHW's, Although the benefits of having on site LHW's was evident, their ongoing employment was uncertain as grant funding was ending and the Province had not committed to funding them.

Pilot studies in high TB burden countries participating in the Hospital DOTS Linkage (HDL) project developed interventions to improve the performance of hospitals in TB control [15, 16]. I was invited to participate in an HDL workshop in Indonesia in 2010, and had discussions with HDL service and research partners developing interventions to improve hospitals performance in TB control[17]. Although some evidence is emerging on the impact of interventions through operational research from the HDL, the evidence base for many of the interventions is still weak.

A literature search as part of a draft policy brief on integration of care for chronic diseases for the Norwegian health services, found little evidence of interventions to improve hospital management and continuity of care of chronic communicable diseases of TB and HIV[18]. However, several systematic reviews of interventions to improve the hospital management and continuity of care for non- communicable chronic diseases were identified.

A workshop with health service providers in the Western Cape as part of the research process included presentations from these projects [13,14,19], as well as baseline data on continuity of care of TB patients discharged from TAH and evidence from systematic reviews on interventions to improve continuity of care for chronic disease patients[20.] Feedback was also provided from the Edendale project to follow up on evaluations of interventions implemented at Edendale Hospital [21]. The workshop developed recommendations on the most appropriate interventions to improve continuity of care between TAH and PHC services in the Western Cape [22].

3.3 The cost of poor hospital TB management and continuity of care for TB patients

Hospitalisation of TB patients (excluding MDR hospitalization) consumes a substantial proportion of financial resources for TB control in South Africa, representing more than one third of the total budget for TB control while providing care for less than 10% of patients[23]. South Africa has the second highest per capita expenditure on TB treatment globally, exceeded only by Russia where long term hospitalization is still the norm[3]. Although TB treatment is recognized as one of the most cost effective interventions to reduce the burden of disease[24], hospitalisation has been shown to be the least cost-effective option for the diagnosis and treatment of TB patients[25].

The impact of TB on exacerbating poverty has been well documented, with the costs of hospitalisation to patients and their families often being catastrophic in poor communities. Patients incur substantial costs as well as a loss of family income as a result of hospitalization[25, 26, and 27].

Given the high costs of hospital TB care, any interventions to improve the quality of hospital TB care and continuity of care should also have positive economic benefits for health services and patients.

3.4 Knowledge Translation

A great deal of research is not undertaken in response to a need, and often results are not published or translated into accessible information for decision making [28]. All primary research and health service interventions should ideally be informed by prior systematic reviews. However, as in the case of continuity of care, most systematic reviews are conducted in high income countries[18], and may not always be applicable in the context of low and middle income settings. The applicability and economic implications in other settings requires interpretation based largely on judgements by the authors and practitioners[29].

The fourth component of the protocol focusses on knowledge translation of the evidence produced by the other three components. It will summarise and synthesise the findings of the overview, the observational and intervention studies.

The findings will be presented in an accessible and user friendly format for decision makers, and will include interactive engagement with decision makers through a policy dialogue.

4. THE CONTEXT OF THE PHD RESEARCH PROPOSAL

4.1 The Study Setting

Tygerberg Hospital (TAH), an academic tertiary hospital in Cape Town receives approximately 30–50% of provincial tertiary referrals and serves a catchment population of about two million people, mostly from poor socioeconomic conditions. The pulmonary TB prevalence among both in- and outpatients at TAH was 510/100,000 (394/77,229) and for staff 1065/100,000 (16/1502) during a six month survey in 2006/7[11]. Only 62% of hospitalized paediatric patients who had culture confirmed tuberculosis, were ultimately registered for TB treatment at PHC services in the Western Cape after discharge form hospital.[30] It is not known what proportion of TB patients are referred or present directly to the hospital, and whether on discharge they are referred to and uninterruptedly completed their TB treatment at other health facilities.

I held exploratory discussions with clinicians and academics (paediatricians, infectious disease specialists, TB and HIV/AIDS researchers) at TAH and the Faculty of Medicine and Health Sciences (FMHS) in 2008 to identify health systems problems which health systems research could assist in addressing. Continuity of care for TB and HIV/AIDS patients treated and discharged from TAH was identified as a major concern, particularly as it was unknown whether patients reached PHC services to continue their treatment. The frequent and potentially 'avoidable' re-admissions of TB and HIV/AIDS patients to TAH[31] was a particular concern.

Hospital, TB and HIV/AIDS Programme managers also identified continuity of care and the poor links between hospitals and PHC services as a problem. I therefore initiated a HSR project to evaluate the current status of continuity of care for TB and HIV patients at TAH in 2009. The initial findings led to further collaborative research with the hospital and PHC services which now forms the basis of the PhD.

4.2 Scope of the PhD

The full scope of the main Continuity of Care project at TAH is much wider than the components which form the basis of the PhD. It included TB and TB/HIV co-infection, and used quantitative and qualitative methods to describe the quality of care for patients in the hospital and continuity of care between the hospital and PHC services, and for the evaluation of the intervention. It also included an economic evaluation.

I developed the original concepts and wrote the proposals for all the main study components. These were approved by the Ethics Committee of FMHS, and by the research committees of the WCGH and City of Cape Town.

For the purposes of the PhD, I will include the studies on the continuity of care for TB only, and exclude the HIV component and the quality of in-hospital TB care. I include the quantitative components of the baseline and the intervention study, and not the qualitative methods. These will be supplemented with an overview of the research evidence on continuity of care, and the development of a policy brief as a knowledge translation strategy. I will submit my dissertation as soon as I have submitted at least 4 first- author articles for publication. This summary of the PhD protocol therefore describes only the components which have been included in the PhD.

4.3 Problem Statement

Poor continuity of care for TB patients between hospitals and PHC services results in suboptimal TB patient outcomes. This increases the risk of TB drug resistance, contributes to the ongoing spread of TB in communities, increases the costs of health care through avoidable re-hospitalisation, results in a poorer quality of life for patients, and increases poverty in families and communities.

4.4 Motivation for the Study

The high personal, social and economic costs of poor continuity of TB care between hospitals and PHC services, and lack of research evidence in Low and Middle Income Countries (LMIC's) to inform policy and practices to improve continuity of care, suggests that further good quality research on the role of hospitals in TB Control is needed. The research should describe the current status of continuity of care; identify factors contributing to poor continuity of care between the hospital and PHC services; identify research evidence on effective strategies to improve continuity of care; and develop, implement and evaluate appropriate evidence informed strategies which are sustainable in the South African context.

4.5 Purpose of Study

This study will describe the current state of continuity of care for TB patients between TAH and PHC services; identify research evidence of strategies to improve continuity of care through an overview of systematic reviews; and develop and test the implementation of 'effective' strategies to improve the continuity of care between the hospital and PHC services. It will, through participatory research methods, include decision makers and service providers in defining the research question, developing the intervention and its evaluation. The knowledge generated will be based on 'best evidence' from systematic reviews, but also be locally relevant, applied and evaluated within the context of health services in the Western Cape. The intervention implemented between TAH and PHC services in the Western Cape will be integrated in routine services, will be sustainable after the withdrawal of the researchers, and health service providers will be in a position to 'roll out' lessons learnt from the project.

Knowledge gained through the study will be 'packaged' and communicated to policy makers through a user friendly policy brief. The development of the policy brief will draw on best practice and evidence from the field of knowledge translation, and will include a 'case study' of the process of development of this policy brief.

Each of the study components will also contribute to developing methods in HSR. The development of overviews of systematic reviews is still fairly new and the experience in conducting such an overview will contribute to the methods; participatory action research continues to be an evolving field within the social sciences which is receiving new attention as an important method in HSR; and lastly the case study of the policy brief will contribute to growing methods in knowledge translation in the health sciences.

5. RESEARCH STUDIES

5.1 Observational Study: Continuity of care for TB patients between Tygerberg Academic Hospital (TAH) and Primary Health Care (PHC) services in the Western Cape

Problem Statement

Case studies have provided evidence of poor continuity of care for TB patients discharged from hospitals in South Africa. Hospital clinicians and TB Control programme staff expressed concern about continuity of care for TB patients between TAH and PHC services in the Western Cape. Prior research and routine data to assess continuity of care was not available at TAH to assess these concerns or to identify factors associated with poor continuity of care. A study was therefore proposed to assess continuity of care between TAH and PHC services in the Western Cape.

Research Questions

Do TB patients discharged from hospital reach PHC services to continue TB treatment? What risk factors are associated with poor continuity of care for TB patients?

Aims

The study will describe TB patients admitted to Tygerberg Academic Hospital (TAH) and the continuity of care for TB patients between TAH and PHC services in the Western Cape.

Objectives

i) To describe the socio-demographic, disease and treatment profiles of all TB patients seen at TAH;
ii) To evaluate continuity of care of TB patients discharged from TAH to PHC services in the Western Cape;
iii) To identify factors associated with poor continuity of care for TB patients.

Methods

Study design

This cross-sectional study will describe hospitalized TB patients, and the outcomes of the discharge process to PHC services. An analytic component will assess associations between the referral outcomes and key explanatory variables.

Study setting, population and study sample

This study of hospitalised TB patients will be undertaken at TAH and PHC services in the Western Cape. All patients admitted to TAH with a confirmed diagnosis of TB during the specified time period, and recorded in the routine information systems, will be included in the study sample. From previous routine data on the number of TB patients admitted to TAH annually, it is estimated that more than 750 patients will be included in this sample.

A random sample of this group of patients will be identified for collection of more detailed data on their discharge process and continuity of care. The sample size was calculated to test associations between key explanatory variables (HIV status, ward, duration of hospital stay, diagnostic tests, notified) and the main outcomes for continuity of care. A Chi Square test with 2 degrees of freedom, a significance level (alpha) of 0.05, and 80% power to detect an effect size (W) of 0.250, was used to calculate the sample size needed for the main outcomes for patients discharged from TAH.

Using an estimate of 0.6 for patients reaching PHC services based on previous studies, a total sample size of 139 patients will be required in order to estimate the true population proportion within a precision of $\pm$ 7%. This outcome has no comparisons and the sample size has been calculated based on confidence intervals for the population parameters. A final sample size of 150 patients was used to account for anticipated missing data.

Measures

- **Explanatory variables**

Demographic: Sex, age, race, area of residence, employment status;

Disease profile: adult or paediatric, pulmonary or extra-pulmonary TB, HIV status, bacteriological diagnosis;

Patient management: In- or outpatient status, ward or department, length of hospital stay, re- admissions for TB, diagnostic tests, drug treatment, notified, discharge letter, mortality.

- **Outcome variables**

Patient reached PHC services as recorded in the national electronic TB register (ETR.net);

Treatment outcome as recorded in ETR.net

Patient reached PHC services as recorded in clinic paper based records.

Data collection and management

Permission for study

Permission was provided by the Health Department of the Provincial Government of the Western Cape and TAH Administration to collect data at TAH and from PHC services; and by the City of Cape Town to review the TB register records and related information sources at clinics; and by the National Health Laboratory Services to access data from the central NHLS data-warehouse for confirmation of TB diagnosis where no data was found at TAH.

Data collection

Data will be collected from the routine information systems at TAH for the period 1 November 2008 to 30 April 2009, including:-

- All patients with an ICD 10 diagnostic code for TB as the main or supplementary diagnosis in Clinicom;
- All laboratory confirmed TB patients from the DISA (laboratory data) database;
- All TB treatments issued from the JAC (pharmaceutical data);
- All notifications for TB from records in the superintendent's office.

Patient folders will be drawn for the random sample of 150 patients.

A 10% sample of the routinely collected data will be compared to patient records in the hospital to validate the data. Data on continuity of care of TB patients will be obtained from the provincial electronic TB register (ETR.net) which records all patients who are registered to receive TB treatment at PHC services, district hospitals and TB hospitals. Additional data will be collected on the 150 subsample of patients from the PHC facilities to which they were discharged to compare to the central ETR.net information. Data will be entered and cleaned in Excel prior to transfer into an appropriate statistical software package (STATA) for the statistical analysis.

Analysis

The quantitative data will be analysed in four sections:-

- Description of the profile of TB patients seen at TBH;
- Description of discharge process of TB patients;
- Outcomes of discharge of TB patients from TAH to PHC services;
- Assessment of associations between outcomes and key explanatory variables.

Examples of data analysis tables are included in Annexure: Data analysis plan.

Ethical Considerations

Ethical approval for the observational study was provided by the Ethics review committee of the Faculty of Health Sciences, University of Stellenbosch (Ref: N09/05/149).

5.2 Research Synthesis: An overview of interventions to improve continuity of care between hospitals and primary care services for chronic diseases.

Problem Statement

A few case studies in South Africa and Asia have provided examples of innovative and successful interventions to improve continuity of care for TB patients. The study designs were however weak and the effects of the interventions are uncertain. A draft policy brief on integration of care for chronic diseases in 2009 did not find any systematic reviews on continuity of care for TB[18]. As there is very little good quality evidence on interventions to improve continuity of TB care, we will conduct an overview of systematic reviews of all chronic diseases (communicable and non-communicable) to identify and synthesise the best available evidence to inform strategies to improve continuity of care for TB patients.

Purpose

This overview will seek to identify and collate the evidence from systematic reviews of interventions to improve continuity of care for chronic diseases, including chronic communicable diseases, which may be appropriate for application to TB in a South Africa or other low and middle income countries. The overview will be registered and published through the Cochrane Collaboration.

Research Question

Which strategies are effective in improving continuity of care for patients hospitalized for chronic communicable and non-communicable diseases in low and middle income countries (LMIC)?

Objective: To summarise the evidence from systematic reviews of interventions to improve continuity of care between hospitals and primary care services for patients with chronic diseases in LMIC.

Methods

The approach to conducting an overview of reviews as described by Becker and Oxman in the Cochrane Handbook for Systematic Reviews will be used [32].

***Types of Reviews*:** We will look for and include all systematic reviews on coordination or continuity of care for chronic diseases between hospital and PHC services conducted in all settings in the last 10 years.

***Types of interventions will include*:-**

- Information, education and communication interventions for patients and health workers;
- Training interventions for health care workers;
- Discharge planning, use of discharge or referral guidelines and forms for health care workers;
- Patient or health worker financial and other incentives;
- Shared care and outreach support from hospitals or specialists to PHC services;
- Disease management programmes

***Outcomes of interest*:-**

Primary outcomes

- Continuity of care (treatment interruption, delays in seeking care)
- Clinical outcomes (e.g. TB cure or treatment completion, diabetic control, quality of life)
- Patient satisfaction

Secondary outcomes

- Compliance with treatment (drug adherence, nutrition, or appointments)
- Provider satisfaction with referral processes.
- Costs of care

***Search methods*:** We will conduct electronic searches of the following registers and databases:-

- The Cochrane Database of Systematic Reviews, Cochrane Library
- Effective Practice and Organisation of Care Group (EPOC) specialised register
- McMaster Health Forum for Health Systems Evidence (www.healthsystemsevidence.org)
- SUPPORT database of summaries of systematic reviews (www.supportsummaries.org)
- MEDLINE (1966 to present)

No language restrictions will be placed on the search strategy. Where necessary, authors will be contacted. Reference lists of included studies will be checked to identify any other systematic reviews, and international experts in the field will be contacted.

Data collection and analysis

Selection of reviews: Two authors will independently screen abstracts to identify all reviews that potentially meet the inclusion criteria and should be retrieved. The same two authors will independently assess each full text article that is retrieved to determine whether it met all of the selection criteria. Any disagreements and uncertainties will be resolved by discussion, and/or the involvement of a third author.

Data extraction and management: Two authors will independently extract the following information from the included studies using a data extraction template.

- Type of review
- Date assessed as up to date
- Study settings
- Characteristics of the study population
- Description of the interventions in each comparison group; i.e. the package of delivery care provided, where it is provided, who provides it, with what training and resources/equipment, and any other differences between the comparison groups in terms of the delivery, financial and governance arrangements
- Main outcome measures as specified by the investigators and any secondary outcomes that were reported
- Results for each reported outcome specified under 'types of outcome measures' above
- Any additional information that potentially may influence interpretation of the quality of the evidence, the applicability of the results or differential impacts across populations or settings.

Data will be double entered and managed using Excel. Results will be summarized in one or more Overview of reviews tables.

Assessment of risk of bias in included reviews: Criteria recommended by EPOC will be used to assess the risk of bias for each main outcome in all studies included in the overview (EPOC Review Group Checklist, 2008) and the quality of the systematic reviews. A checklist for quality of overviews developed for an international meeting on use of evidence in decision making will be used to assess the overviews[33].

Measures of treatment effect: We will record outcomes in each comparison group included in systematic reviews, where a meta-analysis has been undertaken. Where a meta-analysis has not been done, we will report the findings as documented by the systematic reviews.

Assessment of reporting biases: The Cochrane and EPOC Guidelines for the assessment of bias and the quality of systematic reviews and overviews will be used [34].

Although ethical approval is not ordinarily required for the conduct of systematic reviews and overviews of systematic reviews, the candidate has submitted an application to the Ethics Review Committee of the Faculty of Medicine and Health Sciences and is awaiting a decision.

5.3 Intervention Study: Participatory Action Research to develop and evaluate an intervention to improve continuity of care for TB patients between TAH and PHC services in the Western Cape

Problem Statement

As most systematic reviews and primary studies on continuity of care are conducted in high income countries, local decision makers raised concerns about applicability in the South African context, and identified numerous barriers to implementation of the interventions [22]. Concerns were also expressed about the integration and sustainability of interventions developed by researchers without the involvement of service providers. Decision makers also wanted

evidence around implementation of strategies, and not only evidence on the effects of interventions, to improve continuity of care.

A participatory action research approach to developing and evaluating an intervention to improve continuity of TB care was therefore adopted to ensure that the research question, solutions and their implementation included decision maker's in all steps of the research process. A formal evaluation will be conducted, using a quasi-experimental design, and will assess both the processes of implementation, and the effects of the intervention.

Research Question

Does improving discharge management of adult TB patients improve continuity of care between the hospital and primary care services? What are the barriers and facilitators to implementation of such an intervention?

Aim: To develop, implement and evaluate an intervention to improve continuity of care for adult TB patients between TAH and PHC services in the Western Cape using a PAR process

Objectives

1. To develop and implement an intervention to improve continuity of care for adult TB patients;
2. To conduct an evaluation of the process of the implementation of the intervention;
3. To conduct an evaluation of the outcomes of the intervention.

Methods

Participatory action research methods will be used to develop and implement an intervention to improve continuity of care for TB patients. By definition PAR is:-

- Participative, in that it engages health professionals and users throughout the research process;
- Democratic, in that it uses techniques of consensus to decide how research should be directed;
- Action focused, because the research question is framed explicitly by the needs of the individuals or communities themselves. The research is problem focused, context specific and future oriented, involves a change intervention, aims at improvement and involvement, and involves a cyclic process (research, action, evaluation)[35].

A series of interviews, workshops and focus group discussions were held to identify the problem and underlying contributory factors, provide feedback from the observational study and overview of continuity of care, and to identify, select and develop appropriate interventions which could be implemented in the local context. A hospital management team currently coordinates the research process, and has involved ward managers, the UIPC, pharmacy, and PHC representatives. The research team provides monthly updates to the hospital management team, who are overseeing the implementation of the intervention.

A formative evaluation will be conducted to assess the process of implementation of the intervention, and a 'before and after' controlled (quasi-experimental) study design will be used to assess the outcome of the intervention[36]. The process evaluations will describe the extent to which activities are performed as planned, and the outcome evaluation will assess the effects of the intervention [37, 38].

Study Sample

Intervention and control wards will be purposively selected in consultation with hospital management. All adult TB patients admitted to the selected wards during the study period, and who meet the inclusion criteria, will be included in the study sample.

Sample size

The estimated sample size of patients required in each group is 95 patients to measure an effect size of 20% improvement in continuity of care with a power of 80% and significance (alpha) level of 0.05. We will increase this to 120 in each group to accommodate for loss to follow up and patient deaths. The total sample size for the study will therefore be 240 patients. Based on previous hospital admission data for TB patients, we should be able to recruit this sample comfortably within one year.

Description of the intervention

The intervention focuses on improving communication between the health professionals in the hospital, the patients and primary care providers. It includes the development of guidelines and tools for discharge planning and management, and the training of staff in the use of these tools. It also includes training of staff in communication and patient education, information flow in the management of TB patients in the hospital, enhanced governance of TB continuity of care in the hospital, and strengthening linkages between the hospital and primary care services in the management of TB patients.

Data Collection and Analysis

Explanatory Variables

Patient Demographics: Sex, age, race, area of residence;

Disease profile: pulmonary or extra-pulmonary TB, HIV status, drug sensitivity, bacteriological diagnosis;

Patient management: ward or department, length of hospital stay, re- admissions for TB, diagnostic tests, drug treatment, notified, discharge letter, mortality.

Process:

% of targeted ward personnel trained;

Changes in knowledge, attitudes and practices (KAP) of trainees;

Effectiveness of health promotions materials (pamphlets, flipcharts);

Completeness and usefulness of ETR.net as a hospital TB database;

Main Outcome:

Successful referrals to PHC and other levels of care

Continued TB treatment at PHC and other levels of care

Secondary Outcomes:

Successful treatment outcomes of patients

Satisfaction of patients

Satisfaction of hospital and PHC personnel

Data will be collected for the process evaluation from the training records, a KAP evaluation of staff, an evaluation of the completion of records and the use of health promotion materials in the wards, and the completeness of the hospital ETR.net.

Patient data obtained from the UIPC infection control staff will be captured in the electronic TB register (ETR.net) adapted for the hospital use. If as part of the process evaluation, the ETR.net is found to be inadequate for the study purposes, we will revert to using an Excel database. The data will be exported to STATA for analysis.

The data will be analysed in the following categories:-

1. Process Evaluation
    a. Description of numbers and % of staff trained from target groups (nurses, interns, clerks) in each ward;
    b. A description of knowledge, attitudes and practices (KAP) of trained staff in relation to the intervention and continuity of care, compared with KAP of staff from control wards.
    c. Number and % of patient referrals sent to community based services (CBS) of total TB patients discharged from intervention wards;
    d. Number of and participation in project meetings with hospital management and PHC staff over the study period;
    e. Completeness of ETR.net database in comparison to other data sources on TB patients in the hospital.
2. Outcome evaluation
    a. Univariate analysis of data to describe patient demographics and disease profile, and % of patients reaching PHC services in control and intervention groups, before and after the intervention;
    b. Bivariate analysis to compare outcomes in intervention and control groups, before and after the intervention;
    c. Multivariate analysis to test associations of outcomes with explanatory variables, and to control for possible confounders.
    d. (if possible, a time series analysis will be done on the data)

Ethical Considerations

Ethical approval for the study has been provided by the Health Ethics review committee of the Faculty of Health Sciences, University of Stellenbosch (Ref: N09/05/149).

5.4 Knowledge Translation: Policy Brief on Continuity of Care for TB patients

Problem Statement

Health policies are influenced by a variety of factors – values and beliefs, stakeholder power, institutional constraints, and available financial resources, among others. Research evidence is essential if health policies are to be well-informed[39], but is not sufficient on its own to inform policy. Policy development needs more than a presentation of the best research evidence; it needs to take account of the context, decision makers and the process of decision making[40]. This policy brief therefore seeks to take account of the best available evidence from research but goes beyond this to interpret the research evidence in relationship to the specific context, in the presence of modifying factors, needs, values, costs and the availability of resources, and to engage with stakeholders to identify and address barriers to implementation of research evidence.

The process of knowledge translation from this study falls into two categories, the 'exchange' category with decision makers who have been partners with the research team which largely includes Tygerberg Hospital, Provincial and local government health service staff in the Western Cape; and secondly the 'push' category where the policy brief will be used by decision makers who will need to be convinced of the need for the policy and interventions. The NDoH and decision makers from other Provinces would be part of the latter group. The brief will have to take the needs of these different audiences into account.

Aim

To develop a policy brief on continuity of care for TB patients to facilitate the transfer of knowledge on strategies for continuity of care to health decision makers and service providers.

Methods

The approach will draw on processes of SUPPORT and the SURE (Supporting the Use of Research Evidence) project[41, 42] as well as IDRC and SANPAD guidelines on the development of policy briefs[43, 44].

This sub study will consist of two main components, firstly the compilation of the policy brief, and secondly a policy dialogue with decision makers on the policy brief.

Compiling the policy brief

The policy brief will draw on the results of the overview of continuity of care for chronic diseases, the observational and experimental studies.

Key steps in the process and the structure of the policy brief will include the following:-

1. Clarifying the problem
2. Deciding on and describing options to address the problem
3. Identifying and addressing barriers to implementing the options
4. Clarifying uncertainties, and needs and priorities for monitoring and evaluation

We will use the 1:3: 25 format for policy briefs recommended by Lavis, which includes a one page of 'take home' messages; a 3 page executive summary; and a 25 page synthesis[41]. The one and three pager provides sufficient

information on the key findings and policy options to inform decision makers. The 25 pages will contain more detailed content, to be used by decision makers or health service staff involved in developing policies and guidelines, or who would like to scrutinise the supporting evidence more thoroughly in making decisions on continuity of care for TB patients.

Engaging with Stakeholders: the Policy Dialogue

A structured discussion in the form of a policy dialogue can contribute to the development a policy brief by helping to clarify the problem and solutions to develop a shared understanding amongst stakeholders, clarify barriers to implementation and strategies to overcome such barriers, and contribute to the development and implementation of effective policies.

Steps in the process will include:-

1. Clarifying the objectives of the policy dialogue
2. Identifying the participants, including stakeholders and experts who can contribute to the dialogue
3. Deciding how the dialogue will be conducted e.g. consensus development approaches will be considered[45]
4. Evaluating the policy dialogue
5. Producing a report for dissemination, and amending the policy brief if required.

The final output of this component of the study will be a user friendly policy brief which is informed by the evidence from the research, and which has engaged decision makers to ensure that it addresses issues and concerns which are relevant to policy and guideline development, and the implementation of strategies to improve continuity of care for TB patients.

6. POTENTIAL LIMITATIONS

6.1 Observational Study

The observational study is dependent on data collected from routine health information systems at TAH and at PHC services. The completeness and quality of information obtained from the main routine information system (Clinicom) may not be reliable. To control for this, the validity of data in the routine system (i.e. Clinicom) will be assessed by comparing a sample (10%) to the original patient records. Similarly a 10% of patient records will be compared to the laboratory and pharmacy data. Where important data is missing, attempts will be made to source the information from original patient records and laboratory information systems at TAH and the NHLS data-warehouse. The same researchers will extract the data, and uniform data collection tools will be used to ensure consistency.

6.2 Overview

The overview is based largely on existing systematic reviews, and findings are therefore dependent on the available published evidence. We anticipate that there will be more systematic reviews and primary studies applicable to high income countries than from middle and low income countries. We will take aspects of 'applicability' to the South African context into account in compiling the overview.

Summarising evidence requires judgements about what evidence to include, the quality of the evidence, how to interpret it and how to report it. The process of compiling the overview will ensure that at least two researchers

review all evidence, and that all decisions are made by at least two researchers. While we will attempt to be transparent about these judgements, the overview inevitably includes judgements made by review authors and judgements made by the researchers involved in the overview.

6.3 Intervention study

The complex intervention is being implemented and evaluated in the real world setting of a very busy hospital and primary care services, using participatory action research methods. The latter approach will ensure external validity of the study as the implementation conditions are typical of conditions in health services elsewhere in South Africa. Internal validity of the evaluation will be weaker as the study design is not a randomized controlled trial, which was not feasible in this hospital setting. However, the use of a quasi-experimental design (before and after with a control arm, and controls for confounding in the analysis) seeks to ensure that the study provides a 'plausibility assessment' i.e. Causality cannot be directly attributed as in a true experimental design, but it is able to suggest an effect above and beyond other external influences[36]. However, given the complex nature of the intervention it will not be possible to attribute the effect to any particular subcomponent of the intervention. The formative (process) evaluations will seek to document the extent to which the intervention was implemented as planned, and which aspects have been successfully implemented. This will assist in identifying the successes and failures in implementation which may have contributed to the outcomes.

7. DISSEMINATION

This study has a strong participatory action research component and engagement with decision makers is a core strategy of all components of the study. From its inception it involves key stakeholders in describing the problem, defining the research questions, and in identifying, implementing and evaluating solutions. As research findings have emerged from the project, these have been shared with decision makers in the Western Cape who have already begun to act on the findings. The research has therefore actively influenced the development of policies, strategies and health systems to improve continuity of care as part of Provincial Department of Health's Strategic Plans.

Further actions to disseminate the research outputs includes:-

1. Presentations at various forums including, academic meetings at the Faculty, Provincial meetings, and national and international conferences. The processes and findings of the studies have already been presented at all these levels, including international meetings (SURE).
2. Reports on the different components of the study will be submitted to key stakeholders including health service decision makers, and funders.
3. At least 4 – 5 peer reviewed publications will be produced as part of the PhD. Proposed publications are:-
    i. What are the effects of hospitalization on TB treatment? An observational study of continuity of care for TB patients between hospital and PHC services in a high TB burden country.
    ii. Do TB information systems support continuity of care for TB patients? A descriptive study of availability and reliability of information for continuity of care between hospital and PHC services.
    iii. An overview of strategies to improve continuity of care for patient's chronic diseases in LMIC's. Cochrane Collaboration, Overview of reviews.
    iv. Participatory Action Research to enhance implementation of an intervention to improve continuity of care for TB patients between hospitals and PHC services? (Description of PAR approach used in this study, and process evaluation results)

v. Does better discharge management and communication by health care providers improve continuity of care for TB patients? An impact evaluation of an intervention to improve continuity of care between hospital and PHC services in South Africa.

vi. A policy brief on continuity of care for TB patients between hospitals and PHC services: a case study of the development of a policy brief.

4. The process of development of the policy brief will involve a large dissemination component, by involving decision makers in the policy dialogue. In addition to this, the policy brief will be actively disseminated electronically through the Evipnet and SURE websites, the Centre for Health Systems and Services Research website at SU, and other mailing such as the monthly HST newsletters.

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Protocol Annexure .2: Budget

Sufficient funding has been secured to cover the full budget for the research. Sources of funding include an MRC grant, SU (Harry Crossley and Sub Committee C grants), DFID and a SANPAD grant.

BUDGET:: CONTINUITY OF CARE FOR TB &CHRONIC DISEASES BUDGET (SA Rand)					
Budget Item	**Overview and Policy Brief**	**Observational study**	**Intervention study (year 1)**	**Intervention study (year 2)**	**TOTAL**
Funded by grants from	**DFID**	**MRC, SU**	**SANPAD**	**SANPAD**	
Personnel					
Researcher	40000		30000	30000	100000
Research Assistant/Postgrad	20000	62000	90000	90000	262000
Field workers		44 000			44000
Subtotal	**60 000**	**106 000**	**120 000**	**120 000**	**406000**
Operational					
Workshops and meetings	7000	4200	20000	27000	58200
Travel: Local	20000	10000	10000	20000	60000
International	45000		30000	15000	90000
Subsistence and accommodation			60000	50000	110000
Stationery, printing & photocopying	7000	12600	10000	72000	101600
Transcription, data processing		12000	14000	14000	40000
Subtotal	**79 000**	**38 800**	**144 000**	**198 000**	**459800**
Equipment and materials					
Computer equipment		6000	40000	7000	53000
Software		2000			2000

Subtotal	**0**	**8 000**	**40 000**	**7 000**	**55000**
Capacity development					
Courses, conferences		20000			20000
TOTAL	**139 000**	**172 800**	**304 000**	**325 000**	**940800**

Annexure 2: Ethics Approval Letters

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jou kennisvennoot · your knowledge partner

Prof L Dudley
Division of Community Health
4th Floor
Teaching Block
Tygerberg
7505

Dear Prof Dudley

"An evaluation of the management of tuberculosis (TB) and TB/HIV co-infection, and referrals from Tygerberg Hospital to primary health care services in the Western Cape."

ETHICS REFERENCE NO: N09/05/149

RE : PROGRESS REPORT

At a meeting of the Health Research Ethics Committee that was held on 17 November 2010, the progress report for the abovementioned project has been approved and the study has been granted an extension for a period of one year from this date.

Please remember to submit progress reports in good time for annual renewal in the standard HREC format.

Approval Date: 17 November 2010 Expiry Date: 17 November 2011

Yours faithfully

MRS MERTRUDE DAVIDS
RESEARCH DEVELOPMENT AND SUPPORT
Tel: 021 938 9207 / E-mail: mertrude@sun.ac.za
Fax: 021 931 3352

22 November 2010 13:17 Page 1 of 1

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

Verbind tot Optimale Gesondheid · Committed to Optimal Health
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UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot · your knowledge partner

05 June 2012

MAILED

Prof L Dudley
Division of Community Health
4th Floor
Teaching Block
Tygerberg
7505

Dear Prof Dudley

"An evaluation of the management of tuberculosis (TB) and TB/HIV co-infection, and referrals from Tygerberg Hospital to primary health care services in the Western Cape."

ETHICS REFERENCE NO: N09/05/149

RE : PROGRESS REPORT

At a review panel meeting of the Health Research Ethics Committee that was held on 5 June 2012, the progress report for the abovementioned project has been approved and the study has been granted an extension for a period of one year from this date.

Please remember to submit progress reports in good time for annual renewal in the standard HREC format.

Approval Date: 5 June 2012

Expiry Date: 5 June 2013

Yours faithfully

MRS MERTRUDE DAVIDS
RESEARCH DEVELOPMENT AND SUPPORT
Tel: 021 938 9207 / E-mail: mertrude@sun.ac.za
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Ethics Letter

17-Sep-2014

Ethics Reference #: N09/05/149
Clinical Trial Reference #:
Title: An evaluation of the management of tuberculosis (TB) and TB/HIV co-infection, and referrals from Tygerberg Hospital to primary health care services in the Western Cape.

Dear Professor Lilian Dudley,

At a meeting of the Health Research Ethics Committee that was held on 17 September 2014, the progress report for the abovementioned project has been approved and the study has been granted an extension for a period of one year from this date.

Please remember to submit progress reports in good time for annual renewal in the standard HREC format.

Approval Date: 17 September 2014 Expiry Date: 17 September 2015

If you have any queries or need further assistance, please contact the HREC Office 0219389207.

Sincerely,

REC Coordinator
pp. Mertrude Davids
Health Research Ethics Committee 2

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approved with Stipulations New Application

10/10/2017

Project Reference #: 0516

Title: An evaluation of an intervention to improve continuity of care for TB patients

Dear Prof Lilian Dudley

The **New Application/response to modifications** received on 29/08/2017 14:15 , was reviewed by members of the **Health Research** via Minimal Risk Review procedures on 10/10/2017 .

Please note the following information about your approved research protocol:

Protocol Approval Period: This project is approved for a period of 12 months from the date of this letter.

The Stipulations of your ethics approval are as follows:

At least 4 versions of the project title appear in this application. Kindly clarify which is the correct one.

Please remember to use your **protocol number** [0516] on any documents or correspondence with the HREC concerning your research protocol.

Please note that this decision will be ratified at the next HREC full committee meeting. HREC reserves the right to suspend approval and to request changes or clarifications from applicants. The coordinator will notify the applicant (and if applicable, the supervisor) of the changes or suspension within 1 day of receiving the notice of suspension from HREC. HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note you can submit your progress report through the online ethics application process, available at: https://apply.ethics.sun.ac.za and the application should be submitted to the Committee before the year has expired. Please see Forms and Instructions on our HREC website for guidance on how to submit a progress report.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website (www.sun.ac.za/healthresearchethics)

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely

Federal Wide Assurance Number: 00001372 Institutional Review Board (IRB) Number: IRB0005239
The Health Research Ethics Committee complies with the SA National Health Act No. 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki and the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles, Structures and Processes 2015 (Departement of Health).

Annexure 3: Turnitin Report

The sources below for student paper (14%) were my PhD research protocol; and the publications (10%) were links to the two publications on the observational study and qualitative study.

Continuity of Care for TB patients

ORIGINALITY REPORT

25%	12%	7%	18%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	Submitted to University of Stellenbosch, South Africa Student Paper	14%
2	journals.plos.org Internet Source	10%
3	effectivehealthcare.ahrq.gov Internet Source	1%

Exclude quotes	On	Exclude bibliography	On
Exclude matches	< 1%		

Annexure 4: Overview additional tables

Annexure 4.1: Quality Assessment of Included Systematic Reviews

Article	A1.Criteria for selecting studies to include reported	A2.Was the search for evidence reasonably comprehensive?	A3.Is the review reasonably up-to-date?	A4.Was bias in the selection of articles avoided?	A5.Did the authors use appropriate criteria to assess the risk for bias in analysing the included studies	A6.Overall rating of the methods used to identify, include and critically appraise studies	B.1 Were the characteristics and results of the included studies reliably reported?	B.2 Were the methods used by the review authors to analyse the findings of the included studies reported?	B.3 Did the review describe the extent of heterogeneity?	B.4 Were the findings of the relevant studies combined (or not combined) appropriately?	B.5 Did the review examine the extent to which specific factors might explain differences in the results of included studies?	B.6 Overall rating of the methods used to analyse the findings relative to the primary question addressed in the review	Overall rating of the review	Comments on quality assessment
Allen 2014	Yes	Partially	Yes, most recent search was in 2013	Yes	Yes	Reliable (only minor limitations)	Partially	Partially	Partially	Partially	No	Important limitations	This review has important limitations.	The methods of analysis was not adequately described. In particular, the authors stated that there was heterogeneity – but did not elaborate on this and how it may have contributed to results. No meta-analysis was done.
Aubin 2012	Yes	Yes	Yes, most recent search was in 2009	Partially	Yes	Reliable	Yes	Yes	Yes	Yes	Yes	Reliable (only minor limitations)	This is a good quality review with only minor limitations.	Heterogeneity between studies in design, intervention, participants, settings and outcomes

Foy 2010	Partially	Partially	No, most recent search was in 2008	Partially	Yes	Important Limitations	Yes	Yes	Yes	Yes	Yes	Reliable (only minor limitations)	This review has important limitations.	Initially assessed as a good quality review in 2010. However, in 2018 the most recent search was 10 years earlier and it was downgraded to having important limitations
Goncalves 2016	Yes	Yes	Yes, most recent search in 2015	Yes	Yes	Reliable	Yes	Yes	Yes	Yes	Yes	Reliable (only minor limitations)	This is a good quality review with only minor limitations.	Included RCT's. Comprehensive quality assessment of included studies conducted. Subgroup analysis performed.
Gysels 2006	Partially	Partially	No, most recent search in 2004	Partially	Yes	Important limitations	Yes	Partially	No	No	Partially	Important limitations	This review has important limitations.	Types of studies to include in the review were not pre-specified and no detailed search strategy reported. How studies were selected for inclusion was not reported, methods of analysis inadequately described, and narrative reporting of results.
Handford 2017	Yes	Partially	Yes, most recent search in 2011	Partially	Yes	Important limitations	Yes	No	Partially	No	Partially	Important limitations	This review has important limitations.	The search had limitations, no description of heterogeneity was provided to justify not doing a meta-analysis. Narrative reporting of individual study results only.
Hansen 2011	Yes	Partially	Yes, most recent search in 2011	Partially	Partially	Important limitations	Partially	Partially	No	No	No	Important limitations	This review has important limitations.	Limitations were related to the methods of analysis and reporting of results

Lambrinou 2012	Yes	Partially	Yes, most recent search was in 2009	Partially	Partially	Important limitations	Partially	Yes	Yes	Yes	Yes	Reliable (only minor limitations)	This is a good quality review with only minor limitations.	
Mistiaen 2008	Yes	Partially	No, most recent search was in 2003	Yes	Can't tell	Important limitations	Partially	Yes	Yes	No	Yes	Important limitations	This review has important limitations.	In addition to limitations in methods to identify, include and appraise and analyse studies, by 2018 the most recent search was 15 years old.
Mitchell 2015	Yes	Partially	Yes, most recent search in 2012	Partially	Yes	Important limitations	Yes	Partially	Partially	No	Partially	Important limitations	This review has important limitations.	Limitations were based on the inadequate description of and quality of the analysis. Authors indicated that the studies were heterogeneous, no description of this was provided nor any attempt to do a meta-analysis of subgroups of the studies despite several trials with the similar interventions and outcomes. A narrative reporting of results was provided.
Rotter 2010	Yes	Yes	Yes, most recent search was in 2009	Yes	Yes	Reliable (only minor limitations)	Yes	Yes	Yes	Yes	Yes	Reliable (only minor limitations)	This is a good quality review with only minor limitations.	

Smith 2017	Yes	Yes	Yes, most recent search was in 2015	Yes	Yes	Reliable	Yes	Yes	Yes	Yes	Yes	Reliable (only minor limitations)	This is a good quality review with only minor limitations.	
Takeda 2019	Yes	Yes	Yes, most recent search was in 2018	Yes	Yes	Reliable (only minor limitations)	Yes	Yes	Yes	Yes	Yes	Reliable (only minor limitations)	This is a good quality review with only minor limitations.	Included only RCT's. Comprehensive quality assessment of included studies conducted; subgroup analysis; meta-analysis of data as appropriate.

Annexure 4.2: Excluded Studies

Article	Reason for Exclusion	Assessment date
Allen D 2008	Not continuity of care between levels.	2018
Arditi C 2017	Not continuity of care between levels.	2018
Aslakson R 2013	Not continuity of care between levels.	2018
Balas 2004	Not continuity of care between levels.	2010
Bennet 2003	Not continuity of care between levels.	2010
Black A 2011	Not chronic diseases nor continuity of care study.	2018
Bosch M 2009	Not chronic diseases nor continuity of care study.	2018
Bower 2006	Primary Care and not continuity of care between levels. Based on primary studies of Gilbody 2003 which was published more than 15 years ago.	2010, 2018
Brennan A 2014	Excluded after AMSTAR quality assessment.	2018
Brown-James PR 2017	Not continuity of care between levels.	2018
Cabana MD, 2004	Not chronic diseases nor continuity of care study nor systematic review.	2010
Carriere BK 2009	Not chronic diseases nor continuity of care study.	2018
Cedric Mabir 2013	Not chronic diseases nor continuity of care study.	2018
Chaudry B, 2006	Not chronic diseases nor continuity of care study.	2018
Chen HM 2014	Not in English.	2018
Coleman 2009	Not continuity of care between levels. Not a systematic review.	2010
Craven 2006	Not a systematic review.	2010
Dieterich M 2010	Not continuity of care between levels.	2018
Dorr 2007	Excluded after AMSTAR quality assessment.	2018
Dy SM 2013	Not continuity of care between levels.	2018
Eastwood 1996	Not continuity of care between levels. Review is out of date.	2010
Fernandez 2007	Not chronic diseases nor continuity of care study.	2010, 2018
Finkelstein J 2013	Not specifically on chronic diseases or continuity of care.	2018
Fox MT 2013	Not chronic diseases nor continuity of care study	2018
Garg AX 2005	Not chronic diseases nor continuity of care study.	2018
Gilbody 2003	Focus on Primary Care and not continuity of care between levels.	2010, 2018
Gillies D 2015	Not continuity of care between levels.	2018
Glynn 2010	Not continuity of care between levels.	2010
Greenhalgh PM, 1994	Not a systematic review. Discussion paper.	2010
Griffin 1998	Not chronic diseases. Review is out of date.	2010
Grimshaw 2004	Not chronic diseases nor continuity of care study.	2010
Gruen 2009	Study is dated, published more than 15 years ago. A more updated better quality review by Smith 2017 includes most primary studies previously included.	2010, 2018
Guldberg 2009	Not continuity of care between levels.	2010
Hardwick R 2012	Not a systematic review. Realist review protocol.	2018
Harris M 2005	Not continuity of care between levels.	2018
Health Quality Ontario 2013	Not chronic diseases nor continuity of care study.	2018
HEN 2003	Not continuity of care between levels.	2010
Hesse 2007	Not chronic diseases nor continuity of care study.	2014
Hisashige A 2013	Excluded after AMSTAR and Overview quality assessment.	2018
Houben CH 2014	Not continuity of care between levels.	2018

Huntley AL 2013	All elderly, not specifically chronic diseases. Not continuity of care between levels.	2018
Jamal J 2009	Not chronic diseases nor continuity of care study.	2018
Kauppi K 2014	Not continuity of care across levels. Outpatient care, compliance with meds.	2018
Kawamoto K 2005	Not chronic diseases nor continuity of care study.	2018
Kelly BJ, 2011	Rapid review, not a systematic review.	2014
Kripalani 2007	Not a systematic review.	2010
Lau F 2010	Not chronic diseases nor continuity of care study.	2014
Lei X 2015	Not continuity of care between levels.	2018
Lemmens 2009	Included in Martinez 2014 and Damery 2016.	2018
Lim WK, 2003	Not continuity of care between levels nor a systematic review.	2010
Lion KC 2014	Not continuity of care between levels.	2018
Luckett T 2014	Not continuity of care between levels.	2018
Mabir C 2013	Protocol. Not chronic diseases.	2018
Martin 2008	Not chronic diseases nor continuity of care study.	2010
McAlister 2001	Included in Owens 2005 and Martinez 2014.	2010
McDonald KM, 2007	Not chronic diseases nor continuity of care study.	2010
McGibbon KA 2011	Not continuity of care across services or levels of care.	2018
M'Imunya JM 2012	Not continuity of care between levels.	2018
Mitchell 2002	Included in Martinez 2014. Study is also dated, published more than 15 years ago. A more updated review by Mitchell in 2015, and a better quality review by Smith 2017 includes most primary studies previously included in Mitchell 2002.	2010, 2018
Mitchell 2008	Included in Martinez 2014.	2018
Moeinedin 2009	Not continuity of care between levels.	2010
Montgomery 1998	Study is dated, published more than 15 years ago.	2010, 2018
Neumann I, 2012	Protocol	2018
Neumeyer-Gromen 2004	Same review as Weingarten.	2010
Niesink 2007	Not continuity of care between levels.	2010
Nolte 2008	Not a systematic review.	2010
Norris 2002	Not continuity of care between levels.	2010
Nurjannah I, 2014	Not a systematic review.	2018
Ofman 2004	Same study published as Weingarten, and included in Martinez 2014.	2010
Ouwens 2005	Included and updated in Martinez 2014.	2018
Ouwens 2009	Included in Martinez 2014.	2018
Parischa A 2011	Not continuity of care between levels.	2018
Peikes 2009	Not chronic diseases nor continuity of care study nor systematic review.	2010
Peytremann-Bridevaux's 2008	Included in Martinez 2014 and Damery 2016.	2018
Phillips CO 2004	Part of Mistaen 2007 and Martinez 2014.	2010
Ponniah 2007	Excluded after AMSTAR quality assessment.	2018
Preyde M, 2009	Not chronic diseases specifically. Not systematic review.	2010
Qureshi N 2002	Not chronic diseases nor continuity of care study.	2010
Renders 2000	Not continuity of care between levels.	2010
Renders 2002	Part of Ouwens 2005.	2010
Renholm 2002	Not a systematic review.	2010
Robinson L 2012	Not continuity of care between levels.	2018

Roccaforte R, 2005	Included in Martinez 2014 and Damery 2016.	2018
Shojani KJ 2009	Not continuity of care between levels.	2018
Singh 2005	Not continuity of care between levels.	2010
Smith 2009	Not chronic diseases nor continuity of care study.	2010
Smith L, 2007	Not continuity of care between levels.	2010
Steffen 2009	Excluded after AMSTAR quality assessment.	2018
Sutherland D, 2009	Not continuity of care between levels.	2018
Suwankeerre 2014	Not continuity of care between levels.	2018
Tsai 2005	Not a systematic review. Not continuity of care between levels.	2010
van Herck 2004	Not a systematic review.	2010
Van Servellen 2006	Not a systematic review.	2010
van Walraven C, 2010	Not chronic diseases.	2018
Walling A, 2008	Not continuity of care between levels.	2010
Warsi 2004	Not continuity of care between levels.	2010
Weingarten 2002	Part of Ouwens 2005, and Martinez 2014.	2010
Williams 2008	Not continuity of care between levels.	2010
Woltmann E 2012	Not continuity of care between levels.	2018
Wong WC 2012	Not continuity of care between levels.	2018
Yu DS 2006	Excluded after AMSTAR quality assessment.	2018

Annexure 5: Process evaluation additional information.

Annexure 5.1 Document list

Documents for content analysis: Implementation of intervention May 2012 - Dec 2013						
		Project	**Hospital**	**Provincial**	**National**	**International**
1	**Policies**		Containment of PTB Transmission at TAH.Final Draft Jan 2009	2009 ID POC TB for different levels of care	National Core Standards, 2011	
				H 18 0f 2013: Care pathways for TB patients	NSP TB 2007-2011	
				H 22 of 2013: SOP TB dx and Rx	NSP TB & HIV 2012-2015	WHO End TB strategy, 2014
				H 30 of 2012 Service Coordination Structures		
2	**Guidelines**	Programme Theory 09 March 2013		Service Quality Improvement 2012	National TB, HIV & AIDS Clinical Guidelines, 2000	HDL 2009
		TB TGH Map 20 April 2011			National TB Mx 2009	WHO Roadmap for TB research, 2011
		Draft Project Plan March 2012			National TB Mx 2014	
		Project flow diagram				
3	**Reports**	Description of intervention				SANPAD 4 July 2014
		Training evaluations				
		Health promotion tools evaluation				
4	**Workshops**			30-Sep-10		Report on Hospital DOTS Linkage Workshop, Yogyakarta, Indonesia, 25-29 January 2010
				29-Aug-14		.
				01-Sep-15		
6	**Presentations**			Workshop 30 Sept 2010		
			TAH 21 Aug 2012	Bexco 30 May 2012		
			Oct 2013 UIPC Day	Dexco 5 June 2012		
7	**Proposals**			Evaluation of referral and discharge practises, 2012		SANPAD 2010

8	**Meeting minutes**	10 research project meeting minutes between 2013 &2014	TEXCO 24/01/2012 + powerpoint			
			Managers: 17 April 2012			
			Unit Managers meeting 25/01/2013			
			22 TB CoC coordinating meetings minutes between June 2011 and June 2015			

Annexure 5.2: Key informant Interview Guide

Please describe your role and involvement with the intervention to improve continuity of TB care which was implemented at Tygerberg Hospital in 2013.

Post/position …….

Role ……..

Question 1. What in your view was the main purpose of the intervention?

Question 2. Can you describe the components of the intervention? Who was targeted by these components?

Question 3: In your view, how well was the intervention implemented at Tygerberg Hospital? And within the primary health care services?

Question 4. In your view, what factors assisted the implementation of the intervention? In particular, how did the following (CFIR domains) affect implementation:-

- Characteristics of the intervention;
- Inner setting (organisational context);
- Outer Setting (external context);
- Characteristics and roles of individuals
- Process of implementation
- Implementation Outcomes

Question 5. What factors made it difficult to implement the intervention? Probe around 6 domains.

Question 6. What advice would you give another institution or team that wanted to implement a similar intervention to improve continuity of care for TB patients discharged from hospital?

Thank you for your participation.

Annexure 5.3: Participant Informational leaflet and consent form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: An evaluation of an intervention to improve continuity of care for TB patients discharged from hospital to primary health care services

REFERENCE NUMBER: 0516

PRINCIPAL INVESTIGATOR: Assoc Prof Lilian Dudley

ADDRESS: Division of Health Systems and Public Health, Faculty of Medicine and Health Sciences, Stellenbosch University, Fransie Van Zyl Drive, Tygerberg.

CONTACT NUMBER: 083 469 5243

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University (reference number 0516) and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- *This study is part of an evaluation of an intervention to improve continuity of care for TB patients discharged from Tygerberg Hospital in 2013 and 2014.*
- *Interviews are being conducted with health service staff at Tygerberg Hospital and primary health care services to improve our understanding of how the intervention was implemented*
- *We will interview hospital managers, clinical and administrative staff, and primary health care managers and staff who were involved in implementing the intervention to get their perspectives on how the intervention was implemented and what components did or did not work*
- *The results will assist in understanding how the intervention worked, so that it can be replicated in other settings*
- *You will be interviewed individually by a researcher.*
- *The interview will take between 30 and 60 minutes, and will be recorded in writing and with a tape-recorder.*
- *The interview will be anonymous i.e. your name will not be linked to the information provided in the interview*

Why have you been invited to participate?

- *You were identified as a health professional who assisted with the implementation of the intervention to improve continuity of TB care between Tygerberg Hospital and primary health care services in the Western Cape.*

What will your responsibilities be?

- *You will be asked to answer a few questions about your experience of the implementation of the intervention to improve continuity of care for TB patients*

Will you benefit from taking part in this research?

- You will not benefit directly from this study. However, the results will help to inform further expansion of interventions to improve continuity of TB care

Are there in risks involved in your taking part in this research?

- There are no risks to you in taking part in this research

If you do not agree to take part, what alternatives do you have?

- *You are under no obligation to participate in the interview and can decline to do so or withdraw at any time during the process*

Who will have access to the research records?

- *The researchers will be the only persons with access to the research data. Once the interviews are analysed the results will be shared in reports and publications. These reports and publications will not include any personal identification details of participants who were interviewed.*

What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

- *The interview will not result in any risk of harm to you.*

Will you be paid to take part in this study and are there any costs involved?

- *No you will not be paid to take part in the study but refreshments will be provided during the interview. There will be no costs involved for you, if you do take part.*

Is there anything else that you should know or do?

- You can contact Dr Lilian Dudley at tel 083 469 5243 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I …….. agree to take part in a research study entitled *(insert title of study)*.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ……. on (*date*) …….. 2005.

…… ……

Signature of participant Signature of witness

Declaration by investigator

I *(name)* …… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ..... on (*date*) ..... 2005.

....

Signature of investigator Signature of witness

Declaration by interpreter

I *(name)* ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....

....

Signature of interpreter Sign

Annexure 6: Qualitative study of continuity of care for TB patients discharged from hospital in Cape Town, South Africa.

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0222421

PLOS ONE

RESEARCH ARTICLE

Continuity of care for TB patients at a South African hospital: A qualitative participatory study of the experiences of hospital staff

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Data Availability Statement: The full transcripts of the focus group discussions contain potentially identifying information and cannot be made publicly available. The transcripts are available upon request to Mr Samuel Simango, Manager of Research Data Services, Library and Information Services, Stellenbosch University at ssimango@sun.ac.za.

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Abstract

Background

Ensuring effective clinical management and continuity of TB care across hospital and primary health-care services remains challenging in South Africa. The high burden of TB, coupled with numerous health system problems, influence the TB care delivered by hospital staff.

Objective

To understand factors from the perspectives of hospital staff that influence the clinical management and discharge of TB patients, and to elicit recommendations to improve continuity of care for TB patients.

Design

Participatory action research was used to engage hospital staff working with TB patients admitted to a central public hospital in the Western Cape province, South Africa. Data were collected through eight focus group discussions with nurses, junior doctors and ward administrators. Data analysis was done using Miles and Huberman's framework to identify emerging patterns and to develop categories with themes and sub-themes. The participants influenced all phases of the research process to inform better practices in TB clinical management and discharge planning at the hospital.

Results

The emerging themes and sub-themes were categorized into two overall sections: The clinical care management process and the discharge and referral process. Nurses expressed a fear of exposure to TB and MDR-TB due to challenges in clinical and infection-prevention control. Clinical hierarchies, poor interdisciplinary teamwork, limited task shifting and poor communication interfered with effective clinical and discharge processes. A high workload,