UNIVERSITY OF CAPE COAST

MANAGEMENT AND CONTROL OF CHILDHOOD TUBERCULOSIS IN SOUTHERN GHANA

PRINCE JUSTIN ANKU

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BY

PRINCE JUSTIN ANKU

Thesis submitted to the Department of Population and Health of the Faculty of Social Sciences, University of Cape Coast, in partial fulfilment of the requirements for the award of Doctor of Philosophy degree in Population and Health

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DECLARATION

Candidate's Declaration

I hereby declare that this thesis is the result of my own original research and that no part of it has been presented for another degree in this university or elsewhere.

Candidate's Signature: ..... Date: .....

Name: Prince Justin Anku

Supervisors' Declaration

We hereby declare that the preparation and presentation of the thesis were supervised in accordance with the guidelines on supervision of thesis laid down by the University of Cape Coast.

Principal Supervisor's Signature: ..... Date: .....

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ABSTRACT

The WHO has called for commensurate attention to childhood TB. However, there is limited research evidence to inform context-specific policies and implementation. Therefore, this study explores the management and control of childhood TB in Ghana. Data were obtained from 31 health providers and 35 primary caregivers for TB-infected children from 15 health facilities in five regions in Ghana. Using the Normalisation Process Model and Salutogenic theory as frameworks, qualitative analyses were done using QSR Nvivo 12 plus. The study found that childhood TB management and control practices in the selected health facilities were largely consistent with recommended practices, though several challenges such as the absence of paediatricians to conduct sputum induction procedures such as gastric lavage exist. Treatment interruption after the intensive phase and contact tracing difficulties were also pronounced. Service providers and primary caregivers are favourably disposed to the idea of partial integration of childhood TB management into child welfare clinics. To improve the management and control of childhood TB, service providers recommended among other things; getting childhood TB firmly on the public health agenda, improving childhood TB active case finding (ACF), and addressing loss to follow-up. Childhood TB exerts considerable negative psychosocial impacts on primary caregivers, TB-infected children, and their households at large. The theoretical frameworks provided a broader understanding of the contextual issues. The National TB Control Programme and the GHS should consider partial integration of childhood TB services into child welfare clinics and provide psychosocial support to primary caregivers.

KEY WORDS

Childhood

Tuberculosis (TB)

Integration

Management

Salutogenic Theory (ST)

Normalisation Process Model (NPM)

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DEDICATION

In memory of my sisters; Vera Jacinta Anku and Constancia Linda Anku

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ACF	Active Case Finding
BCG	Bacillus Calmette-Guerin
BLT	Behavioural learning theories
CHNs	Community Health Nurses
CI	Contextual Integration
COREQ	Consolidated Criteria for Reporting Qualitative Research
CWC	Child Welfare Clinic
CXR	Chest X-Ray
DETECT	Digital Engagement & Tracking for Early Control, & Treatment
DOTS	Directly Observed Treatment, Short-course
EBSCO	Elton Bryson Stephens, Sr. Company
EPI	Expanded Programme on Immunisation
GHS	Ghana Health Service
GRR	Generalised Resistance Resources
HBM	Health Belief Model
ICF	Intensified Case Finding
IDI	In-depth interviews
IPT	Isoniazid Preventive Therapy
IW	Interactional Workability
LMIC	Low- and middle-income countries
LTBI	latent TB infection
MDR-TB	Multi-Drug Resistance TB

MEDLINE	Medical Literature Analysis and Retrieval System Online
MEMS	Medication Event Monitoring Systems
MGIT	mycobacteria growth indicator tube (MGIT)
MNCH	Maternal, Neonatal, and Child Health
MODS	Microscopic Observation Drug Susceptibility
MOH	Ministry of Health
NACP	National AIDS Control Programme
NPM	Normalisation Process Model
NPT	Normalisation Process Theory
NTP	National Tuberculosis Control Programme
PCG	Primary caregiver
PMT	Protection Motivation Theory
PTB	Pulmonary TB
RI	Relational Integration
SCT	Social Cognitive Theory
SEM	Social Ecological Model
SEP	Social Ecological Perspective
SGDs	Sustainable Development Goals
SOC	Sense of Coherence
SP	Service Providers
SRS	Specimen Referral System (SRS)
SSW	Skill Set Workability
ST	Salutogenic Theory
TB	Tuberculosis

TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
TST	Tuberculin Skin Test
UN	United Nations
WHA	World Health Assembly
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

Background to the Study

At the end of 2019, it was estimated that there were 10.0 million new TB cases globally. Of that, 56 per cent of the recorded cases were among men, 32 per cent among women and 12 per cent among children (WHO, 2020). Childhood TB usually refers to TB among children aged <15 years or the age range 0-14 years (The Union, 2016; WHO, 2014; WHO, 2016). For clinical, policy and research purposes, childhood TB has mainly been categorized into age groups (0 – 4 years; 5 – 9 years; 10 – 14 years) (Aw et al., 2017; The Union, 2016). Children, especially those within the 0 – 4 age group (often referred to as children under 5), are regarded as the most vulnerable to TB since they usually develop more severe forms of the disease (The Union, 2016; WHO, 2014).

In 2015, an estimated 210 000 childhood mortality due to TB was recorded in Africa. WHO estimates that about 100 000 childhood TB deaths occur in Africa each year, with one-third of those co-infected with HIV (WHO, 2016). This makes TB one of the deadliest infectious diseases among children, with increased mortality risk among those co-infected with HIV even when TB treatment has been initiated (Jenkins et al., 2017). Evidence point to a synergistic relationship between childhood HIV infection and increased risk of

developing TB (Anígilájé, Aderibigbe, Adeoti, & Nweke, 2016; Dodd, Prendergast, Beecroft, Kampmann, & Seddon, 2017; Walters et al., 2014).

Childhood TB can mimic several known childhood diseases/conditions, including pneumonia, malnutrition, general infections (both viral and bacterial), and HIV infection (Swaminathan & Rekha, 2010; Tsai et al., 2013). Consequently, many children with TB continued to be missed by the healthcare system and many of them die without ever being diagnosed (Jenkins et al., 2017; WHO, 2020). The management and control of childhood TB present several challenges to services providers, especially in resource-limited settings where there are limited capacities to identify and diagnose children (Oliwa et al., 2020).

Management of childhood TB involves screening for TB, case-notification (diagnosis), adherence counselling, initiation of the appropriate treatment regimen, and follow-up (monitoring and record-keeping) to ensure successful treatment completion for children < 15 years (The Union, 2016). As part of efforts to address the persistent challenge of missed childhood TB cases and consequent mortality, including mortality due to TB-HIV co-infection, the WHO has acknowledged the need for the implementation of integrated, family and community-centred strategies where childhood TB services are integrated into other programmes and services, including maternal, neonatal and child health (MNCH), HIV, nutrition, immunization, and child welfare clinics (CWC) (WHO, 2018). However, this recommendation is yet to fully take off in many resource-limited settings in Africa, including Ghana.

Control of childhood TB fundamentally involves "identifying the source of infection (individuals with pulmonary TB), usually through community-wide active case-finding and putting them through therapy so that they are no longer infectious." In resource-limited settings, the focus of the search is on the household or the family unit (Fox, Dodd, & Marais, 2019). This is because childhood TB usually is an indication of current transmission from an infectious adult or adolescent and is largely regarded as a sentinel event from a public health perspective (Kalu et al., 2015).

Historically, childhood TB has not received much attention from clinicians, researchers/academics, advocacy groups and policymakers (Hummel, Ahamed, & Amanullah, 2020; Starke & Cruz, 2014). This is, to a large extent, a result of childhood TB being considered paucibacillary and understood to be non-infectious from a public health standpoint. The risk to the community is also considered very minimal. In addition, there have been misplaced convictions (unconditional trust) in the BCG vaccines, even though it has proven to be effective in some settings, but less effective in others (Marais & Schaaf, 2010; Nguipdop-Djomo, Heldal, Rodrigues, Abubakar, & Mangtani, 2016). However, with the realisation of the enormous contribution of paediatric TB to the burden of the epidemic, especially in high-burden countries, there is a growing consensus for commensurate attention (Marais & Schaaf, 2010; Dodd, Gardiner, Coghlan, & Seddon, 2014). The call for commensurate attention is even critical in light of the commitments of the international

community to the "End TB Strategy" and the Sustainable Development Goals (SDGs) (Hummel, Ahamed, & Amanullah, 2020).

The WHO for the first time in 2012 provided an estimate of the burden of childhood TB in its yearly global TB report, thereby highlighting a shift in focus concerning some neglected aspects of the fight against the TB epidemic (WHO, 2012). Since then, there has been a growing interest in issues relating to childhood TB. This interest in TB among children stems from the fact that childhood TB without prior HIV infection is a sentinel event which suggests current transmission from an infected adult in the community or family unit. Childhood TB is a neglected public health concern that has resulted in high morbidity and mortality for children, especially in resource-limited countries of Africa and Asia (WHO, 2017). Therefore, increasing efforts to address the gaps in TB control requires that children with TB are given special attention since it has been one of the neglected areas in the past (WHO, 2017).

In Ghana, the management and control of childhood TB (and TB in general) are under the auspices of the National Tuberculosis Control Programme (NTP) which was established in 1994 (NTP, 2019). The NTP in collaboration with its partners developed comprehensive guidelines for the management and control of childhood TB in Ghana (GHS & Stop TB partnership, 2012). It is possible to diagnose a child with TB in outpatient settings based on careful clinical assessment, as well as relying on comprehensive NTP guidelines. History of contact with TB is an important part of the assessment for childhood TB diagnosis and prevention/control. In

addition, obtaining a BCG vaccination history from the primary caregiver (PCG) of the child is recommended by Ghana's NTP (see, GHS & Stop TB partnership, 2012). For children under 5, the guideline recommends that service providers should carefully examine the Child Health Records for evidence of poor growth.

A child suspected of TB or diagnosed with TB should also be tested for HIV after the PCG has been counselled and the test result should be deliberated. Largely, children with TB respond well to the treatment regimen and the existing anti-TB medicines are well-tolerated. Children (less than 15 years) should be routinely registered with the NTP as per national guidelines (WHO, 2014). As part of the control strategy for childhood TB in Ghana, the NTP recommends that any child contact with symptoms should be screened for the disease. If the source case is the child's parent and confirmed as HIV-positive, all the children should be tested for HIV. Screening can be undertaken at the primary health care level since the screening of child contacts can be based on symptoms alone (see, GHS & Stop TB partnership, 2012).

Management and control of childhood TB, especially in resource-limited settings can be very challenging due to the peculiarities of the disease in children (Reuter, Hughes, & Furin, 2019). In many resource-limited settings, there exist limited capacities to identify, diagnose, manage, and control childhood TB, especially at the lower level of the healthcare system (Trajman & Schwartzman, 2020).

Aetiology and Complexities regarding Mycobacterium TB in children

TB is an airborne infectious disease that is caused by *Mycobacterium tuberculosis*, largely preventable and can be cured by adhering to the recommended treatment regimen (Tesfahuneygn, Medhin, & Legesse, 2015). Children are highly vulnerable to TB infection but often neglected due to various reasons such as difficulties in diagnosis and the disease not being considered a public health threat due to its paucibacillary nature (Tsai et al., 2013). Younger children, especially those below age five (age < 5) often interact with adults and other members of the family and are therefore generally exposed to infections from their family units.

The age of a child and household characteristics (composition, physical structure, and sleeping arrangements) largely influence the risk of exposure to TB among children (Mandal, Anand, Gautam, Das, & Tahziba, 2017). The infection is often initiated by the inhalation of the TB bacilli coughed out by a sputum-positive adult with pulmonary TB. For transmission to occur, the units ought to be sufficiently fresh to transfer a viable causative agent (Decker, 2007; Nardell, 2015). It is, however, important to note that TB is not spread by fomites, such as plates, cups, linen, and other substances used by an infected patient (Amo-Adjei & Kumi-Kyereme, 2013).

Generally, children with TB are considered not to carry a high risk of transmitting the disease, even though TB infection among children (especially without prior HIV infection) is considered a sentinel event for ongoing transmission (Kalu et al., 2015). The clinical manifestation of TB among

children varies from that of adults. Among children, signs and symptoms are mainly not specific and could either be minor or life-threatening. Childhood pulmonary TB is characteristically manifested by the formation of a primary complex in the lungs. In most cases, bacteriological confirmation is difficult to obtain through laboratory examination (Carvalho, Cardoso, Martire, Migliori, & Sant'Anna, 2018). The ability of the bacilli to cause infection is influenced by the age of the child, the veracity of the host's immune system, and the virulence of the causative agent. As such, childhood TB is influenced by a multiplicity of factors and it is not always easy to differentiate disease from infection (Tsai et al., 2013; Carvalho, Cardoso et al, 2018).

Diagnosing childhood TB continues to pose a major challenge to the fight against the epidemic among children. International guidelines emphasized clinical, radiological, and epidemiological presentations as the best evidence of active TB in children. As a result, the method of TB diagnosing among children is informed by the following broad criteria – extensive clinical history taking (including a history of contact with an adult TB-infected person, and symptoms indicative of TB); a detailed clinical investigation with a specific focus on features of growth during childhood; the tuberculin skin test (TST) result, chest X-ray results (when available); bacteriological confirmation if possible; specific examination of the organ involved in a suspected case of pulmonary and extra-pulmonary TB; and testing for HIV. In addition, the WHO consensus statement emphasizes the importance of pursuing bacteriological or molecular

confirmation of *M. tuberculosis* and resistance to rifampicin (Xpert MTB/RIF) and discourages the practice of the supposed "therapeutic test" (WHO, 2014).

However, in most resource-limited settings, the use of Xpert MTB/RIF in diagnosing is restricted to only major healthcare facilities. Thus, the absence of sensitive and child-friendly means of diagnosis presents a major challenge to the control of childhood TB. Other key challenges to childhood TB control include – systematic screening for TB and Isoniazid Preventive Therapy (IPT) for children under 5 years and children living with HIV are hardly implemented or reported; poor community engagement and knowledge; the emergence of MDR-TB with no child formulation of second-line TB medications; poor adherence to the treatment regimen (leading to the development of resistance); and the dwindling protection from Bacillus Calmette-Guerin (BCG), especially when children come into contact with an infected adult (WHO, 2016). To achieve the rather ambitious goal of ending TB by 2035, these challenges, as well as many others, need to be addressed.

Statement of the Problem

Children are disproportionately disposed to the harms resulting from TB (e.g., affects personal growth, development, education, and social relations) and are more likely than adults to develop extra-pulmonary and life-threatening forms of the disease (Hummel, Ahamed, & Amanullah, 2020). Also, children are more susceptible to broader, non-medical effects of TB (Basu Roy et al., 2016). As such, prevention and early detection of childhood TB are needed to ensure that

children do not suffer a great deal from the negative impacts of TB (Fox, Dodd, & Marais, 2019).

Yet, identifying and diagnosing childhood TB can be very challenging, especially in resource-limited settings like Ghana (Reuter, Hughes, & Furin, 2019). This is largely due to the complex clinical manifestations of the disease, and the lack of access to appropriate means of diagnosis in children (Marais et al., 2021). Consequently, many children with TB infection remain undiagnosed (Dodd, Yuen, Sismanidis, Seddon, & Jenkins, 2017). An undiagnosed child is likely to be deprived of effective treatment options until the disease has progressed, even though treatment can be initiated based on suggestive symptoms, history of TB exposure, and physical examination findings (WHO, 2014). Among children co-infected with TB and HIV, the difficulties are even more pronounced due to the reduced specificity of TB symptoms and the overlaps in clinical presentations of childhood TB and HIV infection (Trajman & Schwartzman, 2020).

A critical problem in childhood TB control is the absence of large-scale contact tracing/screening and provision of TB preventive therapy to eligible children in many resource-limited settings (WHO, 2020). In LMICs, childhood TB disproportionately affects the most socio-economically vulnerable households. However, the existing childhood TB treatment (especially for MDR-TB and extra-pulmonary TB) still frequently requires extended hospitalisation and a long-term treatment regimen (Weld et al., 2017). This situation can impose multiple financial, interpersonal, and social costs on

families (Franck et al., 2014). The prevailing global call to end the TB epidemic by 2035 (see WHO, 2014) will require research evidence to inform context-specific policies and strategies for the management and control of childhood TB (Barry, 2018).

In Ghana, it is estimated that 44,000 people developed TB in the year 2020. Of that, only 12,674 were put on the treatment regimen, highlighting the gap in treatment for TB in the country (Stop TB Partnership, 2021). However, the disaggregated data for childhood TB is not readily available, making estimates difficult. This notwithstanding, the prevalence of childhood TB is closely linked to adult TB. Therefore, we assumed that given the prevalence of adult TB, childhood TB is likely to be relatively high (see Srivastava, Faridi, & Gupta, 2020). Just like in many resource-limited settings, childhood TB has been acknowledged in Ghana as a public health concern with the development of comprehensive management guidelines (GHS & Stop TB partnership, 2012). Despite this effort, bottlenecks still exist in the management and control of childhood TB in Ghana (Ohene, Fordah, & Boni, 2019). Understanding the dynamics of childhood TB is important for policy formulation toward better management and control of the disease. Failure to control childhood TB will ultimately perpetuate the TB epidemic and serve as a drawback in the fight toward the elimination of the disease (Reuter, Seddon, Marais, & Furin, 2020).

The peculiar obstacles that confront childhood TB demand deliberate attempts to understand programme-related control contexts and how these can be leveraged for better treatment outcomes among children. To this end, some

outstanding questions remain, which this study addresses. First, what challenges confront health providers in the management and control of childhood TB in Ghana? Is integration of childhood TB into child welfare clinics (CWCs) an option for service providers and caregivers? How does the psychosocial context of childhood TB influence adherence to the treatment regimen?

Objectives of the Study

The general objective of the study is to explore issues surrounding the management and control of childhood TB in Ghana. The specific objectives of the study are to:

1. Assess how childhood TB is managed and controlled in the selected health facilities;
2. Examine the challenges faced by service providers in the management and control of childhood TB;
3. Explore the perspective of service providers on integration of childhood TB management into child welfare clinics (CWCs);
4. Explore the views of service providers on ways to improve the management and control of childhood TB in Ghana;
5. Investigate how parents/caregivers follow the treatment regimen for children with TB (healthcare-seeking and psychosocial contexts).

Research Questions

1. How is childhood TB managed and controlled in the selected health facilities?

2. What challenges confront service providers in the management and control of childhood TB?
3. What are the perspectives of service providers on the integration of childhood TB management into CWCs?
4. How can childhood TB management and control be improved in Ghana?
5. How do patients/caregivers navigate through the treatment regimen for their children?

Significance of the Study

The "End TB Strategy" of the WHO with the ultimate aim to end TB by 2035 has been launched and implemented across several countries (see, WHO, 2016). To achieve this ambitious aim, efforts have to be intensified, including research to inform policy direction. This study will offer insights into the dynamics of childhood TB in Ghana, which can go a long way to informing policy on childhood TB management and set out the country on the move towards eliminating TB by the 2035 target.

Children are considered among vulnerable groups and TB-HIV co-infection among children has received some attention in recent times. However, studies on childhood TB have mostly focused on diagnosis and risk factors. As such, very little is known about adherence to the treatment regimen among infected children. In recent times, there have been heightened calls for more attention to be directed at childhood TB, including the understanding of the treatment regimen. As such, the study will contribute to filling the knowledge gap by exploring issues relating to treatment adherence among children and how

parents/caregivers navigate through the treatment regimen. The findings from the study could be valuable in informing policies and interventions for enhancing the management of childhood TB in Ghana and other LMICs.

Goal 3, target 3.3 of the SGDs seeks to end TB by 2030 (UN, 2015)– an even shorter time for TB elimination than what was stipulated in the "End TB Strategy" by the WHO (WHO, 2014). Currently, efforts are underway in many countries including Ghana towards achieving this ambitious strategy. Childhood TB contributes a significant, but often neglected percentage to the epidemic. As such, there is a scarcity of research evidence to inform policy and interventions towards addressing the TB epidemic among this vulnerable group. The call for exploring the social context of TB has been heightened in recent times (Shete, Reid, & Goosby, 2018). This study will, therefore, be valuable in providing research evidence on the psychosocial context of childhood TB. The result will be valuable to policymakers in their effort to further understand childhood TB and formulate evidence-based interventions toward addressing the epidemic among children in Ghana and similar resource-limited settings.

Finally, the study will contribute to the current evidence on the management and control of childhood tuberculosis in Ghana as well as in similar resource-limited settings. The findings will serve as reference materials for researchers and academics who may be interested in issues in the field of TB in general, and childhood TB in particular. Knowledge gaps in this study will also offer pointers for further research on childhood TB.

Definition of Terms and Concepts

Several epidemiological concepts and terminologies were used in this study. This section provides definitions/explanations for the concepts and terms.

Childhood: The UNICEF through the Convention on the Right of the Child defines childhood as "any person under the age of 18" (UNICEF, 2019) while "the International Union Against Tuberculosis and Lung Disease and the WHO define childhood TB as "TB among children aged <15 years or the age range 0-14 years" (The Union, 2016; WHO, 2014; WHO, 2016). Given the focus of this thesis, I subscribed to the latter definition.

Childhood TB control: It essentially involves "identifying the source of infection (individuals with pulmonary TB), usually through community-wide active case-finding and putting them through therapy so that they are no longer infectious (Fox, Dodd, & Marais, 2019; The Union, 2016).

Childhood TB Management: It involves screening for TB, case-notification (diagnosis), adherence counselling, initiation of the appropriate treatment regimen, and follow-up (monitoring and record-keeping) to ensure successful treatment completion for children < 15 years (The Union, 2016).

Co-infection: A person who is infected with more than one disease-causing agent simultaneously and both organisms complement each other to produce more harm. In this instance, the term is used to refer to a child who is infected with both TB and HIV.

Integration: This refers to the coordinated provision of services to ensure effectiveness and efficiency. In this case, offering a complete package of childhood TB and CWC services delivered by one health care team at the same facility and at the same time. Integration could assume different forms/models.

Regimen: A set of plans or lay down procedure that guides the management and access to treatment for a disease (TB and HIV in this case).

Organization of the Study

This thesis is organized into a total of ten chapters. The first chapter situates the study in perspective by providing the background to the study. It provides an explanation of the clinical synergy between childhood TB and HIV as well as issues concerning childhood TB management and control. Additionally, it highlights the aetiology and challenges associated with TB among children using the existing documented evidence. To put the study into context, a brief description of the background to TB management in Ghana has been provided in this chapter. The chapter also provides the statement of the problem where I synthesized the available research evidence as well as the current policy direction to make a case for the conduct of the study. In addition, the chapter also includes the research questions, the significance of the study, and information on the organization of the study.

In chapter two, an empirical scoping review of literature was carried out. The review considered mainly peer-reviewed articles which have been published in the last decade (2011-2021) and were deemed relevant to the

problem definition. However, some grey literature such as reports, perspectives, comments, and conference materials that have been published in the last decade in reputable journals or publishing houses were also considered in the write-up where appropriate.

The third chapter is dedicated to theoretical issues. Relevant theories have been reviewed and their applications to the management of chronic infectious diseases (focusing on TB) were assessed. In addition, relevant studies that employed these theories were synthesized and reviewed to assess the applicability, strength, and weaknesses of each of the theoretical perspectives. A justification for the adoption of specific micro-level theories to provide the foundation for the theoretical framework for the study was also provided in this chapter. Finally, a framework was adapted to drive the study.

Chapter four of the thesis has been devoted to the methods that were used in this study. It addresses issues relating to the research philosophies that were employed to guide the study. It also includes detailed information on the study design, study area, sources and types of data, sampling techniques, sample size, instruments for data collection, pre-testing, data collection procedures, data management, processing and analysis, trustworthiness criteria, and ethical considerations.

Chapters five to nine were dedicated to results and discussions of the major findings based on the specific research questions. Qualitative findings were presented under themes, sub-themes, and categories with quotes that reflect each theme. Each chapter was dedicated to results/findings that

addressed a specific research question and its attendant objective. The results were discussed with empirical literature that were reviewed. The theoretical framework that has been developed for the study was also critical in the data analyses and the discussion of the results.

The last chapter of the thesis is concerned with the summary of the main findings, conclusions from the study based on the results, and the recommendations of the study. The chapter also provides reflections on the theoretical framework used, its applicability, strength, and weaknesses. In addition, the chapter also outlines suggested areas for further studies.

CHAPTER TWO

UNDERSTANDING CHILDHOOD TUBERCULOSIS: A SCOPING REVIEW

Introduction

In this chapter, a scoping review of relevant literature was done. It comprises empirical evidence in the field of childhood TB management and control. Taking pointers from Munn et al., (2018), a scoping review was a preferred choice as the purpose of the review is not to answer a specific question, but to identify, synthesize, and map the existing evidence. In addition, given that this is an academic work, a scoping review provides the opportunity to organize the review around specific issues that are relevant to the study. Literature was obtained by searching electronic bibliographic databases including PubMed, MEDLINE, BioMed Central, EBSCO host, and Google scholar. Specific journals, including; the International Journal for Tuberculosis and Lung Disease, Lancet, Lancet Infectious Disease, and New England Journal of Medicine were also searched for relevant literature.

Overview of the literature search strategy

The selection criterion was limited to studies on childhood TB that were published in English within the last decade (2011-2021). This period was chosen to ensure that the basis for knowledge synthesis is neither too old nor too current. After obtaining access to the selected electronic bibliographic databases using a UCC license, I used the terms “childhood tuberculosis” and

"childhood TB" (and their alternative words; paediatric tuberculosis or TB) and ("management" "control" "epidemiology" "effective management" and other terms describing management and control). The literature search yielded a total of 845 published articles, including reports. The titles of 635 non-duplicated materials were vetted for inclusion. Of that, 322 full text and abstracts were additionally evaluated for eligibility bearing in mind the time of publication as an inclusion criterion (2011 - 2021). In the end, 115 papers (peer-reviewed articles and reports) satisfied the eligibility criteria and were included.

Studies on childhood TB in Ghana

Generally, there is limited scientific evidence on childhood TB in Ghana. As such, very little is known in terms of the dynamics of childhood TB in Ghana and how children follow the treatment regimen. Even considering the general TB epidemic, relatively few studies have been carried out in Ghana in the last decade. A systematic search for literature in online bibliographic databases including PubMed, Google Scholar, the Cochrane Library, MEDLINE, EMBASE, and EBSCO host on TB in Ghana within the last decade (2011-2021) yielded only a total of 49 published articles on TB in Ghana. These studies covered various aspects of the TB epidemic in Ghana – clinical studies, the clinical linkage between TB and HIV, health systems/implementation science, stigma, non-adherence to the treatment regimen, epidemiology, and community involvement in TB control (see Table 1).

Table 1: Studies on TB in Ghana: 2011-2021

Focus of studies	Frequency	Per cent (%)
Clinical studies	29	59.2
Clinical interface between TB & HIV	2	4.1
Health system/Implementation science	8	16.3
Treatment seeking experience	2	4.1
Distribution of TB burden	1	2.0
Community perspective on TB control	3	6.1
Epidemiology	1	2.0
Social and Policy	3	6.1
Total	49	100.0

Source: Author's Systematic Review, 2021

Like in many countries, most of the literature on TB leans toward the clinical perspective of the epidemic. Even though the balance of the existing evidence in Ghana is tilted toward clinical studies, only two of such studies focused on childhood TB (Kwara et al., 2016; Ohene, Fordah, & Boni, 2019). The rest of the studies dealt with the manifestation of TB bacteria, characteristics and disease progression, case notification and prevalence within limited settings. For instance, Ohene (2018) studied the "yield of tuberculosis among household contacts of tuberculosis patients in Accra, Ghana". Other studies were largely in the area of TB policy with a focus on obstacles to TB

control and how to improve control strategies (Amo-Adjei, 2013; Amo-Adjei, 2016; Ohene et al., 2018). The clinical connections between TB and HIV have also been studied (Osei, Der, Owusu, Kofie, & Axame, 2017; Osei, Oppong, & Der, 2020).

In recent times, many policy/programme implementation studies have also been published on TB-HIV service integration (Amo-Adjei & Awusabo-Asare, 2013; Amo-Adjei, Kumi-Kyereme, Amo, & Awusabo-Asare, 2014; Ansa, Walley, Siddiqi, & Wei, 2012; Anku, Amo-Adjei, Doku, & Kumi-Kyereme, 2018). Although these specific studies have advanced our understanding of TB control as a whole, the peculiar obstacles that confront childhood TB demand deliberate attempts to understand programme-related control contexts and how these can be leveraged for better treatment outcomes among children. With the limited scientific evidence on childhood TB in Ghana, context-specific issues regarding the TB epidemic among this vulnerable sub-population are yet to be well understood.

Epidemiology of Childhood TB

The incidence of childhood TB (especially, pulmonary TB) is closely linked to the prevalence of TB among adults who have been in contact with children (Piccini, Chiappini, Tortoli, de Martino, & Galli, 2014). The risk of developing TB among children is often higher in settings where there is a considerable number of active adult TB, poor sleeping arrangements where people are overcrowded in a room, and in houses with poor ventilation (Seddon & Shingadia, 2014; Attah et al., 2018). At the end of 2020, childhood TB

accounted for an estimated 11 per cent of all new TB notifications globally (WHO, 2021), which is the same as the previous year (WHO, 2019). This trend makes childhood TB a persistent public health concern as there has not been much improvement since 2015 (see WHO, 2016). The burden of childhood TB is highest in three regions of the world – South East Asia, Africa, and the Western Pacific. These three regions are responsible for 35 per cent, 30 per cent, and 20 per cent of the global burden of TB respectively (WHO, 2017).

Notwithstanding the availability of safe and effective treatment regimens for children, mortality due to TB among children (<15 years) remains a major concern, especially in Asia and Africa. At the end of 2018, the actual TB mortality among HIV-negative children was 14 per cent of all TB deaths, indicating a disparity between estimated cases (11%) and actual mortality. The higher share of mortality among children compared with estimated cases highlights difficulties in access to diagnosis (WHO, 2019). This figure may even not be a true reflection of the actual situation as there may be misreporting in many countries.

The literature suggests that childhood TB mortality is often underreported, because, for several children who die from TB, the cause of death is often reported as pneumonia, HIV/AIDS, malnutrition, or meningitis, (Kendall, 2017; Dodd, Yuen, Sismanidis, Seddon, & Jenkins, 2017). Many of these children who died from TB never received TB treatment (Dodd et al., 2017). This is unacceptable, especially considering the fact that children exhibit

favourable TB treatment outcomes even with MDR-TB (Huynh, Thwaites, Marais, & Schaaf, 2020).

Evidence suggests that a large proportion of persons exposed to *M. tuberculosis* do not become ill after the primary infection, but rather develop the latent form of TB (Floyd, Glaziou, Zumla, & Raviglione, 2018). This is however not the case among children as they are at greater risk of developing active TB following exposure to the bacteria, occasionally presenting the extra-pulmonary or disseminated forms of the disease. This is partly a result of their immature immune system allowing for the fast progression (manifestation) of the disease instead of latency (de Martino, Lodi, Galli, & Chiappini, 2019; Driessche, Persson, Marais, Fink, & Urdahl, 2013). However, there are disparities in childhood TB as the risk of developing active TB is greatest among children 0-4 years with current research evidence signifying that children can become infected roughly 15-20 minutes following exposure to the causative agent (Luzzati, et al., 2017). Also, in comparison with children 5-14 years, children under-5 present the greatest diagnostic challenge and lower rates of treatment success (Ramos et al., 2019).

Following infection, TB can manifest at any point in the life of the child. But this depends on the viability of the pathogen and the immunity of the host, even though many children will present active TB within 12 months following their infection (de Martino, Lodi, Galli, & Chiappini, 2019). As such, it is critical to obtain the history of contacts with pulmonary TB so that transmission within the community can be cut and children who have been in contact with

infected persons can be placed on preventive therapy (Laghari et al., 2019). Indeed, evidence suggests that this is an effective way of controlling childhood TB and control programmes have been encouraged to pursue this strategy (Martinez et al., 2017). The observed disparities between childhood TB and adult TB are mainly a result of the pathophysiology and clinical presentations of the disease, making diagnosing TB among children very challenging (Elhassan, Elmekki, Osman, & Hamid, 2016). The factors which account for these disparities include age, immune status (immunity), nutritional status, and BCG vaccination among others (Dockrell & Smith, 2017; Aibana et al., 2016).

In children below age 2, primary TB infection often evolves into a severe manifestation of the disease, without any major prior symptoms. This usually takes place within the first 12 months following contact with active TB cases. Among children between 2-10 years, hardly do primary infection evolves into a severe disease state (Roya-Pabon & Perez-Velez, 2016). However, when it does happen, it is often accompanied by major clinical indications such as severe cough, difficulty in breathing, and weight loss among others (Marais et al., 2021). In children above 10 years (10-14 years), primary infection usually progresses to the form of TB that is commonly observed among adults (Cowger, Wortham, & Burton, 2019). The possibility of severe forms of the disease among this age group and transmission in the community can be mitigated with timely and effective interventions (Laghari et al., 2019).

In a systematic review and meta-analysis, there was evidence that the risk of developing TB among exposed children, especially infants is very high.

Children develop TB within weeks of exposure and so late initiation of contact tracing might not be able to prevent infection through the administration of prophylaxis. Therefore, an alternative preventive strategy like timely initiation of preventive therapy through intensified case finding of adults with TB is recommended (Martinez, Cords, Horsburgh, Andrews, & PTBCSC, 2020).

Childhood TB has been found to follow a similar trajectory in immunocompromised children as in children with immature immune systems (usually children under 2 years) (The Union, 2016). The evolution of TB in children after pulmonary infection involves several phases. The first phase starts 3-8 weeks following the primary infection. After the preliminary asymptomatic period, children may experience allergic reactions, including "fever, erythema nodosum, a positive reaction to the tuberculin skin test (TST)", and the development of primary complex, which may be visible on a chest X-ray.

In the second phase (usually 1-3 months following the primary infection), there may be "occult hematogenous dissemination" all through the period of incubation (Carvalho, Cardoso, Martire, Migliori, & Sant'Anna, 2018). This period conveys the highest risk for the development of TB meningitis and military TB in children under 2 years of age, although manifestation may happen at any time after hematogenous dissemination. Phase 3 starts 3-7 months following the primary infection (Carvalho et al., 2018). This period may be characterized by pleural effusion in children over 5 years while those under 5 years may experience bronchial disease (López Ávalos & Prado Montes de Oca, 2012).

Phase 4 stretches from the conclusion of phase 3 until the calcification of the primary complex, which takes place 1-3 years after the primary infection. This phase may be characterized by the development of osteoarticular TB in children below 5 years while adult-type can occur among older children and adolescents. Overall, the danger of disease advancing is low when calcification happens. Nonetheless, adult-type active TB which is a delayed manifestation after primary infection may develop even after calcification has occurred (López Ávalos & Prado Montes de Oca, 2012). The final phase (Phase 5) starts once the calcification is completed, usually after 3 years following the primary infection. This phase involves the period of late manifestation of TB, including reactivation of pulmonary TB (Carvalho et al., 2018).

Exploring the epidemiology of childhood TB is essential as it helps understand the chances of a child having TB or not after exposure. Besides, it defines the pre-test possibility of TB before the clinical investigation, thereby providing pointers for the understanding of test results. At the programme level, epidemiology of childhood TB is essential for policy-makers and public health professionals to plan interventions aimed at better management and control of TB among this vulnerable group. In addition, exploring the epidemiology of childhood TB provides the necessary platform for advocacy for childhood TB, - a long-neglected aspect of the global fight against the epidemic (Seddon & Shingadia, 2014).

Clinical Manifestation of Childhood TB

Childhood TB presents several difficulties for both service providers, primary caregivers, and the children themselves. From a clinical viewpoint, childhood TB presents different signs and symptoms that deteriorate with time. A few children with active primary TB can be asymptomatic, in which case active primary TB can be mistaken clinically for latent TB infection (Roya-Pabon & Perez-Velez, 2016). The major signs and symptoms of childhood TB include; loss of appetite, fatigue, weakness, night sweat, evening fever, and weight loss (Hu, Yin, Gu, & Zhang, 2013). When TB attacks the lungs, the child may experience chest pain, and cough that could either be productive or non-productive with hemoptysis in rare cases (Roya-Pabon & Perez-Velez, 2016).

The pulmonary form of the disease, which is the most common form is often accompanied by a persistent cough which could either be productive or not (Hu, Yin, Gu, & Zhang, 2013; Roya-Pabon & Perez-Velez, 2016). Other notable signs and symptoms of childhood TB include fever (moderate, but persistent for 15 days or more, and usually happens in the evening) significant reduction in weight, anorexia, pallor, hemoptysis, lymphadenopathy, and hepatosplenomegaly. A consistent cough (either productive or unproductive) is the vital indication of pulmonary TB, which is the most common form of childhood TB (WHO, 2021). Notwithstanding cough being the main symptom, erythema nodosum, keratoconjunctivitis, and joint pains may as well be present in children with TB. It is however necessary to note that hemoptysis can be

present among adolescents with TB but is very rare among children, especially those below 5 years old (Carvalho et al., 2018).

Despite pulmonary TB being the most common type of disease, TB can also affect other organs of the body apart from the lungs. When this happens, it is termed extra-pulmonary TB (WHO, 2021). In extra-pulmonary TB cases, symptoms vary depending on the organ(s) that have been affected. It can affect the lymph, kidney, bones (including the spine), and meninges among others (Aygün, Akçakaya, Çokuğraş, & Camcıoğlu, 2019). One of the most critical forms of the disease among children is military TB, which comes about mainly as a result of the haematogenous dissemination of *M. tuberculosis* which increases the risk of the child suffering from meningitis (Aygün et al., 2019).

Among HIV-positive children, the clinical manifestation of TB is mostly impacted by the extent of immunosuppression. Generally, the diagnostic investigation for children with TB-HIV co-infection is similar to those of adults and the general population (Trajman & Schwartzman, 2020). Also, due to the higher occurrence of extra-pulmonary and disseminated forms of TB in HIV-positive children, a suitable clinical investigation for diagnosis involves invasive procedures to obtain clinical samples. These specimens include; fluids (pleural fluid, cerebrospinal fluid) or biopsy samples from solid organs such as lymph nodes and pleura (Kohli et al., 2017).

The difference between childhood TB and adult-type TB as far as pathophysiology and clinical indication make the diagnosis of the disease in children very difficult (Mulenga et al., 2015; Oliwa et al., 2020). The dynamics

of latent TB progression to active TB seem to be shaped by several factors, including age, BCG vaccination, nutritional status, and the development of the immune system (Carvalho, Cardoso, Martire, Migliori, & Sant'Anna, 2018; de Gijsel & von Reyn, 2019).

Management of Childhood TB

An accurate diagnosis of TB is based on the confirmation of the presence of *M. tuberculosis* in a clinical specimen. However, in children, diagnosing TB presents a major challenge to the management of the epidemic, as children are not able to produce viable sputum for testing. Besides, TB among children can mimic many known childhood illnesses such as malnutrition, pneumonia, general viral and bacterial infection, and HIV infection (Swaminathan & Rekha, 2010; Tsai et al., 2013).

The consensus which was echoed by the WHO emphasizes that "clinical, radiological, and epidemiological features are the most indicative of active childhood TB" (WHO, 2014). In effect, the approach to diagnosing childhood TB involves; thorough clinical history taking; a full clinical assessment with specific attention to aspects of childhood development; the tuberculin skin test result; results of a chest X-ray; bacteriological confirmation where possible; specific assessment of the organ involved in suspected cases of pulmonary and extra-pulmonary TB; and HIV testing (Reuter et al., 2019).

It is imperative to note that the WHO consensus recommendation also emphasises the need for bacteriological or molecular confirmation with the molecular test for *M. tuberculosis* and resistance to rifampicin (Xpert

MTB/RIF). However, the guideline does not encourage the supposed "therapeutic test" – the practice of establishing diagnosis by starting the treatment for childhood TB with the hope that the child will respond clinically to the treatment (WHO, 2014). In HIV-positive children, it is recommended that TB should be considered during all regular clinical visits or scheduled clinical appointments by inquiring about the existence of the four main symptoms – "fever, cough, night sweats, and weight loss". The existence of any of these symptoms are indications of a possible active TB, thereby suggesting the need for a more thorough examination (Hanifa et al., 2019; WHO, 2011).

Radiological investigation of TB among children is a very important aspect of diagnosing the disease among this vulnerable population. The radiological aspects most often associated with the pulmonary form of the disease are those observed in children under 10 years and those found in children above 10 years of age. In children less than 10 years, there are typically images that are suggestive of primary TB infection or primary complex. For such children, the primary complex is still developing and its manifestation typically takes 5 years following primary infection. Such manifestations include hilar lymphadenopathy, military images, and features of chronic or slowly developing pneumonia which is also referred to as "expansive pneumonia" (Carvalho et al., 2018). In children more than 10 years, the radiological aspect is similar to adult-type TB. In such children, the images often show cavities in the lungs (Carvalho, Cardoso, Martire, Migliori, & Sant'Anna, 2018; García-Basteiro et al., 2015).

Generally, the confirmation of a diagnosis of TB using bacteriological testing is challenging in younger children, but viable in children older than 10 years since they typically develop bacteriological pulmonary TB. Evidence suggests that most children with primary TB may present sputum smear-negative test results or produce paucibacillary specimens, making diagnosis difficult (Piccini, Chiappini, Tortoli, de Martino, & Galli, 2014). Children below 8 years hardly produce viable sputum for testing. As such, the diagnosis of childhood TB is often made regardless of bacteriological confirmation in the majority of cases. Concerning children who cannot produce sputum, the best practice is that samples should be obtained through gastric lavage if possible (WHO, 2014). The challenge is that this invasive procedure often requires experts such as paediatricians to perform. Besides, the use of induced sputum samples in children has shown to be more sensitive than gastric lavage and it is generally well-tolerated (Planting et al., 2014).

Despite the availability of frameworks for the management of childhood TB, the paucibacillary nature of the disease among children remains the main obstacle to the diagnosis and management of the disease. Currently, even though there are advanced means of diagnosis such as “mycobacteria growth indicator tube (MGIT), Microscopic Observation Drug Susceptibility (MODS)”, Xpert MTB/RIF (Brent et al., 2017) and its later version which is known as Xpert MTB/RIF Ultra assay to overcome diagnosis challenges, their uptakes have been suboptimal. The lack of uptake of the more advanced methods of diagnosis is mainly a result of cost, the absence of technically trained staff, and the

unavailability of biosafety level 3 facilities in many resource-limited settings (Ardizzoni et al., 2015; Oga-Omenka et al., 2020).

The treatment regimen for childhood TB is similar to that for adults. The combination of medicines used in treating paediatric TB is targeted at eliminating vigorously replicating and dormant/near-dormant mycobacteria with less toxicity as much as possible while safeguarding against resistance to the various drugs (Graham, 2011). However, new evidence suggests that higher doses, especially rifampicin may be required for children than initially recommended by the WHO (Yang et al., 2018). TB treatment comprises two phases – "an intensive phase that deals with a combination of bactericidal drugs to terminate the fast-growing bacilli and a continuation phase that involves the combination of fewer drugs to eliminate the slower-growing but persistent bacilli" (Graham, 2011).

A fixed-dose combination of pills is recommended to improve adherence to the treatment regimen. In children, however, the sharp variations in "absorption, distribution, and excretion of pharmacological agents" may require dose adjustments for the various childhood age groups (Vijayasekaran, 2011; Yang et al., 2018). Studies have shown that age is a significant factor in serum levels for all the first-line anti-TB medications, with infants and young children having lower peak serum levels compared to older children or adults (Graham, 2011; Koul, Arnoult, Lounis, Guillemont, & Andries, 2011; Tsai et al., 2013).

In Ghana, management and control of all forms of TB are under the auspices of the NTP in the various health facilities. Consistent with the WHOs call and recommendations, childhood TB in Ghana has been recognised as a public health concern that needs special attention to address. To this end, the Ghana Health Service (GHS) and the Stop TB partnership developed comprehensive guidelines for the diagnosis and management of TB in children as part of efforts toward addressing childhood TB in Ghana (GHS & Stop TB partnership, 2012). According to the guidelines (see GHS & Stop TB partnership, 2012), all children with TB are expected to have ethambutol included in their intensive phase of the treatment regimen, while all children with TB meningitis and osteoarticular TB are required to have at least a 12 months of anti-TB treatment with ethambutol during the intensive phase.

In addition, the use of steroids is recommended in cases of endobronchial TB, large pleural effusion, pericardial effusion and TB meningitis. However, the duration of steroid use is not expected to go beyond one month. In cases where the benefits outweigh the risks, it is recommended that the clinician or paediatrician may consider the use of streptomycin during the intensive phase but under strict observation. The administration of isoniazid preventive therapy (IPT) is recommended for all young children (< 5 years) and HIV-positive children of all ages that are household contacts of a case with sputum smear-positive TB regardless of evidence of TB (GHS & Stop TB partnership, 2012). Also, it is recommended that for TB-exposed neonates, breastfeeding should be continued whiles the mother is on anti-TB treatment.

The guideline also clearly recommends the use of advanced means of diagnosis such as GeneXpert and TST in the confirmation of childhood TB as they are easier and more effective (GHS & Stop TB partnership, 2012).

Prevention and control of childhood TB

Currently, the available health intervention to prevent TB infection among children is the treatment of latent TB infection (LTBI) and vaccination with BCG. By definition, LTBI is "a state of persistent immune response to exposure to *mycobacterium tuberculosis* without clinical or radiological evidence of active TB" (WHO, 2015). Children who have been in contact with smear-positive pulmonary TB adults are at an increased risk of latent TB infection and also a development from LTBI to active disease (Marais et al., 2021). The pharmacological treatment (preventive therapy) of latent TB infection is a major strategy that is capable of stopping the development of the active form of the disease in children who have been in contact with smear-positive adults (WHO, 2021).

Children, especially those below 5 years are the most susceptible to TB infection and represent the sub-group for which there is strong evidence of the benefits of testing for and treating LTBI (Getahun et al., 2015). The WHO (Getahun et al., 2015), The Union (The Union, 2016), and the International Standards for Tuberculosis Care (TB CARE I, 2014) are unanimous in the recommendation that, after active TB has been ruled out, latent TB infection should be treated in the two high-risk groups: children under 5 years of age and HIV-positive children who have been in close contact with bacteriologically

confirmed pulmonary TB infected adult. Screening children under 5 years for active TB and latent TB infection is the recommended strategy by the WHO, even in resource-limited settings (Getahun et al., 2015; WHO, 2012).

As part of preventive and control efforts, administration of the treatment regimen for latent TB infection in children below 5 years who are in close contact with smear-positive pulmonary TB cases is recommended regardless of whether latent TB infection has been confirmed or not (TB CARE I, 2014; WHO, 2015). Just like in adults, the diagnosis of latent TB infection in children is grounded on the results of a tuberculin skin test which may be carried out by the Mantoux method. However, it is imperative to note that the interpretation of the test results may vary due to the extent of exposure to the index case and BCG immunization status (Carvalho et al., 2018). Despite TST presenting a major opportunity for diagnosis of latent TB infection among children, its uptake has been challenging, especially in resource-limited settings as there are often stock-outs of tuberculin to perform the test (Salazar-Austin et al., 2021).

As part of the treatment regimen for latent TB infection, the WHO recommended the following treatment; "6-months isoniazid, or 9-months isoniazid (depending on the clinical assessment), or a 3-month regimen of weekly rifapentine plus isoniazid, or 3-4 months isoniazid combined with rifampicin, or 3-4 months rifampicin alone" (WHO, 2015). It is important to note that the 9-month isoniazid regimen is the only one that is recommended by the "U.S Centre for Disease Control and Prevention for use in children". Also, the combined regimen for isoniazid plus rifapentine weekly for 3 months is not

recommended for children below 2 years of age or HIV-positive children on ART.

The success of treating latent TB infection with isoniazid for 6-12 months (preferably, for 9 months) is estimated to be 60-90%, with no clear disparities in the level of protection among the treatment for the various durations. Evidence from a systematic review and meta-analysis revealed that administration of isoniazid to HIV-positive children in Africa decreases the risk of active TB and mortality among children enrolled on ART, though there was no clear evidence of it being beneficial to those on ART (Zunza, Gray, Young, Cotton, & Zar, 2017). For children and adults in contact with MDR-TB cases, there is currently no preventive therapy even though a trial is currently underway in this regard (Seddon et al., 2018).

For over a century, the Bacillus Calmette–Guérin (BCG) has been available as a vaccine for the prevention of primary TB among children. Whereas the vaccine can prevent 60-90% of cases of severe forms of active TB (disseminated TB and TB meningitis) in children, it is not effective in preventing the disease among adults (Herzmann et al., 2014; WHO, 2014). Contrary to this long-held scientific position, recent evidence from a review of prospective trial studies showed that childhood BCG immunization protects against pulmonary TB (de Gijsel & von Reyn, 2019). Notwithstanding this new piece of evidence, it is essential to note that contemporary understanding of the efficacy of BCG against pulmonary TB is vital to the development and evaluation of potential vaccines intended to replace or boost BCG protection.

The modest decline in the incidence of TB globally, especially in the last two decades emphasizes the need for a more effective vaccine(s) against TB, especially those that can protect against all forms of TB in the different age categories (Carvalho et al., 2018). Evidence suggests that there is high coverage of BCG vaccination in Ghana (Budu, Darteh, Ahinkorah, Seidu, & Dickson, 2020). The high coverage, however, may or may not have a substantial impact on the number of children who become infected with pulmonary TB or less severe forms of extra-pulmonary TB. Nonetheless, it provides optimism for successful future efforts to address TB among children through vaccination. As of August 2021, there were 14 new potential vaccines against TB which were in various phases of clinical trials, and comprise contenders to prevent TB infection and TB disease, as well as contenders to help improve outcomes of treatment for TB disease (WHO, 2021).

Children, especially those below age 5 have difficulties in accessing TB care, are most susceptible to developing severe forms of TB (e.g., TB meningitis and disseminated TB) and bear the brunt of TB deaths (Dodd, Yuen, Sismanidis, Seddon, & Jenkins, 2017). As such, children should be a priority group for TB preventive therapy efforts. Even though documented evidence suggests that TB preventive therapy almost doubled from 2018 to 2019 (i.e., 2.2 million to 4.1 million people received therapy in respective years), most of the gains were among people living with HIV, suggesting a robust approach by authorities of HIV control programmes. In contrast, the number of household contacts to whom TB programmes provided preventive therapy only increased modestly

from 423,607 in 2018 to 538,396 in 2019 (WHO, 2020). This is an indication that TB control programmes remained insufficiently resourced to undertake routine household contact management. Even among susceptible young children, only a third of the estimated 1.3 million eligible child household contacts received TB preventive therapy. These figures are below the formulated targets at the "UN high-level meeting on the fight against TB in 2018" (WHO, 2020).

Enhancing access to TB preventive therapy requires a radical upscaling of household contact tracing and investigation with National TB control programme strategies and adequate resource allocation which is consistent with WHO recommendations (Reuter, Seddon, Marais, & Furin, 2020). The prioritization of household contact investigation is critical for TB prevention and control as it helps in active TB case-finding (Fox, Dodd, & Marais, 2019). Despite most of the TB transmission among children occurring in the community (Martinez et al., 2019), household contact tracing provides an effective avenue for prevention, while challenges of childhood TB diagnosis and treatment reinforce the need for preventive therapy among vulnerable children. Evidence from a systematic review and meta-analysis reinforce the need to differentiate and accurately identify the main focus of contact investigation in vulnerable children to prevent active TB and death soon after primary exposure or infection through the administration of preventive therapy (Martinez, Cords, Horsburgh, Andrews, & PTBCSC, 2020).

Notwithstanding the availability of expanded and more child-friendly TB regimens, TB preventive therapy implementation and upscaling remain sub-optimal in many resource-limited settings (Teklay, Teklu, Legesse, Tedla, & Klinkenberg, 2016). This undesirable situation can possibly be reversed if childhood TB preventive therapy is regarded as a priority by TB control programmes and major donors with clear goals and a practical implementation plan (Marais et al., 2021). There is a pressing need to explore creative task-shifting for TB preventive therapy initiation to enable decentralized client-centred approaches to service delivery, particularly in vulnerable young children in whom the benefit is enormous (Zawedde-Muyanja et al., 2018).

Challenges of childhood TB management

Childhood TB management and control present several challenges to service providers. One of the key challenges encountered by service providers, especially in resource-limited settings is in the area of diagnosing childhood TB (Trajman & Schwartzman, 2020). Despite the emergence of advanced means of diagnosis, resource-limited settings continue to struggle in dealing with diagnostic challenges mainly due to skills, competence, and provider experience, among other things (Oliwa et al., 2020). Diagnosing TB among children below 5 years continues to pose a major challenge to service providers (Marais et al., 2021). Children might present extra-pulmonary or paucibacillary TB, and although many do present typical features of pulmonary TB (Ramos et al., 2019), many children are missed due to diagnostic and screening strategies that were rather developed for adults (Faddoul, 2015). Also, many children with

TB might be missed when they report for child-focused health services such as routine vaccination or Child Welfare Clinic and through screening for other health conditions, including pneumonia and malnutrition (Oliwa, Karumbi, Marais, Madhi, & Graham, 2015).

Although there is a recognition that passive case finding may not be sufficient to deal with childhood TB, there are some disagreements regarding how best to actively search for children with TB. The literature point to some experts advocating for a household-based approach whereby all children are screened whenever a household member is confirmed with active TB (Szkwarko et al., 2017). Nevertheless, studies have revealed that most children with TB are not exposed to contacts in the household, necessitating the advocacy for a broader screening approach (Luzzati et al., 2017; Said et al., 2019). Other studies advocate for targeted, non-household screening such as in malnutrition wards/units of health facilities, especially among children diagnosed with pneumonia and or malnutrition (Arscott-Mills et al., 2014; Munthali et al., 2017).

Another challenge relating to childhood TB diagnosis is recognising the best screening strategy to employ since strategies vary due to diverse case-finding approaches. Whereas some authors maintain that symptom-based screening should be the basis for determining children in need of further diagnostic testing (Triasih, Robertson, Duke, & Graham, 2015), a clear description of the symptomatology to be used during screening is required. Importantly, a definition of the duration of cough as a symptom (i.e. “any cough

vs cough for more than 2 weeks") needed to be clarified (Turner & Bothamley, 2015). Although chronic cough is a common symptom associated with TB among children (Mulenga et al., 2015), evidence suggests that symptom-based screening may not yield the needed results as several children later found to have TB had no reported symptoms, including persistent cough (Marais, 2018).

A practical screening algorithm for children with a history of contact with TB-infected adults has been proposed by the WHO and subsequently implemented in various settings as a purported solution to the challenge of how best to screen children for TB (Martinez et al., 2018). However, this algorithm would require validation using broader screening approaches compared with the adult algorithms. Another simple screening strategy would be to enquire whether any adult in the household has been diagnosed with TB recently. However, considering the stigma and discrimination that accompany a disease like TB, families and caregivers might want to keep their status a secret (Amo-Adjei, 2016). In effect, it would rather be prudent to ask if anyone in the house has been coughing. Similar screening strategies can be employed in child welfare clinics and other child health campaigns and programmes to enhance childhood TB case finding (Detjen, Essajee, Grzemska, & Marais, 2019).

Evidence from some studies revealed that imaging could be used for both screening and diagnosis among children suspected to be infected with TB. Computer-assisted detection of TB with digital chest X-ray is increasingly becoming an important tool for TB screening among adults (Breuninger et al., 2014). However, this diagnostic tool has not been validated for use among

children below 5 years of age. Point-of-care ultrasound has been assessed as a possible screening and diagnostic tool for children suspected of TB and has the added advantage of being able to assess extra-pulmonary forms of TB (Bélard et al., 2018). In addition to imaging, all children suspected of TB should undergo a basic physical examination, including an assessment of height for weight as part of TB screening. Regrettably, several national TB control programmes (NTPs) do not have adequate human and financial capabilities to undertake such work and there is also the need to identify and protect budget lines allocated for children (Reuter, Hughes, & Furin, 2019). Resource-pulling by joining forces with others working in the area of child health could be a way forward.

Even though children can be diagnosed with suspected TB based on history, symptoms, and physical examination (Graham et al., 2015), service providers also pursue bacteriological confirmation of the TB disease. This quest for bacteriological confirmation requires that a viable sample is obtained for appropriate testing to be done. Documented evidence shows that children older than 5 years are likely to have a pulmonary form of the disease and can usually produce respiratory specimens (e.g. sputum) while among children under 5 years, other respiratory specimens might need to be obtained either through gastric aspirate or sputum induction (Reuter, Hughes, & Furin, 2019).

When carried out correctly, both sputum induction and gastric lavage can have a sensitivity and specificity that is comparable to spontaneously expectorated sputum in adults. However, logistical issues might influence which methods are best to be employed in a programme setting (Loos, Cordel,

& Bonnet, 2019). Obtaining multiple samples for TB testing has been found to possibly increase diagnostic accuracy (Zar et al., 2012). Other studies, however, found contrary evidence to suggest that obtaining multiple samples simultaneously for testing does not increase diagnostic yield beyond that of a single high-quality gastric aspirate (Walters et al., 2019).

After a specimen is obtained, there are many options in terms of the type of tests that could be performed to diagnose TB. Whereas modern and more effective means of diagnosis have been in existence for over a decade, sadly, most children's specimens are still subjected to only smear microscopy in resource-limited settings. The challenge is that smear microscopy has low sensitivity and does not provide any information or clue on drug resistance (Ngabonziza et al., 2016). Given that as much as 70 per cent of children with clinical TB are missed, it has been argued that smear microscopy has outlived its usefulness and should no more be the test of choice for childhood TB diagnosis (Seki, Kim, Hayakawa, & Mitarai, 2018).

Instead, the Xpert MTB/RIF assay (Cepheid, Sunnyvale CA, USA) with the Ultra cartridges or culture should be used for all children suspected of TB (Sabi et al., 2018). Xpert MTB/RIF testing can be performed on most samples (even though its sensitivity and specificity are low in liquid from pleural effusions) and should be the gold standard for most paediatric samples and induced sputum samples (Nicol et al., 2018). Evidence suggests that this test is useful under routine programme conditions (which exist in most resource-limited settings of Africa and Asia) (McDowell et al., 2019).

A controversy that exists in specimen acquisition and testing is centred on how to enhance the various possible sampling strategies and diagnostic tools under programme conditions. Even though to suggest obtaining multiple samples and undertaking several tests might be seen as forthright, NTPs do not usually have the resources available to them to implement such a strategy. A likely alternative would be to concentrate on respiratory specimens (including those obtained from the gastrointestinal tract such as gastric aspirates and stool) and examine them with Xpert MTB/RIF Ultra cartridges and culture in paediatrics. This is a viable option since these methods are the most sensitive and also have the added advantage of providing valuable information on drug resistance (Reuter, Hughes, & Furin, 2019).

Another diagnostics issue of childhood TB on which consensus has not been reached is whether or not bacteriological confirmation is required before starting children on the treatment regimen. While over-diagnosis of TB in children might be problematic in some settings due to concerns about a possible development of resistance (e.g., children who have acute cough are started on anti-TB medication), in other settings, TB is overlooked as the substantial cause of morbidity and mortality (Jenkins et al., 2017). In effect, several children with TB are never diagnosed or never treated and several of them who die are not even reckoned as TB-related mortality (Dodd, Yuen, Sismanidis, Seddon, & Jenkins, 2017). Nevertheless, there is documented evidence to show that TB treatment without bacteriological confirmation is safe and effective (Wobudeya et al., 2019). This evidence might essentially hold for rifampicin-resistant and

MDR-TB since health providers might hold the view that children cannot fall sick with these resistant strains of TB or may be reluctant to start children on longer, more toxic rifampicin-resistant and MDR-TB treatment regimens than those used for drug-susceptible TB without proof that the child has drug-resistant TB (Jonckheree & Furin, 2017).

Paradoxically, in some settings, children under 5 years whose parents or close contacts have been diagnosed with rifampicin-resistant TB and MDR-TB are rather started on treatment for drug-susceptible tuberculosis, with subsequent morbidity and mortality (Monedero & Furin, 2015). As part of the way forward, NTPs should rigorously assess the data on children who are started on TB treatment for necessary programmatic actions. If a substantial proportion of children on treatment have bacteriological confirmation, then the programme is probably under-treating and needs to emphasise the significance of clinically diagnosed TB with front-line providers. On the other hand, if a low proportion of children have bacteriological confirmation, then the programme probably needs to focus on improving sample collection and testing in children (Reuter, Hughes, & Furin, 2019).

Despite childhood TB challenges being more pronounced in the area of diagnosis, challenges and controversies also exist in the area of treatment. The "one-size-fits-all model" for TB treatment might not be the best for children. Children with isolated lymph nodes or simple pulmonary disease might require a relatively short treatment duration with few drugs (Harausz et al., 2018), whereas certain forms of severe TB disease (e.g., TB meningitis) might require

a longer duration of treatment with extra drugs that enter the central nervous system (Li et al., 2016). Some medications that are typically administered to adults might be too toxic to regularly administer to children, an example of which is the injections that have been recommended for the treatment of rifampicin-resistant and MDR-TB (Furin, Tommasi, & Garcia-Prats, 2018). One treatment challenge is with regards to children often being denied access to new TB medications, mainly due to dosing and safety concerns, (Harausz et al., 2017) while medications that are no longer recommended for use among adults because of known efficacy and safety concerns continue to be used in paediatric treatment (Reuter, Hughes, & Furin, 2019).

Another difficulty in childhood TB management is the NTPs' continuous use of adult formulations of many of the first-line and second-line anti-TB drugs for children through crushing and cutting (Furin et al., 2015). Cutting, crushing, and mixing adult pills to administer them to children often leads to inaccurate dosing and violates both good clinical and pharmaceutical practise (Taneja, Garcia-Prats, Furin, & Maheshwari, 2015). Reassuringly, enormous progress has been made in the availability and use of paediatric-specific fixed-dose combinations of the first-line TB medications, (TB Alliance, 2020) and approval of paediatric second-line formulations through the "Stop TB Partnership" in several LMICs.

Major obstacles to the utilisation of paediatric formulations are cost (because medicines used for adult treatment are usually cheaper than child-friendly ones), and registration of paediatric formulations with regulatory

authorities. Therefore, it is essential to fund both paediatric-specific scientific research and the inclusion of children and adolescents in adult TB clinical trials to avoid delays in access to innovation for this vulnerable population (Furin, Cox, & Pai, Tuberculosis, 2019). Community engagements with children and their primary caregivers are critical to ensure that the studies minimise risk, answer questions of importance to children, and consider various viewpoints of the affected households (Hoddinott, Staples, & Brown, 2018).

Integration of childhood TB into maternal and child health services

In many LMICs, the capacity to identify, diagnose, and manage childhood/paediatric TB is limited, particularly at the lower levels of the healthcare systems. The diagnosis and treatment of childhood TB are mostly centralised at higher levels of the healthcare system and mainly delivered in separate TB units or DOT centres. As such, there are missed opportunities for paediatric TB diagnosis and treatment (Trajman & Schwartzman, 2020). Paediatric services such as Maternal, Neonatal and Child Healthcare (MNCH)/under-5 services (including Child Welfare Clinics), outpatient clinics for children, paediatric HIV anti-retroviral services, and nutrition rehabilitation services may be the initial entry point for children with TB disease in many countries (Oliwa, Karumbi, Marais, Madhi, & Graham, 2015). The importance of linking TB prevention and care to maternal and child health programs has been long acknowledged (Marais, Graham, Maeurer, & Zumla, 2013). Studies from the HIV perspective have shown that integration of HIV services into other

health services, including TB services is feasible, does not undermine care, and safeguards against loss-to-follow up (Sinai, Cleghorn, & Kinkel, 2018).

In a systematic review on "the impact of interventions to increase tuberculosis case detection among adults at primary healthcare or community-level services", it was evident that service integration results in an increase in TB case detection, especially in the short term (Mhimbira, Cuevas, Dacombe, Mkopi, & Sinclair, 2011). This insight, notwithstanding, the impact of active case finding on treatment outcomes needed further inquiry since most studies included in the review were not intended to address this important question. Also, findings from "the DETECT study in Uganda" provides some optimism in this regard. It demonstrated that enhancing TB services at peripheral health facilities resulted in higher case findings, improved treatment outcomes, and the successful implementation of contact tracing and management (Zawedde-Muyanja et al., 2018).

Largely, studies on the integration of childhood TB care into other child health services are limited. However, the few available studies present grounds for optimism about the feasibility and appropriateness of service integration. A retrospective study reported the feasibility of intensified case-finding efforts in children at nutrition rehabilitation centres. The authors reported that "out of the 440 children with severe acute malnutrition who were screened for TB, 39 (8.8%) were positive". Among these, 87% were enrolled on anti-TB treatment (Pathak et al., 2016). This presents a ground for optimism regarding the feasibility and appropriateness of integrating childhood TB into other child

health services. Another study conducted in Ethiopia"examined intensive screening of children under-5 years in Maternal Neonatal, and Child Healthcare clinics" and it was evident that this approach is possible, even though its impact could not be measured owing to the limitations in the study design (Kebede, 2016).

A study that "assessed the impact of systematic verbal screening at a paediatric outpatient department, with clinical evaluation and free diagnostics on childhood TB detection in rural Pakistan" also reported positive results. The authors reported that the strategy led to a three-fold increase in paediatric TB case detection, thus demonstrating that this approach can find children with TB who may otherwise be missed in rural health settings (Malik et al., 2018). Due to the numerous entry points for children with TB, control programmes can take advantage of MNCH services to diagnose more children and address the persistent problem of missed paediatric TB cases (Detjen, Essajee, Grzemska, & Marais, 2019; Dubois et al., 2020).

Even more reassuring is the evidence to show that integrated case management of multiple diseases by well-trained community health nurses is feasible and will lead to better care-seeking and a reduction in all-cause mortality among under-5 children (Miller et al., 2014). Thus, childhood TB management can be integrated into other MNCH services at the community level of care. It is however worthy to note that childhood TB management is not like any other childhood disease. Indeed, due to the complexities of childhood TB, its management will require expertise to undertake (WHO, 2018).

Service integration, even though is associated with enormous benefits in resource-limited settings, implementation ought to be done with some level of tactfulness due to the programmatic nature of TB. Marais et al., (2013) warned that integrated programming ought to support, not erode the essential functionality of "National Disease Control Programmes" like policy direction, disease surveillance, drug supply, and records keeping. A study conducted in Malawi highlighted the importance of managing workload in ensuring the successful integration of childhood TB into maternal and child health services where nutrition and HIV services are also provided (Verkuijl et al., 2016). Also, system challenges such as inadequate human resources, insufficient training and supervision, poor data management, dysfunctional referral mechanisms, and poor infrastructure need to be addressed (Detjen, Essajee, Grzemska, & Marais, 2019). The existing institutional structures for TB control and the various MNCH services could be leveraged for service integration in various forms (WHO, 2018).

Integrated management and control of childhood diseases and its attendant community-level integrated case management are worthy illustrations of integrated primary health care service delivery for children below 5 years. From a systems point of view, integration requires that all the essential health system challenges are addressed at all levels. Integration emphasises health promotion and disease prevention as well as curative care to ensure comprehensive approaches that boost returns on investment. Even the donor organisations that support disease-specific control efforts (especially the Global

Fund) have acknowledged the significance of service integration and are committed to strengthening integrated frontline services (Detjen, Essajee, Grzemska, & Marais, 2019).

The psychosocial context of childhood TB

Caregivers for children with TB experience several challenges in getting their children diagnosed and navigating the treatment regimen. The multiple clinic visits before TB diagnosis posed a serious concern for families, thus highlighting the need for institutional strengthening through training and sensitization of healthcare providers and advanced TB diagnostic tools (Emerson et al., 2020). The long treatment period, complexities, and associated adverse effects of childhood TB treatment regimen can have substantial negative physical, psychological, and academic impacts on children and their primary caregivers, especially those living in poverty (Franck et al., 2014). Psychosocial support for children with TB and their primary caregivers to alleviate the negative consequences of stigma, and navigate the stressors related to TB are thus urgently needed.

The End TB Strategy's Pillar 1 emphasizes "patient-centred care and support that is sensitive and responsive to patients' educational, emotional and material needs" (WHO, 2014). As such, NTPs need to ensure that harm from institutionalising and/ or isolating children for treatment without a sound medical or public health justification should be avoided (Hummel, Ahamed, & Amanullah, 2020). Moreover, childhood TB has direct and indirect consequences and costs on the entire family. Primary caregivers and children

affected by TB need appropriate counselling, health education, assistance (both financial and material) for coping with intense and prolonged treatment regimens, nutritional, and psychological support because of isolation, stigma, and feelings of guilt (Paz-Soldan, Alban, Jones, & Oberhelman, 2013; Thomas et al., 2016). Children groups with special needs include orphans, street children, children of migrants and children in "child-headed" households (Hummel, Ahamed, & Amanullah, 2020). Eliminating user fees, fair charging policies and refunding clinical costs would go a long way to reducing the poverty-inducing impacts of direct diagnostic costs. In resource-limited settings, support could be prioritised for those most at risk of high expenditure (de Cuevas et al., 2016)

Material support for TB-affected households is crucial, even though that alone may not be enough in averting catastrophic costs due to TB infection and treatment (Barry, 2018). There are direct costs of care, (e.g., for medication and transportation) in addition to the loss of earnings or the need to sell assets to care for the patient (de Cuevas et al., 2016). Evidence points to the vulnerabilities of TB-affected households being exacerbated due to the care demands of the disease both in financial terms and time needed to care for patients, especially in the case of paediatric TB (Batista Lacerda et al., 2014). As a priority area, both the "End TB strategy" and the SDGs aim at eliminating catastrophic costs for TB-affected families. The realization of this goal will however require a concerted effort. For instance, support is crucial if breadwinners or caregivers are not able to engage in their economic activities

for longer periods because they are accompanying their children to health facilities for TB diagnosis and management (Hummel, Ahamed, & Amanullah, 2020).

The responsibility of caregiving for children with TB is mostly borne by women. Difficult parental interactions bring about mothers often bearing the financial responsibilities and general care of children with TB. Consequently, negative interpersonal and inter-household relationships amplified the mother's emotional and economic weakness (Loveday et al., 2018). The likelihood of women serving as primary caregivers is in line with traditional gender roles in Africa. As such, efforts must be directed at mitigating the vulnerability of women. In the case of young children, they may be at a loss as to why they have been admitted to the hospital and be afraid, nervous, uncertain, and confused about the whole happenings around them (Manning, Hemingway, & Redsell, 2013).

Often, children with TB get admitted to the hospital for treatment because of unjustified fear regarding its spread (van Custem, Issakidis, & Farley, 2016). Evidence suggests that a substantial percentage of children will suffer some form of emotional disruption due to the experience of hospitalisation and separation from friends and loved ones (Delvecchio, Salcuni, Lis, Germani, & Di Riso, 2019). Also, children with MDR-TB suffer possibly worse intellectual effects due to their phase in learning and development. Franck et al., (2014) reported that children with MDR-TB tend to exhibit poorer academic performance and behavioural changes when they

return to school following hospitalisation for MDR-TB treatment. Caregivers also reported reduced intellectual capacity in some groups of children with no seeming sign of cerebral involvement. The broader impact of childhood TB on household wellbeing is highlighted by studies reporting an increased risk of negative psychological effects, including depressive thinking, sadness, anxiety, and uneasiness (Loveday et al., 2018; Zhang, Ruan, Li, Wang, & Wang, 2014).

Experts are unanimous in the assertion that children, caregivers, and the affected households are in urgent need of age-appropriate counselling for children, health education based on specific needs (i.e. type of TB, TB-HIV co-therapy), assistance to cope with the treatment regimen, financial, nutritional, and psychosocial support regarding stigma and feeling of guilt (Treatment Action Group, 2013; Paz-Soldan, Alban, Jones, & Oberhelman, 2013).

Conclusion

The scoping review revealed key gaps in understanding childhood TB. The balance of the available evidence is tilted towards clinical studies. Childhood TB, especially MDR-TB in children requires extended periods of hospitalization and can exert multiple financial, and social costs on affected households. However, the impacts of childhood TB treatment on children, their primary caregivers, households, larger families, and their social contexts are yet to be fully understood. Large-scale qualitative studies driven by critical social theories are needed to better understand programme-related and psychosocial contexts of childhood TB (Hoddinott & Hesseling, 2018).

CHAPTER THREE

THEORETICAL ISSUES IN INFECTIOUS DISEASE MANAGEMENT: THE CASE OF CHILDHOOD TB

Introduction

In this chapter, some theories of infectious disease management have been reviewed and their applicability has been examined to offer theoretical perspectives on issues relating to treatment adherence. I searched online bibliographic databases including; EBSCO host, EMBASE, PubMed, MEDLINE, CINARL, PsycInfo, and ScienceDirect using keywords "health and behaviour together with (theory or model)"; "adherence and (theory or model)"; "(adherence or concordance or compliance)"; (treatment perspective) from the inception of the database to October 2020. Also, Google and Google-scholar were searched for relevant theories. A theory or perspective is deemed fit if it addresses at least one aspect of management/organization or had ever been applied to study infectious disease management. All theories that were deemed fit were put together and reviewed comprehensively. Finally, theories that were adjudged to be relevant to the study were included.

Theoretical overview

Theories and models have been used widely in health research and their roles in offering explanations for healthcare delivery and management of infectious diseases have been documented (Rosbach & Andersen, 2017). Therefore, theories play a critical role in the transferability of healthcare interventions

across contexts and settings (Roehrs, 2018). Theories have been employed in the study of a range of diseases; both acute and chronic (Chikovore et al., 2017; Mukumbang, Marchal, Van Belle, & van Wyk, 2018; Rosbach & Andersen, 2017; Willis, 2018). However, the focus of this review is on childhood TB – a chronic disease with a long-term treatment regimen. Therefore, the goal is to understand how these theories predict or explain adherence to a long-term treatment regimen for diseases such as childhood TB.

In addition, a synthesis of empirical evidence that applied these theories to study and promote treatment adherence has also been provided. While the focus of this theoretical review is tilted toward clients (primary caregivers for children with TB), I also subscribed to the assertion that adherence to a long-term treatment regimen for an infectious disease is a complex phenomenon that involves clients, service providers, the healthcare system, and the broader socio-political context (Kardas, Lewek, & Matyjaszczyk, 2013). As such, the review provides theoretical perspectives at the grand level (broader theoretical level) to deal with the complexities associated with treatment adherence in addition to specific micro-level theories that focused on the client and/or service providers. In this review, the term "perspective" is used to depict a grand level theory.

The biomedical perspective

The biomedical theoretical perspective assumes that the patient (in this case a child with TB and the primary caregiver) is a passive recipient of instruction from the medical practitioner or service providers (Patel, Arocha, & Kushniruk, 2002). Here, disease or ill-health is linked back to biomedical causes – "bacteria,

viruses and fungi". Therefore, the treatment is focused on the patient's biological make-up. In line with this perspective on illness and treatment, mechanical remedies like the prescribed pills/medications for the treatment regimen are given prominence (Chia, 2008). Therefore, non-adherence to the treatment regimen is usually blamed on the patient, with the patient's characteristics like age and sex understood as the direct determinants of non-adherence (Okoronkwo, Okeke, Chinweuba, & Iheanacho, 2013).

The use of technology such as Medication Event Monitoring Systems (MEMS), and mobile telephone text messaging for medication adherence are often traced to this perspective (Ngwatu et al., 2018; Thakkar et al., 2016). Even though this perspective is mainly used by health professionals (medical practitioners) it has also been sporadically used in intervention studies (Law et al., 2018). Despite the wide use and acceptability of this theoretical perspective both in practice and in the scientific literature, there are several inherent limitations to the theory.

A basic limitation of the biomedical perspective is that it disregards factors other than the characteristics of the patient that may influence treatment behaviour. These factors include; patients' assessment of their illness (Kosobucka et al., 2018; Pages-Puigdemont et al., 2016), the influence of the psychosocial environment of the treatment (Law et al., 2018), and the role of the socio-economic environment (Kilgore, Pulungan, Teigland, & Parente, 2016). For instance, the socio-economic context of the treatment may serve as a proxy for other factors that are linked with interventions and treatment

adherence for diseases with a long-term regimen like childhood TB (Falagas, Zarkadoulia, Pliatsika, & Ponos, 2008).

In recent times, the biomedical theory of care has been incorporated into the larger "biopsychosocial-environmental" perspective to enhance the broader understanding of the context of care. However, the biopsychosocial-environmental theory may not be considered entirely a biomedical theory. The mere fact that biomedical theory views the patient as a passive recipient of instructions from doctors and its strict focus on biomedical factors makes this perspective not very suitable for adherence to a long-term treatment regimen for diseases such as TB and HIV.

Most importantly, this perspective may not offer much understanding of adherence to TB treatment among children since the role of the primary caregiver is very critical to adherence in this case. In addition, the treatment regimen for TB among children is a complex one that will require an interplay of a multiplicity of factors including, biology, environment, economic, and psychosocial contexts (Sandgren et al., 2012). Parents and caregivers are generally active decision-makers for their children when it comes to ill-health and care-seeking.

Behavioural perspective

This perspective is framed based on behavioural learning theories to offer a broader understanding of how people learn and behave over time. These theories focus on the setting (context) and the teaching of skills to enhance adherence to treatment (Geidi, Semrau, & Pfeifer, 2014). This perspective is

informed by the concepts of "antecedents and consequences" and how they impact behaviour. Here, antecedents may either be internal (thoughts) or external (environmental cues) while consequences may either be punishments or rewards for specific behaviour. The likelihood of a client following the treatment regimen successfully is partially influenced by how antecedents and consequences play out (Náfrádi, Nakamoto, & Schulz, 2017). Instead of the presumption that adherence may be a result of advice from a medical doctor or health service providers or the knowledge that non-adherence will lead to negative health outcomes in the short or long run, the social-behavioural perspective recognizes the multiplicity of underlying factors influencing treatment adherence, sub-optimal adherence, or non-adherence.

However, there is overwhelming evidence to prove that interventions such as patient reminders and SMS alerts to promote adherence to a treatment regimen which is informed by this perspective have not been too effective in improving treatment adherence (Bediang, Stoll, Elia, Abena, & Geissbuhler, 2018; Hermans, Elbireer, Tibakabikoba, Hoefman, & Manabe, 2017; Liu et al., 2015; Mohammed, Glennerster, & Khan, 2016). Notwithstanding, the smartphone-based system has shown some potential to improve adherence to treatment (Molton et al., 2016). When combined with other strategies such as "patient education and counselling, incentives and enablers' packages", as well as community involvement, reminders have helped to improve treatment adherence for TB (Alipanah et al., 2018).

The available empirical evidence (mixed results with a lean towards negative outcomes) only further highlights the limitation of this perspective in terms of its applicability to enhance treatment adherence. This is even exacerbated when considering its applicability to improving adherence to the treatment regimen among children, especially given the complexities associated with childhood TB. Behavioural learning theories (BLT) have been widely critiqued as deficient in terms of an individualized approach and not giving credence to less obvious (but critical) influences on behaviour that are not connected to instant rewards (McLeod, 2017; Peel, 2005). Issues relating to past experiences or behaviour, habits, hesitance, or lack of acceptance of diagnosis could also play important roles in promoting adherence. Also, this perspective is limited by its extreme emphasis on external influences on behaviour, even though empirical evidence has shown multiple influences on behaviour.

It is therefore important that health promotion programmes that seek to enhance adherence to long-term treatment regimens like childhood TB pay close attention to individuals' perceptions of appropriate rewards before employing BLT to drive programmes and policies. Programmes and interventions that draw on BLT often used it in combination with other perspectives, even though sometimes used explicitly. With regards to childhood TB, a behavioural theory may not be an appropriate theoretical perspective to improve adherence due to the multifaceted nature of the treatment regimen. A child's adherence to the treatment regimen reflects the primary caregiver's

commitment to the process and how the various influences, including the healthcare system and service providers play out.

Cognitive perspective

The cognitive theoretical perspective is concerned with the cognitive (reasoning) variables as the basis for behaviour change (adherence to the treatment regimen for childhood TB in this case). The fundamental assumption underlying this perspective is that thoughts and beliefs, as well as prospects of future events and consequences, are key determining factors for health-related events such as adherence to a treatment regimen (Sabate, 2003). This perspective posits that when individuals are presented with a range of options, they are likely to adopt an action that will result in positive outcomes (Bandura, 2004). Theories from this perspective include; "the health belief model (HBM)", "social-cognitive theory (SCT)", "the theory of reasoned action (TRA)" and its later modified version of the "theory of planned behaviour (TPB)", the "protection motivation theory (PMT)" among others.

The cognitive perspective is relevant, especially in the pre-treatment initiation phase for a long-term treatment regimen like childhood TB management. This is because clients are usually taken through an adherence counselling session. It could be employed to help clients in understanding pertinent information about childhood TB and the possible actions to embark on with respect to decision-making concerning the illness and its attendant difficulties such as adherence to the treatment regimen. Also, support groups for TB clients could employ a cognitive theoretical perspective to empower

clients (mothers of children with TB) to navigate through challenges of the treatment regimen and establish supportive relationships which will ultimately reinforce their ability to adhere (Munro, Lewin, Swart, & Volmink, 2007).

Whereas this striking theoretical perspective has been extensively used in health research and practice, there are some limitations to this perspective. Firstly, the perspective's assertion that individuals make repeated conscious deliberation regarding available options seems rather unconvincing (Stroebe, 2000). Secondly, this perspective does not sufficiently deal with the behavioural skills required by the individual to ensure adherence to a treatment regimen (Adefolalu, 2018). Besides, the perspective gives little or no credence to the sources of beliefs and how these beliefs may influence other behaviours. Other factors like "power, relationships, and social standing" which may impact adherence behaviour have also been largely ignored by the perspective (Conner & Norman, 2005).

Also, the perspective ignores the likelihood that risky behaviour (such as non-adherence to childhood TB treatment regimen) may involve more than an individual. The perspective has also been critiqued for its emphasis on a single threat and prevention behaviour to the neglect of likely additional threats that competes for the attention of the individual (Quinlan & Dyson, 2008). Several micro-level cognitive theories have been employed to study health behaviour over the years. Some of these micro-level theories have been reviewed in the subsequent section.

Health Belief Model (HBM)

This is by far one of the commonest models used in health education and promotion. It is a psychological/cognitive model that was propounded in the 1950s and has since been either adopted or adapted to explain various behaviours surrounding long-term and short-term health and illness experiences. This model views health behaviour (adherence to childhood TB treatment regimen in this case) as informed by rational appraisal of barriers/challenges as against the benefits of a specific action (Ritchie, van Hal, & van Den Broucke, 2018). The basic concept of the original HBM is that health behaviour is informed by personal beliefs regarding a disease/health event and the strategies available to decrease its effect by the whole range of interpersonal factors affecting health behaviour. Thus, the perceived seriousness of disease and susceptibility to disease (childhood TB in this case) influence an individual's perceived threat of childhood TB.

In the same manner, "perceived benefits and perceived barriers" interact to inform perceptions of the usefulness of health behaviour (caregivers' adherence to the childhood TB treatment regimen). Therefore, demographic and socio-psychological variables (for both TB-infected children and parents/caregivers) influence both "perceived susceptibility and perceived seriousness", and the "perceived barriers and perceived benefits" (Lawal, Murphy, Hogg, & Nightingale, 2017; WHO, 2003). Thus, behavioural evaluation depends on; the perceived benefits of prevention or therapeutic health practices and perceived barriers, both material and psychological (for

instance “will-power” of caregivers), with regard to childhood TB treatment regimen. The “perceived threat” is informed by “cues to action”, which can either be internal (e.g., symptom perception – profuse coughing) or external (e.g., health communication – adherence counselling) (Ritchie, van Hal, & van Den Broucke, 2018; WHO, 2003).

Cues to action predict different internal and external factors that influence action or health behaviour. For instance, the nature and intensity of childhood TB symptoms (excessive cough and weight loss), mass media campaigns (e.g., TB is curable, seek early treatment), advice from relevant others (family, friends, and service providers – adherence counselling) will motivate healthcare seeking. High-perceived threat (childhood TB can lead to child mortality), low barriers (availability and easy accessibility to the treatment regimen), and high-perceived benefits to action (the treatment regimen can lead to cure) increase the chances of adherence to the treatment regimen (Hardeman et al., 2010).

Generally, the various components or constructs that make up the HBM are regarded as independent predictors of health behaviour (Armitage & Conner, 2000). It is, however, imperative to note that “perceived threats”, particularly “perceived severity” have a weak correlation or association with health behaviour and may even lead to avoidance of protective action (Orji, Vassileva, & Mandryk, 2012). Also worth noting is that “perceived severity” may likewise not be as significant as “perceived susceptibility”. Later improvements in the theory saw the addition of self-efficacy, highlighting the

need to feel competent before adopting a long-term behaviour (adherence to the treatment regimen for children) (Jones et al., 2014).

Despite its wide use in health and other fields of human behavioural studies, the HBM has suffered some critiques. One of such widely publicised critiques is that the theory fails to spell out the interconnectedness between the various variables. The theory also presumed that the variables are not moderated by each other and have strict predictive effects (Jones, Smith, & Llewellyn, 2014). Thus, if for instance, there is a high perceived threat and low susceptibility, the likelihood of an individual adopting the recommended behaviour will be high. Whereas this may hold to a large extent, intuitively, one might assume that the likelihood of action in this instance will be lower if both variables are high (Stroebe, 2000). Also, the theory is based on the assumption that the variables affect health behaviour directly and are not moderated by behavioural intentions (Stroebe, 2000), thereby limiting the predictive power of the theory (see, Jones, Smith, & Llewellyn, 2014). The theory also ignores the positive effects of negative behaviour and the influence of society which are important determinants of health behaviour (Martos-Mendez, 2016).

In addition, behaviours such as alcohol consumption and smoking are more of habits than a decision (Gardner, 2015; Limayem, Hirt, & Cheung, 2007). As such, the tenet of the theory is limited in that regard. Whereas the theory has been able to predict treatment adherence in some contexts, it has not been able to demonstrate such predictive powers in other contexts where reductions in risky behaviours are more linked to social determinants or

spontaneous motivations (Martos-Mendez, 2016). However, concerning childhood treatment (long-term treatment regimen), the theory may hold to a very large extent since mothers/caregivers' adherence to the treatment regimen may be more of a decision than a habit. When applying the HBM to adherence to a long-term treatment regimen (e.g., childhood TB treatment regimen, and antiretroviral therapy), the influence of psychosocial factors needs to be given credence (Skovdal, Campbell, Nhongo, Nyamukapa, & Gregson, 2011). For instance, socio-cultural "misconceptions and myths regarding TB" (Amo-Adei & Kumi-Kyereme, 2013) may hinder the effectiveness of interventions that seek to enhance treatment adherence.

Prediction of adherence to a long-term treatment regimen is difficult due to the multiplicity of factors that come into play. Health-related understanding and beliefs alone are not adequate to ensure behaviour change, particularly in the case of chronic disease conditions such as HIV and TB which require a long-term (life-long in the case of HIV) treatment regimen (Adefolalu, 2018). A recent systematic review concluded that the success of health interventions tends to rather be unrelated to the health belief model constructs that seek to improve treatment adherence (Jones, Smith, & Llewellyn, 2014). Notwithstanding, people can influence or control the events/factors that impact their lives (adherence to the treatment regimen) by integrating social, cognitive, and behavioural sub-skills that are relevant to beliefs of personal efficacy in demonstrating these skills. Despite the obvious limitations in the HBM, it

remains popular among academics and its application to health interventions is overwhelming. Below is the diagrammatical presentation of the HBM.

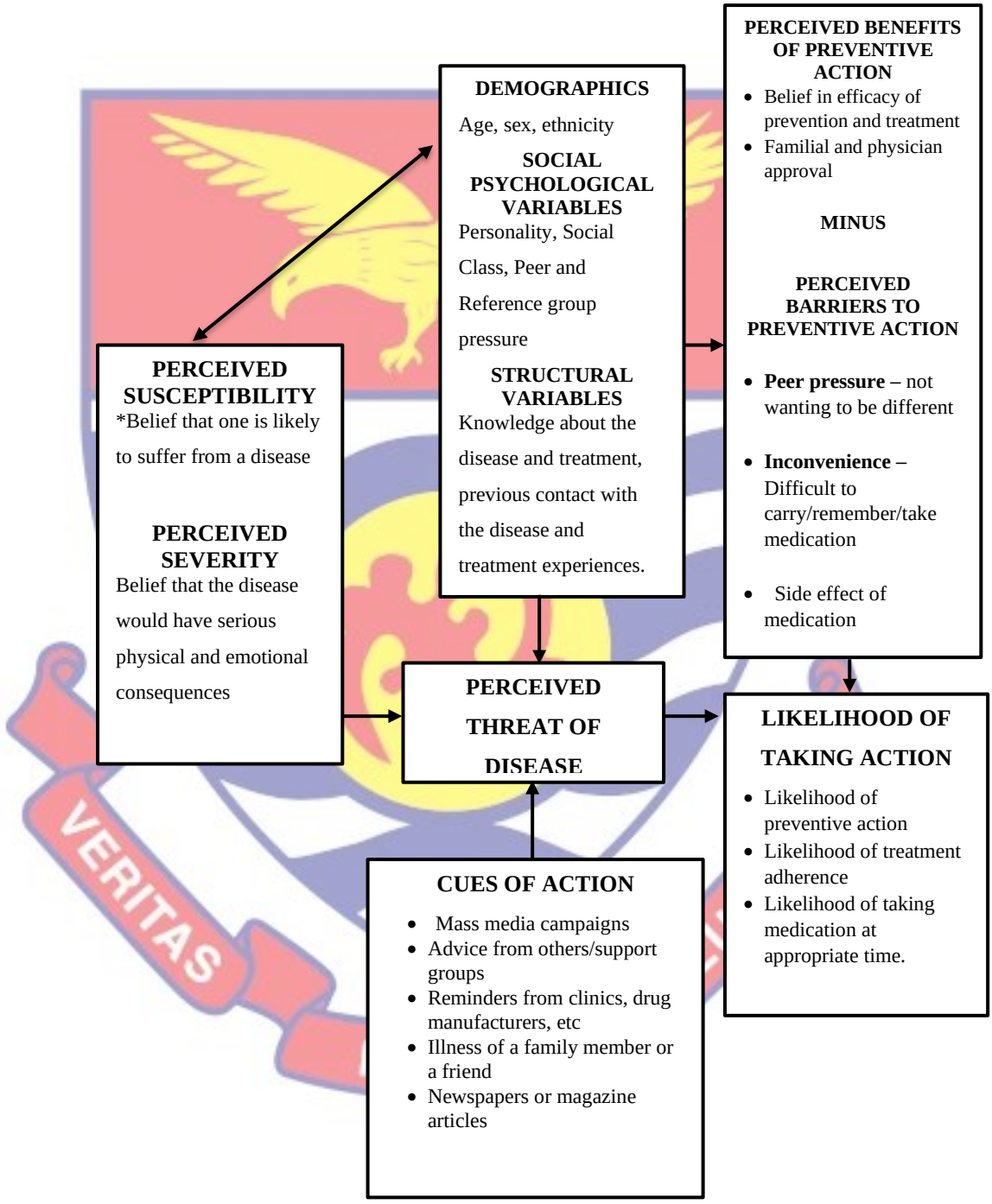

Figure 1: The Health Belief Model

Source: Jones et al., (2014)

The Protection-Motivation Theory

This theory was postulated by Rogers (1975) to explain how an individual is motivated to take action (protection) based on fear. The protection-motivation theory (PMT) posits that behaviour change (adherence to childhood TB treatment regimen) may be achieved by alluring to an individual's fears regarding a particular behaviour (non-adherence to the treatment regimen). The theory postulated three components of fear arousal: "the magnitude of harm from a purported event; the probability of that event's occurrence; and the efficacy of the protective response mechanism". These factors (components) interact to determine the strength or level of protection motivation (Rogers, 1975), thereby leading to a range of activities undertaken out of the desire to protect oneself (Floyd, Prentice-Dunn, & Rogers, 2000).

Mothers' or caregivers' adherence to the treatment regimen for their children is influenced by the *motivation* to protect the child from a negative treatment outcome. Here, protective motivation is regarded as the function of appraisals of threat (death of the child due to TB) and coping. Consequently, adherence is determined by *threat appraisals* as a function of perceived severity and susceptibility to a negative outcome. The coping appraisal is seen as a function of the perceived efficacy of adherence to the treatment regimen and self-efficacy of response to the total costs of adherence (Amico, Mugavero, Krousel-Wood, Bosworth, & Merlin, 2017).

The PMT is perhaps one of the few theories (if not the only theory) within the larger cognitive perspective that overtly utilizes the 'pros' and 'cons'

of present and recommended behaviour to predict the probability of change (Milne, Sheeran, & Orbell, 2000). For instance, a mother/caregiver whose child has been diagnosed with TB will weigh the costs and benefits of non-adhering and adherence to the treatment regimen and then make a decision. Caregivers' adherence to the treatment for their children is influenced by the motivation to protect the child from dying from childhood TB. In essence, mothers/caregivers with higher perceived benefits of adherence and higher perceived susceptibility to the repercussions of non-adherence and beliefs in repercussions being severe will have high threat appraisal. If the aforementioned conditions are combined with a coping appraisal that favours adherence (such as beliefs that adherence will lead to positive treatment outcomes and having confidence in being able to engage in adherence behaviour that outweighs the perceived cost of adherence), this will result in high protective motivation that will lead to treatment adherence (Amico, Mugavero, Krousel-Wood, Bosworth, & Merlin, 2017).

Despite the obvious strength of the theory, there are some inherent limitations. One of such limitations is that the theory is not able to identify several environmental and cognitive variables (e.g. pressure to conform to societal norms) that could influence a change of attitude (Rogers, 1975). The later version of the theory is built on the premise that motivation to protect oneself from an undesirable event is a positive linear function of beliefs that: the threat is severe; an individual is vulnerable; one can undertake the coping response (self-efficacy); and the coping response is effective (Stroebe, 2000). Beliefs that health-compromising behaviour (such as smoking and alcohol) is

rewarding and that giving it up could be costly are presumed to result in negative outcomes (Stroebe, 2000). The critique against this postulation is that the subdivision of perceived efficacy into categories of response-efficacy and self-efficacy is conceivably inapt. Individuals would not see themselves as capable of taking an action independent of the means to do it (Grindley, Zizzi, & Nasypany, 2008).

Evidence from a meta-analysis revealed that the PMT only has a modest effect on behaviour (Floyd, Prentice-Dunn, & Rogers, 2000), highlighting the strength of alternative theories such as the Theory of Reason Action (TRA). However, the later version of the PMT could be less complex to use and more applicable than the TRA as it does not assume that behaviour is always rational (Floyd, Prentice-Dunn, & Rogers, 2000; Munro, Lewin, Swart, & Volmink, 2007). Evidence from qualitative studies showed that the theory offers a coherent framework for understanding health and treatment behaviours (Chambers et al., 2016; Searle, Vedhara, Norman, Frost, & Harrad, 2000).

The PMT could be suitable for adherence interventions since it is very doubtful that an individual will consciously re-evaluate all their routine behaviours such as following the long-term treatment regimen like that of TB. This notwithstanding, it is important that when employing this theory, the influence of social, psychological, and environmental factors on motivation needs to be considered (Grindley, Zizzi, & Nasypany, 2008). Diagrammatical illustration of the original PMT by Rogers, (1975) and a later version that has undergone modifications are provided below.

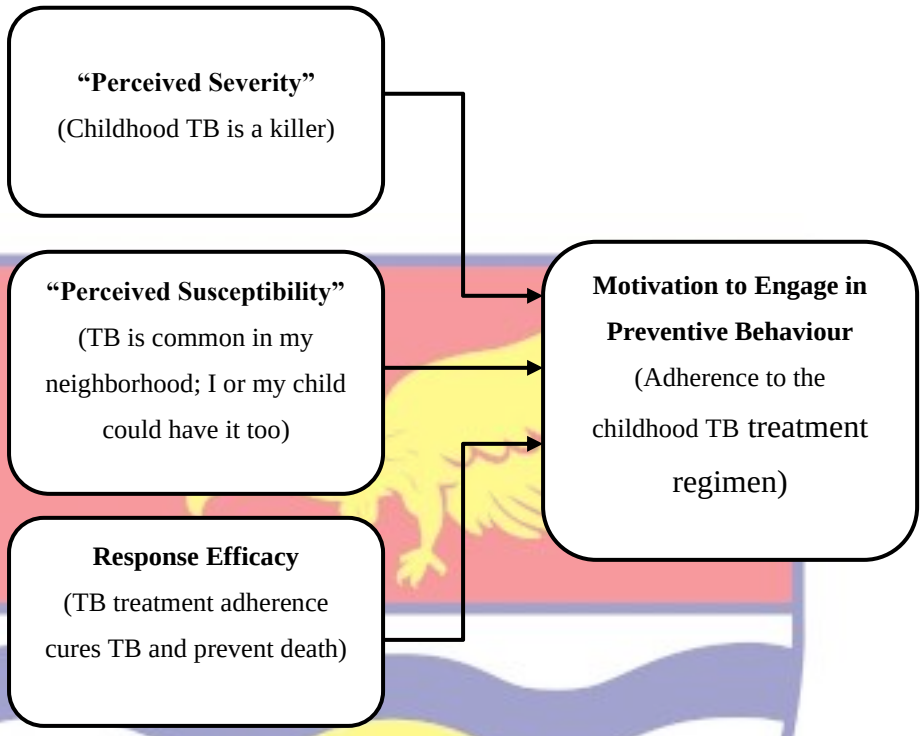

Figure 2: Protection motivation theory
Source: Adapted from Rogers (1975)

Whereas the original version of the PMT remains popular among researchers and its application in health promotion has been overwhelming (Milne, Sheeran, & Orbell, 2000; Milne, Orbell, & Sheeran, 2002; Rajendran & Shenbagaraman, 2017; Wong, Gaston, DeJesus, & Prapavessis, 2016), the theory has undergone some modification. The modification to the theory was necessitated by empirical evidence that revealed that people engaged in appraisals before finally adopting a behaviour. As such the later versions included threat appraisals and coping appraisals to inform protection motivation. The diagram below illustrates the PMT based on the later versions of the theory.

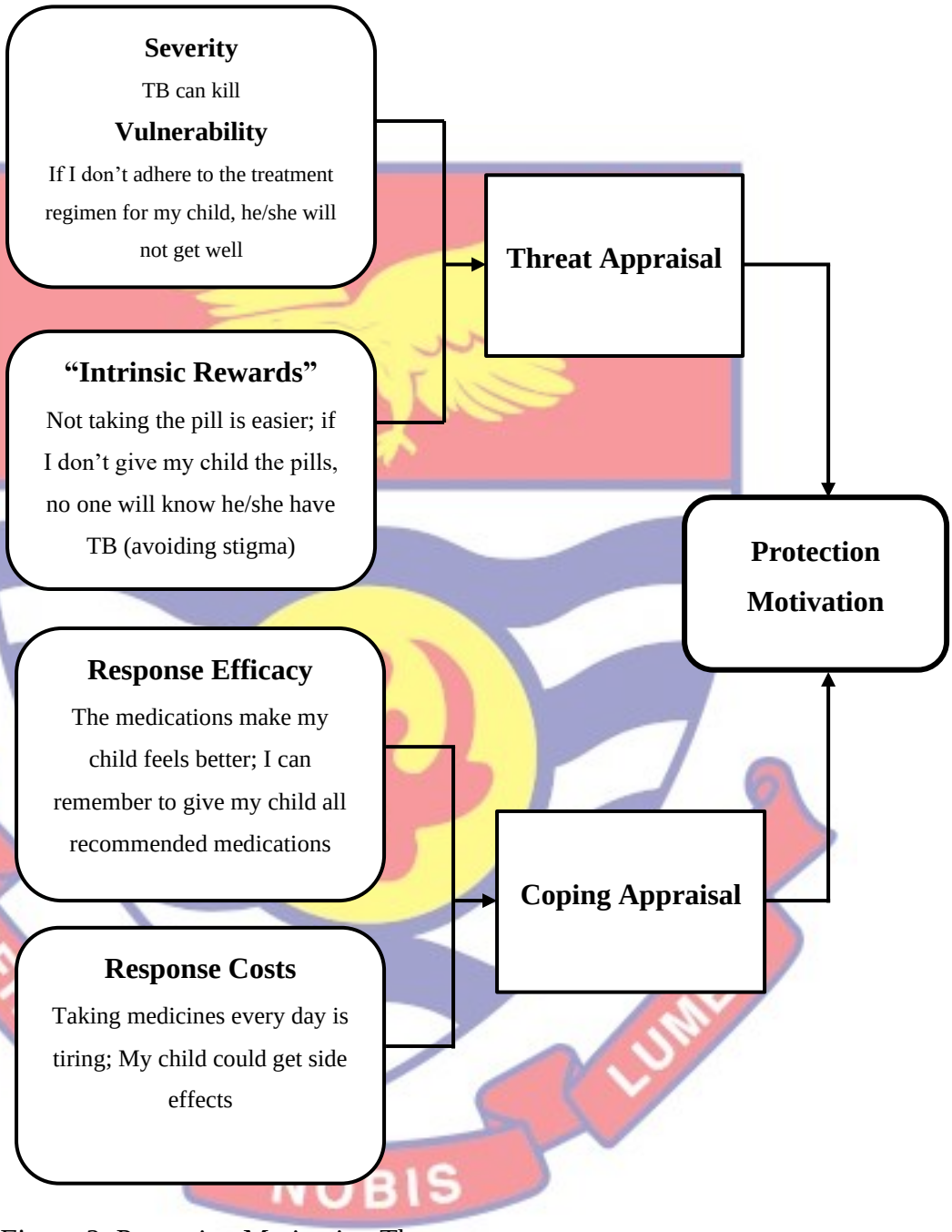

Figure 3: Protection Motivation Theory

Source: Stroebe, (2000) and Amico et al., (2017)

Social-Ecological Perspective

The theoretical review so far has demonstrated that no single perspective (biomedical, cognitive, and behavioural) offers a comprehensive understanding of adherence to a long-term treatment regimen like TB (either paediatric or adult TB). This deficiency is even exacerbated when we consider the peculiarity of childhood TB and its attendant complex treatment regimen with a multiplicity of factors coming into play. This leads me to the consideration of the social-ecological perspective (SEP) or what I can best describe as a *multi-dimensional* perspective. The SEP presents healthcare (management of childhood TB in this case) as an interaction between the child and primary caregiver on one hand and their ecosystem or social web on the other hand. This complex social web includes their family, community, social norms, culture, physical environment, and most importantly the health facility and service providers. It is worth noting that within the social-ecological system, there is a reciprocity of influence – individuals are influenced by their ecosystem and the environment and in the same vein, people influence the ecosystem (Glanz & Rimer, 2005).

The social-ecological perspective is largely deduced from the systems theory. The SEP is made up of person-focused and environment-focused interventions intended to promote health (treatment adherence in this instance). The emphasis here is on the *ecology* which in this context refers to interactions among intrapersonal factors, interpersonal connections, primary groups, community influence, institutional factors, and public policy. Theories in this perspective focus on how people and the environment influence each other

(Golden & Earp, 2012). Here, the assumption is that individual efforts to adhere to childhood TB treatment regimens are more likely to succeed within a supportive environment. The perspective targets social, institutional, and cultural environments together with biological processes.

According to this perspective, one's behaviour is moulded by repeated patterns of activities that occur within an organised environment like the healthcare facility and others, including education, residence, occupation, religion and recreation. These environments exert a collective influence on health and well-being. Embedded in these environmental settings are social roles, personal behaviours, and situational conditions (like access to healthcare facilities) that influence both personal and collective well-being. Therefore, programmes and interventions targeted at improving adherence to long-term treatment regimens like that of childhood TB need to give due cognisance to these factors to maximize adherence behaviour (Mathes, Jaschinski, & Pieper, 2014).

There are several forms of the social-ecological model (SEM) that have been put forward to understand and explain various aspects of healthcare. The original and perhaps the most used SEM is the one put forward by Urie Bronfenbrenner which is known as Ecological System Theory (Bronfenbrenner, 1994). In the SEM, the primary influences are interpersonal/individual, intercultural, community-level, and organizational-level influences. Even though this theory remains popular among researchers, it will not be considered in this study because it is broad, complex, and deemed to be more related to

child development than adherence to a treatment regimen. Therefore, other micro-level theories which are less complex and deemed appropriate to the scope of this study were considered.

Normalization Process Theory

Normalization process theory (NPT) is a group of interconnected sociological elements which are assembled to offer a robust understanding and description of social actions through which novel or modified practices of an idea, implementation and organizing work are undertaken in healthcare and other settings (May et al., 2009). The development of NPT was a response to the observed complexities in integrating new ways of healthcare delivery into the larger healthcare system. Before the inception of the NPT, existing theories such as the diffusion of innovation theory that were employed to study healthcare interventions were regarded as cumbersome and often not applicable to a real-world situation (Cook et al., 2012).

Therefore, NPT offers an easy approach to understanding and assessing the use of evidence in healthcare interventions or policy innovation (Finch & May 2009). It is an upgrade on earlier theories like the diffusion of innovation which has dominated the healthcare implementation literature despite its inherent limitations in measurement. The NPT relies mainly on empirical knowledge and provides a more dynamic but holistic assessment of key issues that are involved in the overall processes; from innovation to incorporating new interventions (such as integration of childhood TB management into child welfare clinic) into everyday care and practices.

The central principle of the NPT revolves around "collective, coordinated, and cooperative social activities to understand the agents" (in this case TB healthcare providers and primary caregivers for children with TB) within the treatment process (May, 2013). An innovation such as service integration is operational through four related mechanisms; "*coherence, cognitive participation, collective actions,* and *reflexive monitoring.".*

The coherence aspect (sense-making of childhood TB management and control) deals with the agents involved (in this instance, service providers for childhood TB and primary caregivers for children with TB) working together to achieve a common goal (in this case effective management of childhood TB). All agents are anticipated to work coherently based on specific procedures to achieve the desired outcome. Agents individually and collectively will have to acknowledge that the management modality (including innovation to the existing modalities) is appropriate and will help them to effectively improve the management of childhood TB. In the case of integration of childhood TB management into CWC, service providers will first have to make sense of this innovation. Thus, they must acknowledge that the proposed policy shift is ideal and will ensure better management of childhood TB.

The second aspect; "cognitive participation" (or how an intervention or policy shift in management could fit into existing ways of service delivery) is about defining and organizing actors to carry out their new roles in a given facility or healthcare system. Here, roles are spelt out clearly for childhood TB service providers. For example, in a linkage model of service integration, when

a child is diagnosed with TB, the NTP official is expected to refer the child to a nutritionist to determine the nutritional status of the child. The child is also expected to be referred to the NACP official to test for HIV if the test is not available at the chest clinic. Similarly, a child who has reported to the malnutrition centre is also expected to be screened for TB. Thus, the different actors recognise and agree on their individual and collective roles in the novelty or policy shift. Roles may overlap though, but the emphasis is on how the individual roles can fit into the collective (May, 2006).

The third component that is called "collective action" is with regards to the implementation of the new policy or intervention. Here, the roles, tasks, and procedures that were recognised at the "cognitive participation" stage are put into actual practice. Accordingly, individual and collective actions are required to ensure that the innovation fits into the existing mechanism to achieve the desired outcome. Distinctively, "Collective Action" which is the focus of this work is also known as the "Normalisation Process Model (NPM)" and is made up of four sub-components; "Contextual Integration (CI), Relational Integration (RI), Skill Set Workability (SSW) and Interactional Workability (IW)" (May, 2006).

The contextual integration concept refers to the circumstances in which healthcare professionals and patients meet one another where the treatment regimen is operationalised. Relational integration construct deals with the network of relations in which clinical appointments between service providers and primary caregivers for children with TB are made, and by which knowledge

and practice concerning the treatment regimen are defined and operationalised. It deals with two critical issues; accountability and confidence. Skill-set workability refers to the entire healthcare labour force (medical and paramedical) and the division of labour or individual roles within a given healthcare facility. It is characterized by two dimensions; allocation and performance. Interactional workability construct is concerned with the capability of a health facility to understand and accept the allocation of control and resources, including infrastructure to implement a complex intervention (in this case integration of childhood TB management into CWC). It involves two activities; execution and realization (May, 2006). (See the *theoretical frameworks for the study* section for details and contextualisation of the normalisation process model).

The last phase, which is "reflexive monitoring" deals with defining and organizing the knowledge upon which appraisal is done. This process involves an appraisal of the worth of the new intervention/policy at both individual and collective levels. Thus, it is the ongoing individual and collective valuation of the benefits of the new policy or healthcare delivery approach, be it for primary caregivers for children with TB or their professional practice. Available evidence points to the fact that periodic appraisals are essential since they will help unearth problems and challenges that need to be addressed to sustain the new intervention and also recognize its value or otherwise (May et al., 2009).

There is overwhelming documented evidence that demonstrates the application of NPT in several health intervention/policy studies and has proven

to provide high-quality explanatory power for why new interventions/policies have been successful or otherwise (Bamford, Heaven, May, & Moynihan, 2012; Gunn et al., 2010; Hooker, Small, Humphreys, Hegarty, & Taft, 2015; Morden et al., 2015). Documented evidence from Ghana where NPT was employed to explore the "experiences of TB-HIV co-infected patients" reported that the theory offers a comprehensive contextual and theoretical explanation for understanding patients' perspective of the treatment experience in the context of service integration (Anku, Amo-Adjei, Doku, & Kumi-Kyereme, 2018).

Evidence from a systematic review of qualitative studies that employed NPT as a framework suggests that the theory provides appropriate tools for studying interventions/changes in healthcare (McEvoy, Ballini, Maltoni, O'Donnell, & Mair, 2014). However, researchers need to put the various constructs of the theory into context. A critical examination of the key constructs of the theory suggests that the theory is tilted towards the healthcare (environmental dimension) context. To this end, the normalization process model (NPM) was deemed appropriate for exploring issues relating to the feasibility of integrating childhood TB management into child welfare clinics.

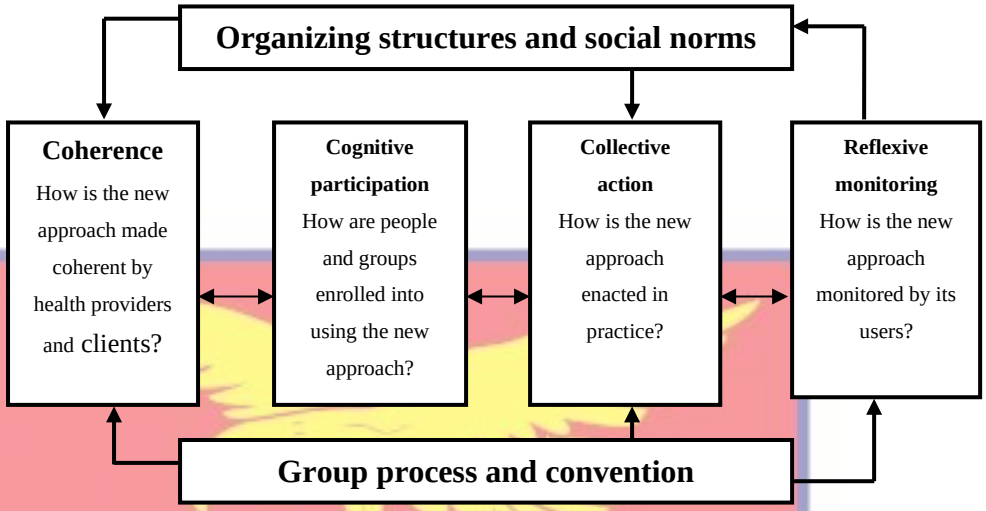

Figure 4: Normalization Process Theory (NPT)

Source: Morden et al., (2015).

Salutogenic Theory

The Salutogenic Theory (ST) was proposed by Antonovsky (1996) as a theoretical basis to conceptualize health promotion while dealing with concerns that other theories focused so much on health education, instead of the wider sphere of health promotion. The theory was developed to emphasize health-enhancing (salutary) instead of risk factors for a specific disease. That is, the theory views an individual in a complete manner instead of the risk factors for disease as well as understanding factors that bring a sense of coherence (SOC) to life. The emphasis is on the health of the individual (a salutogenic orientation), and not the disease (a pathogenic orientation). According to Antonovsky, the focus should be on the ease/dis-ease continuum and not the health/disease continuum (Antonovsky, 1996). This is very critical for adherence to a long-term and complex treatment regimen like that of childhood

TB as the ease/dis-ease of the regimen can influence the primary caregiver or the child's attitude to medication.

Salutogenesis refers to the origins of health determined by a person's sense of coherence. Essentially, salutogenesis is understood as the process of enabling individuals, groups, organizations, and societies to emphasise abilities, resources, capacities, competencies, strengths, and forces to create a "sense of coherence" and thus view life and unavoidable stressful events (e.g., Childhood TB treatment regimen) as *comprehensible*, *manageable*, and *meaningful* (Apers et al., 2016). When faced with live challenges (TB infection of one's child and subsequent treatment regimen), primary caregivers want to be motivated to follow the treatment regimen (*meaningfulness*), to believe that the disease, as well as the treatment regimen, can be understood (*comprehensibility*), and to acknowledge that resources are available to enable them to adhere to the treatment regimen (*manageability*). The strength of an individual's SOC is shaped by the consistency of an individual's life experiences, underload-overload balance, participation in decision making, social status, family structure, occupation, gender, and biology.

A robust SOC motivates an individual to access and utilize resources to minimize the current stressors (following childhood TB treatment regimen, in this case) (Antonovsky, 1996). In Antonovsky's postulation, two concepts are central to the theory – *coherence* and *generalised resistance resources (GRRs)* that helps an individual to avoid disease or the devastating consequence of a disease. GRRs involve "external and internal resources" that enable an

individual to cope with and manage life events. These GRRs facilitate balance, shape health outcomes, create meaning, help one to make sense of life, and enable a robust sense of coherence. Coherence is determined by cognitive, behavioural, motivational, and institutional factors as well as fostering relationships and meaningful pursuits (Lindstrom & Eriksson, 2009). Better GRRs result in strong SOC and a strong SOC (i.e., salutogenesis) creates movement towards health (adherence to the treatment regimen). This is depicted by the larger arrow that links salutogenesis to health in figures 5 and 6.

A major strength of the Salutogenic Theory is that it draws on cognitive, behavioural, and motivational (i.e., availability/accessibility to a healthcare facility and appropriate treatment regimen) constructs to explain a sense of coherence. This is critical for a comprehensive understanding of adherence to a long-term treatment regimen like TB. Antonovsky (1996) emphasised that the concept of SOC is not tied to culture, even though he acknowledged that the evidence upon which the salutogenic theory was built was drawn largely from Western countries. The salutogenic theory has been widely applied in either adopted or adapted forms to understand various health and life events and has shown high predictive and explanation power (Aho, Hultsjo, & Hjelm, 2015; Apers et al., 2015; Apers et al., 2016; Garcia-Moya, Moreno, & Jumenez-Iglesias, 2013). Besides, the power of SOC in improving young people's health and well-being have been documented (Rivera, Garcia-Moya, Moreno, & Ramos, 2013).

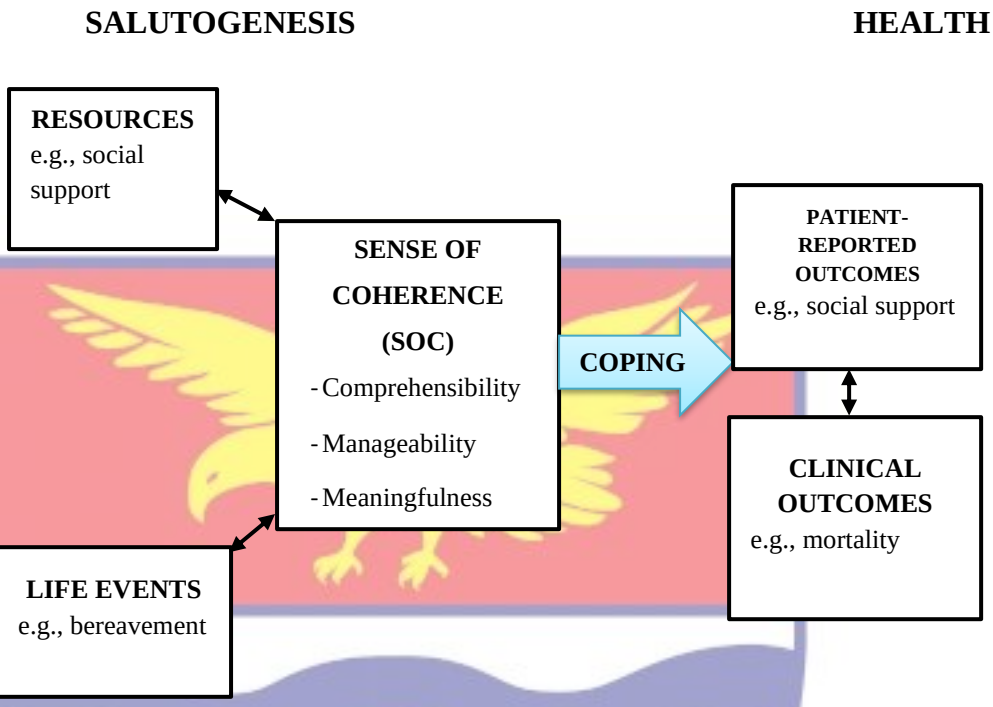

Figure 5: Simplified framework of the Salutogenic Theory

Source: Apers et al., (2016)

Theoretical frameworks for the study

Based on the Salutogenic Theory

The Salutogenic Theory has been adapted as one of the theoretical frameworks for the study after a comprehensive review of health theories and their applicability to long-term treatment regimens like childhood TB. The various grand-level theories were reviewed and some of their attendant macro/micro-level theories were also reviewed. The decision to select Salutogenic Theory as a theoretical framework for the study was informed by its relative advantage over the other theories as far as the goal and direction of this study are concerned. The explanation power of the theory has been demonstrated at the

population, group, and individual levels. The theory has a starting point of seeing an individual in a holistic manner instead of the risk factors for disease as well as understanding factors that bring a sense of coherence to life (Lindstrom & Eriksson, 2009). The decision to employ Salutogenic Theory as a framework to drive this study meant that all aspects; including healthcare, household, and psychosocial contexts can be extensively explored by drawing on the various constructs of the theory.

In summary, "Salutogenic Theory" offers a robust theoretical framework as it will be critical in the data analyses and discussion of the study results. The various constructs of the theory served as important tools in exploring, analysing, and understanding issues surrounding the psychosocial context of the treatment regimen as well as the general management and control of childhood TB. Figure 5 showed a conceptual framework based on Apers et al., (2016). Taking cues from Jones, Clavier, and Potvin, (2017), the theoretical framework has been adapted to operationalize the constructs to better fit the current study by providing contextual explanations of what constitutes the various constructs concerning this particular study (childhood TB management and control). The adapted version of the theoretical framework based on Salutogenic Theory is illustrated in figure 6.

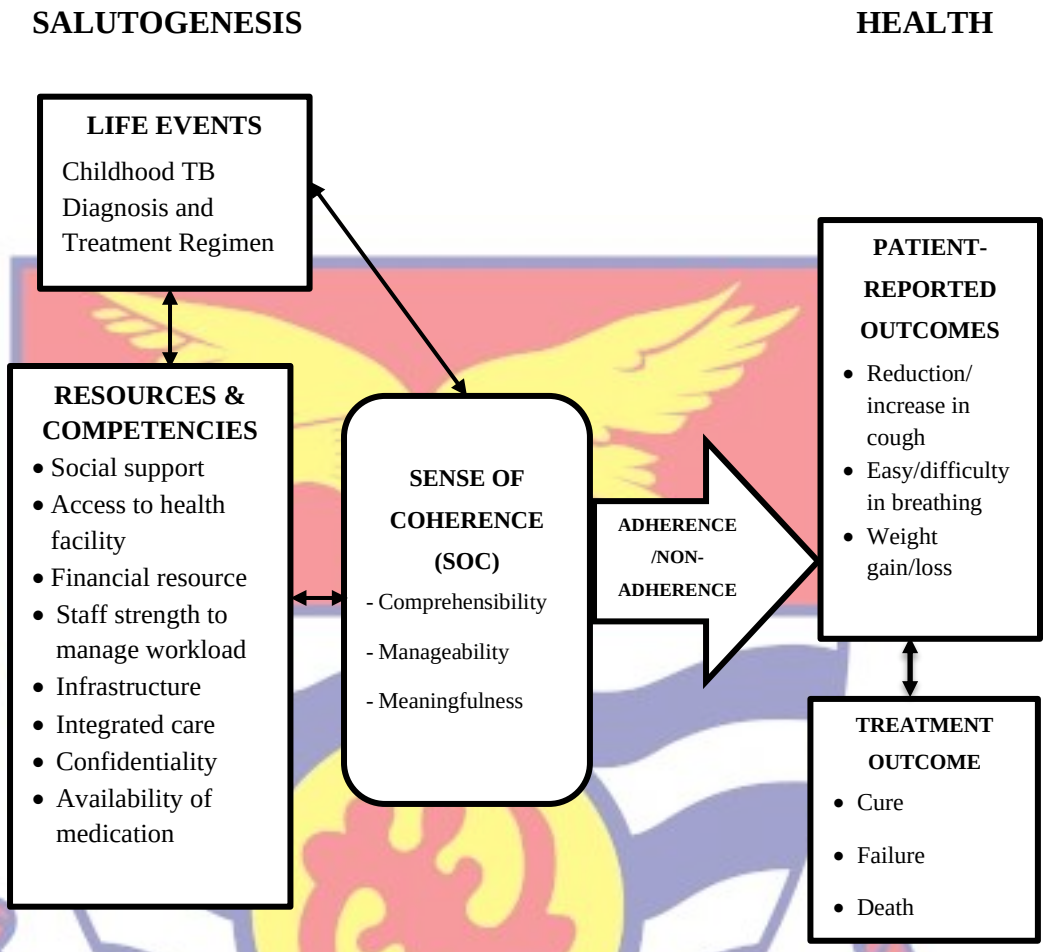

Figure 6: Salutogenic Theory (ST)

Source: Adapted from Antonovsky, (1996)

Based on the Normalisation Process Model

The NPM is concerned with the implementation of a new policy, intervention, or idea aimed at improving the operation of a given system in this thesis effective management of childhood TB in this case through integration. The model relies on four components of the "collective action" construct in the broader NPT to assess the normalization potentials of innovations (new techniques, technologies, working practice, and organizational interventions) in

healthcare settings (May, 2006). These are; "interactional workability (IW), relational integration (RI), skill set workability (SSW) and contextual integration (CI)".

The "interactional workability" construct is concerned with the immediate circumstances in which service providers and clients in this instance children with TB and their primary caregivers (PCGs) encounter each other, and in which a complex intervention such as integration of childhood TB management into CWC is operationalized. The interactional workability is characterized by two dimensions; (i) congruence and (ii) disposal. Congruence, in this case, refers to the order of interactions among agents (e.g. service providers and PCGs for children with TB) within an integrated CWC.

Three components; "co-operation, legitimacy, and conduct" make up the congruence. (i) Co-operation attempt to secure shared expectations regarding the nature of work to be done within the various agents (health workers at the CWC and the TB clinic); to minimize internal and external disruption, and to contain them within the limited time and space. (ii) Legitimacy is concerned with shared beliefs about the legitimate objectives of childhood TB-CWC service integration and the roles of actors. (iii) Conduct deals with formal and informal rules that guide the various verbal and non-verbal conducts in such interaction. Disposal on the other hand refers to the effects of interactions between/among agents in an integrated CWC. It includes three dimensions; (i) goals, (ii) meaning, and (iii) outcomes. This construct posits that a complex intervention (integration of childhood TB management into CWC in this case)

is "disposed to normalization if it confers an interactional advantage in flexibly accomplishing congruence and disposal" (see May, 2006).

Relational integration construct concerns the network of relations in which clinical encounters between service providers and PCGs are located, and through which knowledge and practice regarding the integration of childhood TB into CWC are defined and mediated. It is characterized by two dimensions; (i) accountability and (ii) confidence. Here, accountability refers to the "internal credibility of the body of knowledge and practice possessed by an agent" (service providers at the CWC) relative to childhood TB management as an addition to CWC services. Embedded in this are *validity* (relative agreement about the forms of work), *expertise* (shared or overlapping beliefs about the expertise necessary for the integration of childhood TB management into CWC) and *dispersal* (formal and informal rules that govern the distribution of knowledge and practice within the network of NTP – TB management and control at the facility). Confidence on the other hand is concerned about the external credibility of knowledge and practice through which integration of childhood TB management into CWC is mediated. It includes three components; credibility, utility, and authority. The proposition from this construct is that a complex intervention (integration of childhood TB management into CWC) is "disposed to normalization if it equals or improves accountability and confidence within a network".

The "skill-set workability" concept refers to the formal and informal divisions of labour in healthcare settings and how knowledge and practice about

a complex intervention are distributed. It is characterized by two dimensions; *allocation and performance*. Here, *allocation* refers to the institutional definition of agents and the designation of tasks concerning the integration of childhood TB into CWC and the wider range of activities within the healthcare system. It includes three components; (i) Distribution – formal or informal policies about the assignment of tasks, efforts to minimize internal and external disputes regarding allocation decisions and the structure of work etc. (ii) Definition – formal and informal agreements about the identification and appraisal of critical skills, and the definition and ownership of a given skill-sets. (iii) Surveillance – formal or informal mechanisms for the scrutiny of the work that is done within a healthcare system.

Performance, in this instance, refers to the capacity of agents to organize and deploy a complex intervention (integration of childhood TB management into CWC in this instance) as part of the range of activities within the healthcare system. It includes three components; (i) Boundaries – Formal or informal policies concerning the competencies needed for the work undertaken within the system, and practice that stipulates the permeability of skill-set boundaries. (ii) Autonomy – Formal or informal agreement regarding the degree of autonomy of owners of particular skill-sets, and how they are managed. (iii) Quality – formal or informal expectations about the quality of the work that is done among the various service providers. The postulation from this construct is that "a complex intervention is disposed to normalization if it is calibrated to an agreed skill-set at a recognizable location in the division of labour.

The contextual integration construct of the NPM refers to the capacity of a healthcare facility to understand and agree on the allocation of control and infrastructure resources needed to implement a complex intervention (integration of childhood TB into CWC). Also, to negotiate its integration into an existing pattern of activities. It includes two dimensions; execution and realization. Here, *execution* refers to the ownership of control over the resources and agents needed to implement the integration of childhood TB management into CWC. It includes three components; resourcing, power, and evaluation.

Realisation on the other hand refers to the allocation and ownership of responsibility for the implementation of the intervention within the healthcare system. It includes three components; (i) Risk – Formal or informal negotiations about the modification to the existing system and practices needed to ensure that new ones are possible. (ii) Action – formal or informal agreements about the procurement of resources and about the mechanisms by which these resources are put into practice. (iii) Value – formal or informal expectations of the value of the work that is done within them. The proposition from this construct is that "a complex intervention is disposed to normalization if it confers an advantage on an organization in a flexibly executing and realizing work" (May, 2006). As such, interventions that require radical disturbance of divisions of labour and patterns of an organization may not be a good fit for normalization.

Summary

The theoretical review (as well as the earlier empirical review) has revealed a wide range of determinants for treatment non-adherence or interruptions. These

reasons range from mere forgetfulness to complex social interactions that push people to avoid taking medications to escape disease-related stigma and discrimination (Brown & Bussell, 2011; Gast & Mathes, 2019). There appears to be a move away from the idea that adherence occurs due to advice by a service provider (biomedical perspective) or knowledge that non-adherence will have negative repercussions in the short or long term (cognitive perspective).

Consequently, people are subscribing to the social-ecological perspective that acknowledges a multiplicity of underlying determinants of treatment adherence, sub-optimal adherence, or non-adherence. As in the case of most human behaviour, adherence (or sub-optimal adherence) to a long-term treatment regimen should be seen within a larger context of personal beliefs, social experience, perceived outcomes, and organizing structures and social norms. Whereas the act of self-administration of medication may seem simple and easy, the theoretical issues that were discussed in this chapter suggest a complex process with a multiplicity of factors coming into play (Jones, Clavier, & Potvin, 2017).

CHAPTER FOUR

RESEARCH METHODS

Introduction

Providing readers with the sources of data, including how data was collected, managed, processed, and analysed is central to the assessment of the worth of scientific evidence. In this chapter, various research methods and techniques that were adopted in data collection, as well as processing, management, and analyses of the data are discussed. Specifically, the chapter focuses on the methodological paradigm, study design, study area, sources and types of data, sampling procedure, sample size, and data collection instruments. Additionally, the chapter also highlighted the implementation plan/approach and the specific issues are; pre-testing, data collection procedures, data processing and analysis, quality control (trustworthiness), and ethical protocols that were observed during the study.

Research Philosophy

Research philosophy is a fundamental aspect of social science research because it provides the foundation on which the entire work is built. The philosophical leaning(s) inform the conceptualization, data collection, analysis, interpretation, and presentation of the final research report. This study is situated in the interpretivist philosophical school of thought.

Interpretivism or Interpretivist Philosophy

Interpretivism is about the "centrality of meaning and understanding of the social world" with the belief that there is no universal truth. Therefore, people's reality is socially constructed, multiple, and context-dependent (Myers, 2009). The choice of interpretivism in this study as the guiding philosophy to generate evidence is informed by three interconnected philosophical positions. These are; my approach to unravelling reality (ontology), co-creation of reality/knowledge (epistemology), and ways of knowing (methodology). Firstly, in terms of unravelling reality, my goal is to bring together the multiple or subjective realities that were obtained from the individual study participants. As such, objectivity was not considered an important principle in this regard. Participants sharing conflicting truths at the same time, does not imply objective reality. To this end, in-depth interviews were conducted to draw evidence from the study participants, and themes were generated based on commonalities in the experiences and perspectives shared by the participants.

Of the nature of reality, I sought to employ the subjective theory of knowledge. This theory posits that there is no objective reality in the social world. "Realities are constructed by social actors through social interactions and are subjective, multiple, and context-dependent" (Carson, Gilmore, Perry, & Gronhaug, 2001). In this regard, I sought to *co-create* reality from the perspective of the study participants, thus drawing from individual subjective accounts of their experiences. In line with this, the semi-structured interview guide that was designed to guide the in-depth interview process allowed for

several probes. Also, the flexible nature of the instruments allowed me to digress a bit from the pre-determined questions and ask questions beyond those contained in the guide. This helped in the co-creation of reality with the research participants (service providers and primary caregivers). I argue that as a researcher, I form part of the study and therefore I cannot be completely independent of the study participants. However, conscious efforts were made to ensure a professional distance. As Black (2006) put it, the researcher and the study participants or objects of investigation are linked in such a way that meanings that we ascribed to social phenomenon are central to how we understand ourselves and others through interaction.

As concerning ways of knowing, I relied on qualitative methods of inquiry. Phenomenology was used as a study design while in-depth interviews were conducted to obtain data for the study. The choice of this approach was driven by the nature of the problem under investigation and the study objectives. This is essential to the understanding of how the study participants viewed childhood TB in terms of management and control. The use of qualitative methods helped to avoid imposing meaning or what constitutes the reality of the study participants. In essence, the interpretivist paradigm posits that social reality is created mainly in human consciousness as a creation of the mind. Based on this ideology, interpretivists conceive that knowledge or what constitutes reality is subjective and mainly determined through social interactions. I subscribed to the belief that individuals are proactive in the creation of their realities.

Interpretivists hold the view that human beings contribute freely to the formation and construction of social reality. Therefore, interpretivism assumes an ideographic position about science and posits that epistemological ideas should not be based on universal principles. Therefore, what exists regarding reality are individual interpretations of the social world and these interpretations are distinctive to each individual. The foundation of interpretivist philosophy is built on the premise that science should be based on subjectivity and what is unique to an individual in his/her formation and interpretation of the social world (O'Connor, Netting, & Thomas, 2008). Based on the philosophical leanings of the study, the analytical strategies that were employed include; exploratory analysis, induction, deduction (framework analyses), and qualitative content analysis (Ogilvy, 2006). These methods were considered appropriate because of the nature of the issue under investigation and the phenomenological study design that has been adopted.

It is imperative to note that the interpretivist philosophy in social science research emerged mainly as a critique and an alternative to positivism (a philosophy that has its root in the natural sciences) (Schwandt, 2003). The qualitative research method encompasses a wide range of research conventions such as critical, constructionist, feminist, and post-modern paradigms (Lincoln, Lynham, & Guba, 2011). However, in this study, the constructionist convention was partly used to explore the phenomenon under observation. A major aspect of this thesis is the exploration of the household and psychosocial contexts of childhood TB management. The exploratory nature of the study makes

interpretivist philosophy and its attendant qualitative methods appropriate to help address the research questions and achieve the study objectives.

Implications of interpretivism for research methods and design

The interpretivist philosophy that was employed for this study has implications for the research methods and design. Since every research method needs to be aligned with its underlying philosophy, the qualitative methods in this study are consistent with the interpretivist philosophy. Accordingly, the structure and sequence of the research process put forward by Creswell (2012) have been adapted for this study. Creswell posits that the nature of the research problem is fundamental to the overall research process. Informed by the nature of the research problem and the questions that are to be asked to achieve the research objectives, as well as the initial review of literature that underscores the importance of the problem, I settled on interpretivist philosophy and its attendant qualitative research methods.

The adopted interpretivist philosophy has implications for the entire research procedures – sampling (purposive sampling), data collection instruments (semi-structured in-depth interview guide), the data collection procedures (in-depth interviews), data analysis (thematic/framework analysis with various analytical techniques), interpretation of results (broader meanings of the findings based on emerged concepts), and writing of the final reports (using flexible, emerging structures and trustworthy criteria for reporting). The conceptualisation of the study, study design, data collection methods, analytical procedures, reporting of findings, and conclusions drawn from the study are all

rooted in the qualitative approach to inquiry and the associated interpretivist philosophy. A qualitative approach was adopted for this study because the study primarily aimed at exploring issues surrounding childhood TB management and control, including the psychosocial context of the treatment regimen. This approach helped to obtain a detailed understanding of the phenomenon.

Research Design

I adopted phenomenology as a study design to guide the study (Creswell, Hanson, Plano Clark, & Morales, 2007). The choice of phenomenology was informed by the issue under investigation and deemed appropriate for the method of inquiry. This study, therefore, adopted phenomenology as a research design. Just like in grounded theory research, phenomenological studies collect data on the views and experiences of research participants. However, instead of theorizing from these views/experiences to generate theoretical models (as in the case of grounded theory), this study rather sought to describe and interpret the commonalities and variations in the experiences of the participants. Thus, credence was given to participants' specific experiences and subjective statements rather than deducing from their statements to construct a model for interpretation as in grounded theory.

In line with phenomenology, the goal of this study was to reduce the experiences of service providers for childhood TB on one hand and that of the primary caregivers on the other hand, to a description of the universal essence – "a grasp of the very nature of the thing" (van Manen, 1990). Data was collected purposively from people with valuable experiences concerning

childhood TB (experienced service providers for childhood TB and primary caregivers of children with TB at the various stages of the treatment regimen). This allowed for a comprehensive description of the crux of the experiences of all the participants – what they experienced and how (including the psychosocial context of childhood TB) they experienced it. Phenomenology has been widely used across the humanities and health sciences (Wirth, 2018), including sociology, psychology, nursing, public health, and education (Davidsen, 2013). In each of these disciplines, the design has shown enormous power in providing meaningful insight into people's experiences and unique perspectives.

This study design requires the researcher to, first of all, identify a phenomenon of interest – management of childhood TB in this case. In the process, the researcher reflects on the emergent essential themes to uncover what mainly constitutes the nature of the experiences of the study participants. To this end, themes were developed both inductively and deductively from the data. In line with the phenomenological study design, the findings were written based on the description of the phenomenon (management and control of childhood TB), while keeping a robust relationship with the topic of inquiry (clinical practice and psychosocial contexts of childhood TB) and balancing the parts of the writing to the whole. This process involved a strong reference to the salutogenic theory or the normalisation process model (depending on the specific objective) that was adopted to guide the study.

It is important to note that phenomenology is not only a description of the phenomenon, but also an interpretive process. As such, I connected the

different meanings of the experiences and perspectives shared by the study participants (see Manen, 1990). Also, the study provided a comprehensive interpretation of the emergent themes based on commonalities, variations, and disagreements in statements/views from the study participants. Details of these issues are discussed in the data analysis section. Phenomenology design was chosen because of several reasons. Firstly, the design is in line with the interpretivist philosophical foundation. Secondly, phenomenology is appropriate because of the issue under investigation – an exploration of the healthcare practices as well as the household and psychosocial contexts within which childhood TB treatment takes place. The design allowed for a vivid description and interpretation of the narratives and experiences of the study participants (both service providers and primary caregivers). Besides, this design has been used in a wide range of healthcare research and has proven to be appropriate, especially in providing meaningful insight into a health phenomenon as experienced by clients and service providers alike.

Study Area

Guided by the "intensity sampling" principle (Patton, 2002), the study was conducted in five out of the then ten regions of Ghana (Central, Volta, Western, Eastern, and the then Brong Ahafo). The study was conducted among primary caregivers of children with TB as well as service providers in the selected healthcare facilities. The five regions were explicitly selected because of the relatively high burden of TB in their catchment areas (NTP, 2019). Whereas the focus of this study is on childhood TB, the national data from NTP is

aggregated, making it difficult to determine the actual burden of childhood TB in the various regions (see Stop TB Partnership, 2021). Notwithstanding, it is well established in the literature that childhood TB is closely linked to the incidence/burden of adult TB (Kalu et al., 2015; Srivastava, Faridi, & Gupta, 2020). Therefore, I selected the regions with relatively high burdens of TB as a proxy for this study since specific data on childhood TB could not be obtained.

In the Western region, facilities were selected from Takoradi, Essikadu, and Kwesimintsim. From the Central region, facilities were selected mainly from the Cape Coast Metropolis. Concerning the Eastern region, facilities were selected from Koforidua which is the regional capital, Manya Krobo, and Agormanya which has one of the highest prevalence of HIV and TB in Ghana. In the Volta region, facilities were selected from Ho, Kpando, and Dzodze. Finally, in the then Brong Ahafo region, facilities were selected from Sunyani, Techiman, and Dormaa.

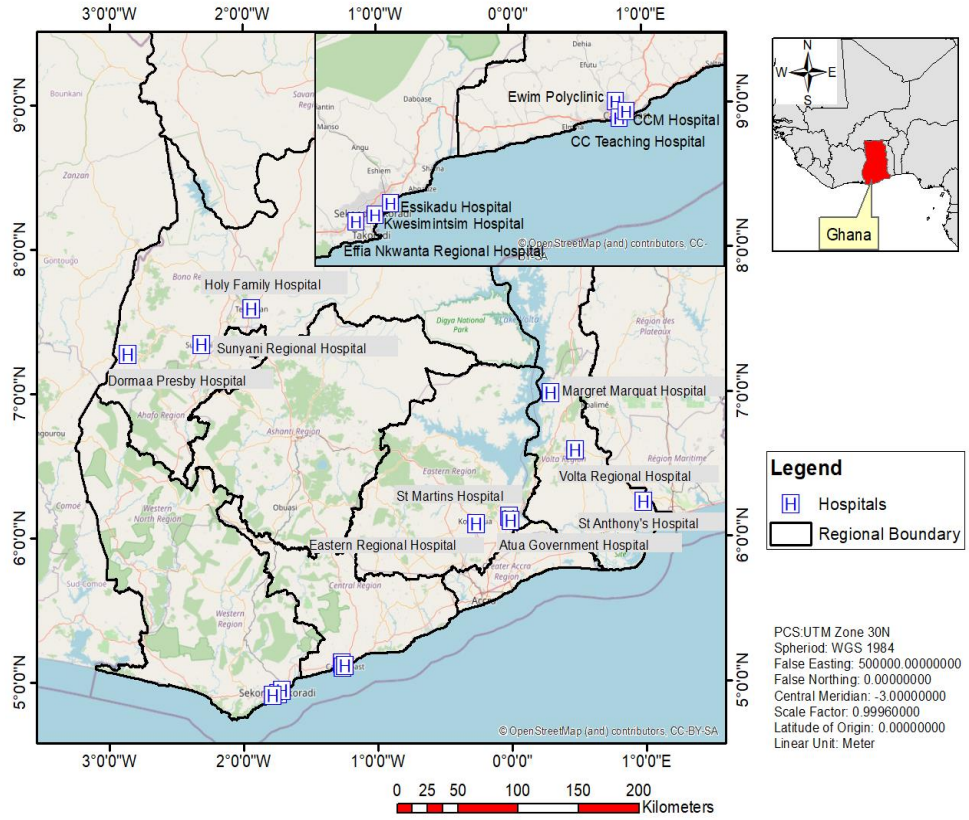

Figure 7: Map of the study area

Source: GIS Unit, Dept. of Geography and Regional Planning, UCC

Sample Size

The sample size for this study was determined and evaluated in three phases; at the time of planning the study, during data collection to continuously appraise the sample size, and finally after the last interview (Guest, Bunce, & Johnson, 2006; Malterud, Siersma, & Guassora, 2016). In the opinion of Morse (2015), there is no predetermined sample size that all qualitative studies must adopt. Instead, the sample may be informed by the nature of the analyses the researcher plans to conduct in the study. During the planning of this study, I envisaged

cross-case analyses. As such, I was guided to determine a sample that is large enough to achieve depth and breadth based on the principle of saturation.

The concept of saturation was first put forward by Glaser and Strauss (1999) as part of an analytical process that requires constant comparison in grounded theory research. However, the concept has since been widely used in various qualitative studies. Guided by the concept of saturation, the final sample size for this study was not determined a priori, but posteriori and evolved during the data collection process (Morse, 2015). Consequently, a total of 66 participants comprising 31 service providers and 35 primary caregivers were deemed appropriate for the study.

The sample ensured both "code saturation" (where no extra *issues* are identified) and "meaning saturation" (where no additional *insights* are obtained). Concerning code saturation, the majority of the codes (60%) emerged in the first two interviews while 94 per cent emerged by the 15th interview. The point of "meaning saturation" was defined based on the last interview in which a fresh code "category" was identified (Hennink, Kaiser, & Marconi, 2017). In this study, meaning saturation was attained earlier for codes representing actual perspectives while codes depicting more conceptual/theoretical perspectives took quite longer – up to the 29th interview for the service providers and 33rd interview for the primary caregivers. However, in both instances, we conducted extra interviews to satisfy the maximum variation principle of the purposive sampling technique that was employed for the study.

I subscribed to the argument that qualitative inquiry can elicit a deeper understanding of issues from participants using the right methods (Morse, 2015). The goal of qualitative research is not to generalize study results and so generalizability was not an important principle in this study. The goal here is to unravel issues surrounding the management and control of childhood TB in the selected health facilities. Therefore, the concern was with the transferability of results across contexts as a way of validating findings (Macfarlane & O'Reilly-de Brun, 2012; Nicholls, 2011).

Sampling Procedures

In addition to primary caregivers, an expert purposive sampling technique was used to select participants (service providers) with long professional involvement in managing childhood TB at the selected health facility. The justification for employing expert purposive sampling in this study is built on the premise that some people are important for the study as they may have an important perspective on the phenomenon of interest – childhood TB in this case (Robinson, 2014). An empirical systematic review of evidence revealed that it is very important to get both healthcare professionals and clients/users involve in policies regarding health care, including treatment options (Légaré et al., 2014). As such, this study considered the perspectives of both service providers and primary caregivers for children with TB. The perspectives of primary caregivers were equally important as that of the service providers since the study among other things seeks to contribute to filling the knowledge gap by exploring the psychosocial context of childhood TB treatment.

Participants recruited from the various health facilities were mainly service providers under the NTP and those working at the Child Welfare Clinics in the five selected regions in the country. These participants were mainly those with long working experience with TB management as well as those who have been at the forefront of issues relating to childhood TB at the facility level (see Robinson, 2014). Informed by the maximum variation principle in purposive sampling (Suri, 2011) efforts were made to include individual healthcare professionals that occupy a range of positions (Paediatricians, Disease Control Officers, Registered General Nurses, Community Health Nurses) in TB management at the selected health care facilities

Three healthcare facilities providing childhood TB services and child welfare clinics were selected from each of the selected regions to represent the levels of care – primary, secondary and tertiary facilities. Again, guided by the maximum variation principle of purposive sampling (Suri, 2011), in each of the five selected regions, the regional or teaching hospital which is the highest point of referral was purposively selected in addition to two other facilities (a secondary-level facility and a primary-level facility). In each of the three selected healthcare facilities in each region, at least 4 participants (2 service providers and 2 primary caregivers for children with TB) were selected. However, in some facilities, more than 2 participants were selected based on the maximum variation principle that was employed.

With regards to primary caregivers, participants were recruited from health facilities in the five selected regions in Ghana. Guided by maximum

variation purposive sampling, at least two primary caregivers were recruited from each of the selected facilities. However, in facilities with a relatively high burden of childhood TB, the number of participants was increased, especially where there were various forms (childhood pulmonary TB, childhood extra-pulmonary TB, childhood MDR-TB, childhood TB-HIV co-infection) of childhood TB. Again, this process was informed by the principle of maximal variation purposive sampling and the concept of saturation. The determination of saturation was assessed together with the study supervisors.

Data Collection Methods

To uncover reality mainly from the experiences of the study participants (service providers and primary caregivers of children with TB), individual in-depth interviews were conducted. Qualitative data collection methods that involve the use of in-depth interviews are considered appropriate when applying a theory to obtain an in-depth understanding of a particular social or health phenomenon (O'Cathain, Thomas, Drabble, Rudolph, & Hewison, 2013). Since the focus of the study is to explore issues relating to childhood TB, including the psychosocial context of the treatment using the Salutogenic Theory and Normalisation Process Model, a qualitative approach with in-depth interviews as a data collection method was accordingly considered appropriate for the study.

In the postulation of Ong and colleagues, qualitative methods that draw on established theories are suitable means for assessing and responding to how healthcare professionals adopt an innovation in a particular context (Ong et al.,

2014). Since the integration of childhood TB into child welfare clinics is an innovative intervention to ensure effective management of childhood TB, a qualitative approach is, thus, considered appropriate to explore issues concerning this intervention. Both the service providers' and the caregivers' perspectives were obtained for the study. This allows for a comprehensive dataset that enhanced the scholarly scope and the applicability/transferability of the study findings (Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014).

Data Collection Instruments

Data for this study were obtained using highly flexible semi-structured interview guides as data collection instruments. This afforded the study participants the freedom to discuss and address as many issues as possible regarding childhood TB management and control in their respective healthcare facilities and households. In line with interpretivism and its attendant qualitative methods, the questions were well crafted to avoid yes or no responses, but rather conversationally to elicit detailed responses. The instruments were designed such that, the study participants would be able to share experiences about the phenomenon of interest, thereby allowing for rich themes to emerge (Mcintosh & Morse, 2015).

Informed by the objectives of the study, two separate interview guides (one for the service providers and the other for primary caregivers) were used for the data collection. One IDI guide was used to elicit the perspectives of service providers and was structured into 5 main sections. The first section

(Section A) is concerned with background information on the participant. The background information among other things includes; sex, age, programme affiliation, working experience, and current position. Section B was concerned about questions that bordered on how service providers manage childhood TB routinely. Issues such as diagnosis procedure, prescription of an appropriate treatment regimen, contact tracing (follow-up), and other management-related issues were explored here. Challenges confronting service providers in the management of childhood TB and how those challenges can be addressed were explored in section C. Section D consist of issues that sought to explore the perspectives of service providers on the integration of childhood TB management into child welfare clinics or maternal, neonatal, and child health. The last section (section E) was made up of questions that elicit views of service providers on ways to improve the management of childhood TB in Ghana as part of the way forward.

The other IDI guide that was used to collect data on primary caregivers consists of 4 main sections. The 'A' includes information on the socio-demographic characteristics of the participants and their children. It included; age, sex, marital status, educational level, occupation, duration (time) child has lived with TB, and the duration or length of time the child was put on the treatment regimen. Section 'B' consists of questions that bordered on experiences regarding how primary caregivers navigate the treatment regimen daily. In this section, emphasis was placed on the clinical/healthcare context of the treatment regimen. Section 'C' involved questions that elicit views on

disclosure and community experiences with regards to childhood TB and treatment. The last section which is section 'D' concerns discussions on the household burden, finances, and subjective assessment of the impact of a child's TB on the household.

Pre-testing of Instruments

The semi-structured interview guides that were used for the data collection were piloted in January 2019 at the Catholic Hospital, Anfoega, after ethical clearance was issued by the Ghana Health Service Ethical Review Board (GHS-ERC). In the piloting of the instruments, three service providers and three primary caregivers for children with TB were recruited. The facility for the piloting was specifically selected because it is one of the major healthcare facilities in the North Dayi Municipality where TB services are provided. Also, it has similar characteristics in terms of institutional structure and service delivery to those that were included in the actual data collection. The pre-testing was undertaken to correct errors and shortcomings that were inherent in the instruments.

In this study, piloting was essential as it provided a snapshot of the appropriateness and the applicability of the theoretical framework for the study. It also provided me with the chance to assess whether the questions were clear and whether the language used was appropriate for a quality dialogue (Adams, Khan, Raeside, & White, 2007). The interviews that were conducted during the piloting were transcribed verbatim. The transcripts were analysed and led to the generation of some sort of themes and categories. The appropriateness of the

instruments (interview guides) was assessed based on the results from the pre-test. Little adjustments were made to the instruments in consultation with the study supervisors to ensure that the instruments have the greatest potential to sustain a quality dialogue which is fundamental to achieving the research objectives.

Data Collection Procedures

After pre-testing the instrument and little adjustments made in consultation with study supervisors, actual data collection activities were carried out in the selected healthcare facilities over 6 months. Before the data collection, the authorities of each of the selected study facilities were contacted to seek their approval for the study to be conducted. Ethical clearance notes and a letter of introduction from the Department of Population and Health were presented to the authorities of the various study facilities to allow me access to the TB units or Chest clinic depending on the facility.

At each of the facilities, the institutional TB coordinator checked through the TB register and identified the various childhood TB cases. The coordinator then contacted their primary caregivers via phone calls to explain the purpose of the study and sought their consent to participate in the study. This was done in order not to breach the fiduciary role that exists between service providers and primary caregivers. Primary caregivers who agreed to participate in the study were then given a detailed description and purpose of the study by the interviewer and their consents were sought. The first three primary caregivers who agreed to participate were then recruited.

In line with the study design, in-depth interviews were carried out to obtain the perspectives of the selected service providers as well as the primary caregivers who were included in the study. The interviews were based on one-on-one interaction between the interviewer (who is the Principal Investigator) and each of the study participants. According to Creswell (2012), "one-on-one interviews are useful when the phenomenon of interest is sensitive" and it also offers the opportunity for participants to ask questions and provide detailed information even beyond what the questions demand. Most importantly, it allows me to probe issues in detail and sought clarifications to responses given by the participants (Creswell, 2012). All interviews were carried out in designated rooms or places at the respective facilities to safeguard the privacy and confidentiality of the participants. It was also to ensure that there are counsellors available to help the participants to deal with any emotional distress that might arise due to the recollection of past experiences.

The participants were reminded to provide detailed narratives of their experiences concerning the management of childhood TB, including the psychosocial context of the treatment. With the consent of the participants, the interviews were tape-recorded while adhering to strict ethical issues that guide the conduct of interviews (Nordstrom, 2015). On average, each interview lasted 60 minutes. As a measure of ensuring reliability, after each interview process, portions of the recorded audio were played back to the participant to further agree on the issues and make clarifications if they so wished. The interviewer made written notes of all the explanations that were made by the participants

and incorporated them into the data during transcription. At the end of each interview day, I played back the recorded interviews and took note of both old and new emerging issues. The emergence and evolution of possible themes were discussed with study supervisors in order to guide the subsequent interviews. All interviews were personally conducted by the author.

Data Management, Processing, and Analyses

The audio-recorded interviews were transcribed verbatim to capture the exact responses from the study participants. To enhance speed in the transcription process and ensure the accuracy of the transcripts, audio recordings were uploaded onto "oTranscribe" (A free HTML5 app) and transcribed verbatim. After transcription, the audio recordings were played back while at the same time reading through the transcripts to ensure accuracy and consistency. Cleaning and proofreading of the transcripts were done by checking for grammatical and typographical errors. The transcripts were then formatted to allow for computer-assisted coding and analysis with QSR NVivo 12 Plus computer software for qualitative data analyses. After cleaning the data, they were imported into the software for coding.

The preliminary analyses were done by auto-coding the data using the software and then word clouds were developed. Word trees were also created to assess context-specific issues. The actual data coding and analyses were done at two levels using the *inter-rater* coding technique (Bernard, Wutich, & Ryan, 2017). This technique requires two or more researchers to independently code and re-code the data based on a pre-agreed coding plan. Codes that were

common to both coders allowed for greater confidence, thereby ensuring the reliability and validity of the codes and ultimately the study results (Campbell, Quincy, Osserman, & Pedersen, 2013).

At both stages of the analyses, we employed inter-rater coding technique to ensure reliability in the codes. In the first stage, we relied on an inductive coding approach where several key emergent issues in the data were identified leading to the development of several codes. The decision to undertake the inductive coding first was borne out of efforts to avoid imposing the theoretical framework on the data, but rather allowing themes to emerge freely in accordance with the interpretivist philosophy that has been adopted for the study. Taking cues from Macfarlane and O'Reilly-de Brun (2012), I (principal investigator) actively endeavoured to "bracket" out my knowledge of the Salutogenic Theory and the Normalization Process Model at this stage of the coding. There was no need for the other coder to bracket since he was not familiar with the theoretical framework at this stage. Codes that were obtained were shared and reviewed independently by the coders. The few inconsistencies in the codes were resolved together. Afterwards, related themes and sub-themes were merged into various categories.

In the second stage, we followed a deducted coding approach where themes and categories that fell under the key constructs of either the Salutogenic Theory or Normalisation Process Theory that made up the theoretical frameworks for the study were independently and extensively explored by the coders (Macfarlane & O'Reilly-de Brun, 2012). The themes and categories that

emerged from the data using the deductive coding approach were reviewed by the coders as well as the study supervisors. Again, the few inconsistencies were resolved together. The second stage of the framework-based (deductive) codes were compared with the earlier inductive codes before codes were collectively refined by the study team.

All coding and analyses were done with the assistance of QSR NVivo 12 Plus computer software for qualitative data analysis. Word clouds and word trees were developed with the assistance of the software and their contexts were analysed comprehensively. Themes and categories were developed using the "nodes" function of the software. The issues that made up the themes and categories were further analysed for commonalities, variations, and disagreements across cases by querying the data (Morse, 2015). Deviant cases were further analysed using some keywords in the data that are related to specific themes and matching them against the context in which they were used with the help of the "Queries" functions of the software. The final issues that emerged from the analyses formed the basis for the discussion of the results. The Salutogenic Theory and Normalisation Process Model that were used in the building of the theoretical framework also guided the discussion of results. Reporting of the findings of the study followed the "consolidated criteria for reporting qualitative research" (COREQ) requirements.

Trustworthiness Criteria

Despite the advancement in qualitative research methodology, qualitative studies have not received full acceptance in some circles, including some

academic disciplines. Whereas this could largely be a result of conflicting perspectives regarding the ontology and epistemology of "science" in social research, it may also be the product of inadequate clarifications regarding the standards and principles in qualitative methodology (Kumar, 2011). As such, in this thesis, trustworthiness criteria were provided to ensure adequate clarifications regarding the standards and principles inherent in the methods that were employed in the study. Trustworthiness, as applied in qualitative research, refers to procedures the researcher follows to meet the criteria of *credibility*, *transferability*, *dependability*, and *conformability* in his/her research (Harrison, MacGibbon, & Morton, 2001; Lincoln & Guba, 1985) and *reflexivity* (Harrison, MacGibbon, & Morton, 2001).

Credibility

Steps that were taken to ensure credibility in this study include; taking the findings to a section of the study participants (10 interview transcripts were randomly selected) for confirmation, validation, congruence, and approval, or what is broadly termed as *member-checking*. With the highest possible outcome of member-checking (all the 10 service providers as well as the 10 primary caregivers confirmed and validated their earlier narratives), the credibility of the findings from this study is guaranteed (Aguinaldo, 2003). Aside from member-checking, other strategies that were employed to ensure credibility include; a purposive selection of context and participants, an approach to data collection (in-depth interviews involving the use of semi-structured interview guides), and negative case analysis (Creswell, 2012). The semi-structured nature of the

instruments ensured that questions posed to the participants are relevant to the phenomenon of interest, while the interviewer remains responsive to the study participants (Bartholomew, Henderson, & Marcia, 2000).

Credibility deals with establishing that the findings or results from qualitative research are credible or believable from the perspective of the study participants (Trochim & Donnelly, 2007). Since this study is mainly concerned with the exploration of experiences, views, feelings, and behaviour of study participants, they are the best people to determine whether or not the research findings have adequately reflected their perspective. To this end, the decision to send the results back to some of the participants for member-checking ensured the credibility of the findings.

Transferability

Transferability refers to "the extent to which the findings of a qualitative study can be transferred across contexts or settings" as in the case of generalizability in quantitative studies (Trochim & Donnelly, 2007). Even though findings from this study cannot be generalized in the same way as quantitative studies, I am aimed at theoretical generalization by adopting robust and appropriate theoretical frameworks to guide the data analyses and discussions. The tenets of the theoretical framework were considered in the development of the instrument, albeit minor role. Since the tenets of the salutogenic theory and the normalisation process model are well tested and established in scientific literature, the findings can be theoretically generalized and so the results can be transferred across contexts and settings (Macfarlane & O'Reilly-de Brun, 2012).

Dependability

Dependability as a criterion for trustworthiness in qualitative research is concerned with whether the researcher will observe the same thing or come out with the same results if he/she could study the same people twice (Trochim & Donnelly, 2007). As a way of ensuring dependability, a detailed description of the methods of the study has been provided. In addition, detailed accounts of my interactions with the study participants and field experience have been provided at the end of the study. Again, the adoption of semi-structured interview guides to collect the data was key to ensuring dependability. By the very nature of the semi-structured interview guides, questions are open-ended and formulated to elicit somewhat structured responses conversationally.

The questions/items on the instrument were asked to each participant in the same way and in a systematic order with the freedom to diverge slightly from the script. Thus, I was afforded some level of variability (within the limits of the envisaged replicability of the study) to rephrase questions to elicit the relevant response or to provide further clarification (Mcintosh & Morse, 2015). As such, dependability is guaranteed to a reasonable extent since almost the same responses will be obtained when the same participant is interviewed at different times. In the views put forward by Guba and Lincoln (1994) this is very comparable to the concept of reliability as applied to quantitative research. To this end, I extensively documented the processes for others to replicate. Thus, this study conforms to this requirement by providing details of the

research methods and practical ways of applying the various qualitative research techniques.

Confirmability

All conclusions that were drawn at the end of this study were strictly limited to the study findings. A critical step that was taken to ensure confirmability is the adoption of the "inter-rater" coding technique. I and a colleague PhD student independently coded and re-coded the interview data following both inductive and deductive techniques. Codes that are mutual to both of us allowed for greater confidence, thereby ensuring reliability and validity of the results which ultimately safeguarded the confirmability of the study results (Campbell, Quincy, Osserman, & Pedersen, 2013).

Confirmability refers to the extent to which the results could be confirmed or corroborated by other researchers (Trochim & Donnelly, 2007). Confirmability is also to a large extent comparable to the concept of reliability in quantitative research. An important issue under this criterion is the extent to which the findings are affected by personal interests and biases. Here, the emphasis is on the neutrality of the data rather than the neutrality of the researcher. As such, if the research is confirmable, then the conclusions are grounded in the data (Creswell, 2012). This is exactly the case in this study as all conclusions are grounded in the data.

Reflexivity

Even though not one of the criteria put forward by Guba and Lincoln (1994), reflexivity is an important criterion as far as the trustworthiness of qualitative research is concerned. The concept is, however, a broad one that applies to several issues. The methods that were employed in this research are clearly stated and an acknowledgement of my role as the researcher was provided leading to more technically-oriented reflexivity. Even though I was actively involved in the co-construction of reality (through questioning and probing), I made conscious efforts to maintain a professional distance (see Kumar, 2011). In terms of epistemology, I uncovered reality from the perspectives of the study participants within the acceptable remits of interpretivism. During the data collection, I actively questioned my epistemological stands, and where necessary, I adapted them accordingly. I do not have any personal biases that could affect the study findings. Besides, I also do not have any personal or professional relationship with any of the study participants.

Ethical Considerations

Ethical consideration is at the core of the scientific research enterprise (Marlowe & Tolich, 2015) and this particular study was no exception. The initial contacts with the study participants were made by the institutional TB coordinators at the various study sites. This was done to safeguard the fiduciary role that exists between service providers and the primary caregivers for children with TB. A prior, free and informed consent was sought from each participant before the interviews were conducted. An information sheet that describes the nature of

the study, duration of the study, potential risk, benefits, and anticipated costs were made available to the study participants to read and make an informed decision on whether to participate or not.

To guarantee confidentiality and anonymity, the names of the study participants were not included in the demographic data and there was nothing that openly identify or link a particular participant to a specific interview aside from a unique ID. Thus, I maximized the protection of participants' identities while at the same time maintaining the worth and integrity of the data (Saunders, Kitzinger, & Kitzinger, 2015). The participants were sufficiently educated about their voluntary participation in the study and were also prompted that they were free to not respond to questions that they were uncomfortable with and can withdraw from the interview at any stage without consequences. The audio-recorded interviews, as well as the transcribed data, were protected using *MyLock Box* computer software. The hard copy of the transcribed data was hidden from sight and access to it was restricted to only the research team.

Ethical approval was given by the Ghana Health Service (GHS) Ethics Review Committee (ERC) (ID: **GHS-ERC 006/05/19**) before the fieldwork. Permission was also sought from the various regional health directorates as well as the selected health facilities before the data collection. At the facility level, an introductory letter from the Department of Population and Health, University of Cape Coast, and copies of ethical clearance notes were presented to the various hospital authorities. In facilities with institutional review boards/committees, their facility-specific ethical clearance arrangements were

followed. The design and writing of this thesis followed COREQ requirements and all necessary ethical principles were adhered to. I hereby declared that I have no competing interest.

Summary

The research philosophy adopted for this study has several implications for the various methods of the research. In terms of data collection, IDI was considered more appropriate because the interest is not in group dynamics, but in the subjective accounts of each participant. Besides, people are likely to give more in a one-on-one qualitative interview than they will probably offer in a group discussion due to the likelihood of one or two talkers hijacking the discussion and others assuming a reticent position (Yin, 2011).

Again, the adopted philosophy allows me to rely on non-probability sampling (various purposive sampling techniques) in deciding where and whom to be included in the study. In addition, interpretivism limits me to the use of a relatively "small" sample size and so the findings cannot be generalized in the same way as quantitative studies. However, the analytical procedures allowed for the results to be transferred across contexts or settings. Since one of the main assumptions underlying interpretivist philosophy presupposes that there is no objective reality, there was the need to design an instrument that will help elicit subjective accounts of the study participants. In line with interpretivism and its associated qualitative methods, the focus here was not to generalize the results in the same way as positivists do, but rather aimed at theoretical generalization (Collins, 2011; Macfarlane & O'Reilly-de Brun, 2012).

CHAPTER FIVE

PERSPECTIVES OF SERVICE PROVIDERS ON THE MANAGEMENT AND CONTROL OF CHILDHOOD TB

Introduction

The Ghana "national TB control programme" has implemented several of the WHO's recommended strategies over the years to effectively manage childhood TB, albeit with some implementation challenges. Management of childhood TB is complex and requires concerted efforts. Many of the policies, strategies and tools required to adequately control and manage childhood TB are already in place, but they need to be prioritized, strengthened and fully executed to move the global community nearer to ending TB (WHO, 2018).

This chapter explores the perspectives of service providers on how they carry out childhood TB management and control in the selected health facilities in the Eastern, Volta, Western, and Brong Ahafo regions of Ghana. The results are organized based on the emergent themes from the data and discussed in light of recommended practices. Word clouds and coding tress from NVivo are attached as appendix F.

Background characteristics of the participants

A total of 31 health providers were interviewed from the selected health facilities in five selected regions of the country. However, based on the focus of this chapter, 7 transcripts were excluded and the analyses considered only 24 study participants. The 7 transcripts were excluded because those participants

were only interviewed on specific child welfare clinic issues that were not covered in this chapter. The ages of the study participants were between 25 and 59 years. All the participants have at least 3 years of working experience in TB management with the most experienced service provider being involved in TB management for over 30 years. The majority of the participants (75%) have between one to nine years of working experience in TB management.

Participants occupied various positions in TB management at the selected health facilities. They include 10 institutional TB coordinators, 5 disease control officers, 4 nurses who were permanently attached to the TB units, 3 district TB coordinators who also work at the facility, a regional TB coordinator, and a public health physician who has been at the forefront of TB management and control at one of the major health facilities. The study health facilities include; teaching hospitals, regional hospitals, metropolitan hospitals, municipal hospitals, district hospitals, sub-district hospitals, and a polyclinic. Twenty-two of the participants were affiliated with the National TB Control Programme (NTP) while two were affiliated with both NTP and National AIDS Control Programme (NACP) in an integrated system. Table 2 provides a summary of the background characteristics of the service providers that were involved in the study.

Table 2: Socio-demographics of the service providers

Background Characteristics	Number (n)
Sex	
Male	9
Female	15
Age	
25-29 years	11
30-34 years	9
35-39 years	2
50-54 years	1
55-59 years	1
Types of Facility	
Teaching/Reg. Hosp.	5
Metro/Municipal Hosp.	5
District Hospital	10
Sub-District Hospital	3
Polyclinic	1
Prog. Affiliation	
NTP	22
NTP/NACP	2
Years of Experience	
1-9 years	18
10-19 years	5
30-39 years	1
In-Service Training on CTB	
No	20
Yes	4
Current Position	
Inst. TB Coordinator	10
Disease Control Officer	5
Public Health Physician	1
Nurse_TB Unit	4
District TB Coordinator	3
Regional TB Coordinator	1

Source: Field Survey, 2020

Peculiarity of Childhood TB

The peculiarity of childhood TB makes it almost a neglected aspect of the global fight against the TB epidemic. In most of the selected health facilities, the participants revealed that they do not regularly diagnose children with TB. Consequently, only a few of the children were put on the treatment regimen. However, participants accentuated that the seemingly smaller number of children that are diagnosed and put on treatment does not necessarily mean childhood TB is not a public health concern. The service providers shared the conviction that there are a lot more children with TB in the community that remain undiagnosed. Notwithstanding, the participants acknowledged that the difficulties in diagnosing children with TB are largely the reason why most children with the disease remained undiagnosed. The following quote is reflective of the perspectives shared by the study participants on the frequency of childhood TB.

> *…Last Monday, we recorded three cases. So it depends. Sometimes in a week, you can get about five cases, and also for months we will not record any case [at all]. But I will say it is common, however, we usually misdiagnosed because for this one [childhood TB], you will need a specialist to diagnose.* (SP_BA_F2_002 – Male, 33 years, Institutional TB coordinator with 5 years working experience; Municipal Hospital)

A common theme that emerged from the narratives of the service providers is referrals between facilities. Childhood TB diagnosis poses a major challenge to service providers. As such, advanced procedures such as gastric lavage for

medical examinations are sometimes required. Most of the advanced means of diagnosis are only available at major health facilities such as the District, Regional, and Teaching hospitals. It was evident that due to the difficulties that are associated with childhood TB case notification, diagnoses are mostly done by the major facilities with advanced means of diagnosis. However, due to the application of the DOTs strategy in TB management, cases are referred to facilities that are closest to the community where the child and the primary caregiver live. Thus, it is a common practice for one facility to diagnose a case, initiate the treatment and then the child is referred to another facility for the continuation phase of the treatment. In some cases, one facility just diagnosed the case and then refer the client to another facility for the initiation of the treatment regimen. Below is a quote that highlights this finding.

> *Okay, it [TB among children] is not all that frequent but we are getting the cases. Most of the cases we are getting are not registered [with us], we refer them to other facilities after the initial diagnosis. So we do get the cases but it is not frequent as the adult TB.* (29-year-old Male TB coordinator with 4 years of working experience with TB – SP_ER_F1_001)

Childhood TB and HIV co-morbidity

Participating service providers knew and frequently mentioned the observed synergy between childhood TB and HIV. Participants recounted that most of the children that were diagnosed with TB (especially pulmonary TB) were also co-infected with HIV. Speaking mainly from their experiences, service

providers asserted that the children are usually infected with HIV by their mothers and then TB manifests as a result of non-adherence to antiretroviral therapy (ART). In some cases, the children are not screened for HIV until TB is diagnosed before the child is tested for HIV as part of the routine diagnosis protocol. Therefore, participants highlighted that childhood TB among this vulnerable group is mainly a result of the children becoming immunocompromised due to HIV. Where the child has already been diagnosed with HIV, service providers shared the view that non-adherence to the treatment regimen is often due to the death of the mothers of these children. As a result, the caregiving responsibility is shifted to grandmothers or other relatives who are not in the position to ensure adherence.

> *…The children who are HIV positive mostly get it [TB]…Because their immune system is suppressed, when they are exposed to the TB bacteria they get the disease [TB]. Most of the cases are pulmonary TB. When they do the sputum test, it might show negative but based on the x-ray results, we put them on the treatment. Some of them are brought by parents who are also HIV positive or by their grandmothers who become caregivers because their mothers are dead.* (SP_BA_F1_001; Institutional TB coordinator, 29 years old, with 6 years working experience, Municipal Hospital)

Again, it was also found that a child with TB may or may not have any parents infected with the disease. However, in most of the cases where children were

diagnosed with a pulmonary form of the disease, at least one of the parents or a household contact usually had a history of TB infection.

> *Well, I think that for the few that I can recall, most of them had retroviral [HIV] infection. So I think that retroviral infection is a risk factor for TB… some of them had also come across adults who had TB and then got infected... But from what I have seen, the underlying thing is the retroviral infection. Again, if I cast my mind back, one client was living with the grandparents because the parent had died. That child had extra-pulmonary TB. And another person also had pulmonary TB and they were [both] staying with their grandmothers.* (SP_VR_F1_001; 36 years old Public Health Physician, Medical Officer-In-Charge, with 10 years of working experience with TB; Municipal Hospital)

Management of childhood TB-HIV co-infection follows similar guidelines as adult TB-HIV management. When a child is diagnosed with HIV, the child is also screened for TB. Similarly, if a child is diagnosed with TB, the child is also tested for HIV. If the child is co-infected but has never been put on treatment before, service providers usually start with the intensive phase of the TB treatment regimen before introducing the anti-retroviral therapy (ART). This protocol seeks to safeguard against drug interactions and ensure that the client is in a better condition for co-therapy administration. It was evident from the data that participating service providers follow these guidelines in diagnosing and initiating the treatment regimen for their clients.

> *We follow the same guidelines as the adults... If the child is diagnosed with TB today and the child is already on HIV treatment, then we will start with our [TB] treatment. But if HIV and TB were diagnosed on the same day, what normally happens is that we start with the TB and then ask the patient to come for review after two weeks. If we are not comfortable with the improvements, then we will reschedule them for another two weeks until we are comfortable with the improvement in TB before we start the HIV treatment.* (SP_BA_F2_002; Male, 33 years old Institutional TB coordinator with 5 years working experience; Municipal Hospital).

Repeatedly, participants highlighted the essence of providing TB services taking into consideration HIV because of the association between these two epidemics. Service providers accentuated that to achieve the best possible treatment outcomes for their clients, there is the need for co-investigation of the syndemic and follow-up of children on treatment. This is particularly critical during the intensive phase of the TB treatment regimen as most children are diagnosed when they are very weak and presenting clinical signs and symptoms.

Management of TB and HIV in Ghana are under two control programmes; the NTP and NACP. Due to the association between TB and HIV, the two control programmes have been working closely, especially following the WHO policy on TB-HIV service integration. Participants shared the assertion that their facilities are committed to service integration. They also

provided accounts of the convivial working relationship between the HIV clinics and TB/Chest clinics at the various facilities albeit with a few challenges.

> *It is very relevant because TB and HIV are like siblings [laugh]. So when you screen for TB, you have to screen for HIV. If the child is positive, then we can start the two treatments early. Let's say if we start the TB and we don't screen for HIV because the child is not on the HIV medication, they will not recover early.* (SP_BA_F1_002; Female, 35 years old Senior Technical Officer with 5 years working experience; Municipal Hospital)

> *I will say we are twins [referring to the two units] because we have a very good working relationship. If all units had the same working relationship, it would be better. As I said, before treatment, we have to consult ART [the HIV unit] else you would be treating TB but you will not know the underlying condition. So we have a very good working relationship.* (SP_CR_F2_001; Male, 26 years old Disease Control Officer with 3 years working experience; Polyclinic)

Management modalities for childhood TB

Clinical Investigation and Diagnosis

In all the selected facilities, childhood TB management follows a similar algorithm to that of adult TB. History of TB in the family (mainly close contacts such as parents and siblings), prolonged cough, extensive weight loss, and HIV-positive status were frequently mentioned as pointers for possible TB infection

among children. If a child is suspected of having TB, the diagnostic procedure is initiated as soon as possible. Due to the peculiarity of childhood TB, the diagnosis procedure is dependent on a multiplicity of factors. Consistently, participants highlight the importance of age in determining the strategy to adopt for the diagnosis. Older children, usually aged 10 – 14 years are encouraged by the service providers to produce sputum for testing.

Gene Xpert and X-ray were the two commonly mentioned clinical diagnostic tools available at the major health facilities that were recruited for this study. Whereas Gene Xpert is the most preferred choice among service providers for the diagnosis of childhood TB, there are situations where they have to resort to the use of X-rays. Participants revealed that where the child is not able to produce sputum for testing, coupled with the unavailability of a paediatrician to undertake gastric lavage (a procedure to obtain secretions/samples from the stomach using a tube) for testing, an X-ray becomes the obvious option. However, results from the cross-tab analysis showed that, in facilities with a paediatrician, service providers usually undertake the procedure for gastric lavage so that Gene Xpert can be done to diagnose the child.

> *It depends on the age and the condition the child presents. If the child is* [older] *about 8 or 9 years and the child can produce sputum, we start with the sputum first. If the child is coughing but cannot produce sputum, we will have to do the gastric lavage, get the secretion and take it to the lab for testing. Secondly, based on the age of the child, you know*

children are not supposed to be exposed to radiation, so we prefer to do the chest x-ray for only those 5 years and above. Then based on the signs and symptoms they present, we can also do an ESR for them. Normally when the ESR is elevated, it is a suspicion of TB. (SP_BA_F2_002; Male; 33 years old Institutional TB coordinator with 5 years working experience in TB; Municipal Hospital)

Similar accounts were shared by a Public Health Physician who has been at the forefront of TB management and control in one of the study districts. This is how he put it:

We do the Gene Xpert first. Anybody who coughs and is producing sputum, the gene expert is the first. But for children, because they are unable to produce sputum, you cannot rely on Gene Xpert because you don't have the sputum in the first place and it is also difficult to convince mothers to sleep over so that we do gastric lavage for Gene Xpert. But if they are in the wards [on admission] *we do the gastric lavage. So in those instances that we cannot get sputum, we have to go for a chest x-ray as the first line of action but usually, the Gene Xpert is the preferred first line of action.* (SP_VR_F1_001; Male; 36 years old Public Health Physician with 10 years of experience in TB management, District Hospital)

Intensified Case Finding and Contact Tracing

As part of the "End TB Strategy" in Ghana, the NTP is determined to ensure that service providers reach out, diagnose, and treat as many TB cases as possible. In effect, service providers at the point of care have been encouraged by the NTP to adopt the "intensified case finding (ICF)" approach to deal with the issue of missed TB cases. The data analysis revealed that most of the facilities have adopted this approach albeit with some challenges. The ICF approach is not only limited to childhood TB but TB in general. However, the narratives from the interviews point to the fact that some units of the facilities are not committed to the approach as they regard it as increasing their workload. In facilities where there are "Task-Shifting Officers," the approach appears to be more welcoming. Participants, however, shared the view that task-shifting officers alone cannot carry out effective and efficient ICF. Some participants even shared their frustrations regarding why other hospital staff will participate in NTP's workshop on ICF but would not be committed to its successful implementation at the facility. The following excerpt from the thematic analysis highlights this finding.

> *The task-shifting officer has been posted from Korle-Bu [Office of the NTP] to this place… So he does the screening every day at the OPD and collects samples for the Gene Xpert. They do it [screening], particularly for antenatal and reproductive health. The Korle Bu people will come and talk to management, organize workshops here, and feed them, but yet the wards will not do the screening... They say it is increasing their*

workload [sigh]. – (SP_VR_F2_001; Female; 57 years old Principal Nursing Officer with over 30 years of experience working in TB management; District Hospital)

Contact tracing has been regarded as an effective mechanism in the global fight against TB. Childhood TB, especially without prior HIV infection is regarded as a sentinel event that signifies ongoing transmission from an infectious adult. As such, as part of the management strategy for childhood TB, health providers at the point of care are expected to undertake contact tracing for all persons diagnosed with the disease. The narratives point largely to a mixed result. Whereas some service providers gave accounts of how they carry out contact tracing as part of their management and control strategy, others indicated that they are not able to undertake contact tracing mainly because of resource constraints. The following contrasting excerpts are testaments to this observation.

Now that we have the x-ray machine, we ask for the family members to be screened [as part of contact tracing]. We used not to do it like that because we didn't have money and resources. But now that we have the x-ray machine, that is what we do. We book them for Friday because that is when the radiographer will come... So, as for the screening that is what we do; we screen the family. If they are coming from far distances, we don't go to their homes but rather, we invite them here. (SP_CR_F1_001; Female, 28 years old Disease Control Officer with 3 years working experience; Teaching Hospital)

> *We are supposed to be doing contact tracing but we don't do much of it because of funds and logistics. We have a motorbike that we encourage the disease control officer to use but that bike has a problem. So service providers are not motivated to do contact tracing. We are not doing so well in contact tracing.* (SP_VR_F1_001; Male; 36 years old Public Health Physician with 10 years working experience; Municipal Hospital)

Despite the contrasting accounts that highlight the fact that some facilities are currently not undertaking contact tracing, participants were however unanimous in their acknowledgement of the critical role of contact tracing in childhood TB management and control. Repeatedly, participants mentioned that contact tracing is not only geared toward case identification but also prevention and control of the disease. They also accentuated that contact tracing also provides them with the opportunity to identify where their clients live so that they can follow up on them during the treatment period. Thus, making contact tracing an integral part of childhood TB management and control. The narratives showed that as part of contact tracing activities, service providers usually give Isoniazid Preventive Therapy (IPT) to children below 5 years who have been in close contact with an infected adult but have their test results been negative.

> *It is really important because once a child has TB [without HIV infection], then it must tell you that the child is getting it from an adult contact. So, the contact tracing will help you know vividly that it is from the community... You may get other cases.* (SP_CR_F1_002; Female, 29

years old Technical Officer with 5 years working experience; Teaching Hospital)

It helps us to diagnose and treat as early as possible. Most of the time, when the mother herself is coughing, we can trace and get the children diagnosed… so we traced the case and we gave the children prophylaxis [IPT] to prevent them from getting the TB. That is what we do. So if we didn't prevent the children, they would have gotten it… (SP_VR_F1_002; Female, 29 years old Institutional TB Coordinator with 4 years working experience; Municipal Hospital)

Adherence Counselling

Treatment adherence is critical in the management of chronic infectious diseases like TB and HIV. Whereas the management of TB requires a long-term treatment regimen lasting between 6 months and 24 months depending on the type of infection, HIV management on the other hand is life-long. Therefore, adherence counselling is geared toward ensuring that clients understand the disease condition, the recommended treatment regimen, and develop mechanisms for taking their medication. With the emergence of scientific evidence that links the development of MDR-TB to non-adherence, further prominence has been given to adherence counselling in TB management.

In the case of childhood TB, the role of adherence counselling is even more critical as there is a need for the primary caregiver (PCG) to understand the disease, the recommended treatment regimen, and be committed to helping

the child to complete the treatment regimen. Participants indicated that treatment is not initiated without adherence counselling which is usually offered to the primary caregiver of the child. Thus, the PCG for each child diagnosed with TB is taken through adherence counselling before the treatment is initiated. As part of the adherence counselling, service providers often visit the house where the PCG and the infected child live to ensure that follow-up visits can be made in the course of the treatment.

> *When a paediatric is diagnosed with TB, we involve the caregivers of the child. If the client is coming from our district, we will register the person and educate the parents on the 'dos and don'ts'. Moreover too, they come for the drug every month. Before that, we do pay a visit to their house to see where they are staying so that if they don't come, we can do a follow-up…* (SP_ER_F1_001; Male, 29 years Institutional TB coordinator with 4 years working experience; District Hospital)

> *As much as possible, we counsel the mothers because the treatment of the child depends on the caregiver so we counsel them so that they appreciate their role in the treatment…* (SP_VR_F1_001; Male, 36 years Public Health Physician with 10 years of working experience in TB management; Municipal Hospital)

Discussion

This chapter seeks to examine the perspectives of service providers on the management of childhood TB in Ghana. Generally, it was evident that case

notification for childhood TB was less common, with only a few children on the treatment. However, the childhood TB situation in most of the facilities included in this study may not necessarily reflect reality. Indeed, there is documented evidence that suggests that childhood TB in resource-limited settings is often underdiagnosed due to it being regarded as less public health priority as compared to adult TB (Brent, 2012; Oliwa et al., 2019).

In many LMICs, low case notification for childhood TB has been reported due to challenges such as poor surveillance systems and diagnostic difficulties which have characterized most health care systems in these countries (Fatima et al., 2019; Dangisso, Datiko, & Lindtjørn, 2015). There is therefore a need to strengthen the diagnostic system for childhood TB in resource-limited settings like Ghana. It is just not enough to have advanced means of diagnosis like Gene Xpert in place, but also having the personnel to pick up suspected cases for testing remains crucial in addressing existing gaps in childhood TB diagnosis (Bacha et al., 2017). Notwithstanding, advanced means of diagnosis are playing crucial roles in childhood TB management and control as it has been found to offer better sensitivity as compared with microscopy for the diagnosis of pulmonary TB in children (Detjen et al., 2015). Therefore, it is expected that facilities will collaborate to ensure that where advanced means of diagnosis are required, clients can still access such services through hospital referrals (du Preez et al., 2020).

The study also found that service providers were aware of the synergy between childhood TB and HIV. There is overwhelming documented evidence

that highlights the close link between HIV infection and the development of childhood TB (Walters et al., 2014; Anígilájé, Aderibigbe, Adeoti, & Nweke, 2016; Dodd, Prendergast, Beecroft, Kampmann, & Seddon, 2017; Fry, Barnabas, & Cotton, 2019). The comprehension of the synergy between TB and HIV among the service providers is critical for early case detection as children with HIV would have to be screened/monitored for TB even if they are already on ART (Anígilájé, Aderibigbe, Adeoti, & Nweke, 2016).

This finding is consistent with the salutogenic theory that highlights that in order to ensure better management (case finding, diagnosis, treatment, monitoring, etc), health service providers will need to develop an understanding/comprehensibility of the peculiarities of childhood TB. With a proper understanding of childhood TB, service providers will develop a strong sense of coherence (SOC) which according to the salutogenic theory is critical in service delivery (see Figure 6). Treatment follow-up and continuous monitoring also emerged as important in childhood TB management. This corroborates a recommendation from a study on the need for service providers to ensure follow-up of children on anti-TB treatment as part of efforts to ensure successful treatment, especially in rural communities (Kebede, Taye, & Matebe, 2017).

This study also revealed that the clinical investigation and diagnosis of childhood TB in most of the study facilities are consistent with the WHO and GHS guidelines. Even though not so reliable due to the impact of HIV, clinical features such as smear-positive close contact, malnutrition, chronic cough, and

weight loss are suggested clinical features for probable TB infection among children (GHS & Stop TB partnership, 2012). The use of Gene Xpert is the preferred means of diagnosis among service providers. This is consistent with best practice as the use of Gene Xpert in childhood TB diagnosis is very efficient (Das, Anupurba, Mishra, Banerjee, & Tripathi, 2019).

Concerning ICF, the evidence largely points to the fact that this strategy is currently underway in most health facilities. However, the narratives suggest that the focus was not on childhood TB as participants were somewhat silent on how child welfare clinics (CWC) could be leveraged for ICF for childhood TB. Evidence from a resource-poor setting in Nigeria revealed that ICF, especially when combined with other strategies such as "capacity building, provision of work aids/guidelines, and health education on TB can improve childhood TB case notification" (Oshi et al., 2016). It is therefore imperative that challenges to ICF for childhood TB are addressed and the strategy is scaled up as part of efforts towards achieving the "End TB Strategy" (WHO, 2014).

This study revealed that whereas some facilities carry out contact tracing, others are unable to do so due to institutional challenges such as budget constraints and transportation. Evidence suggests that in LMICs, contact tracing is suboptimal even though it is a recommended strategy in TB management (Rehman et al., 2014; Pothukuchi et al., 2011). Barriers such as transportation, budget constraints, workload, distance, and discrimination against household contacts have been documented as impeding contact tracing in LMICs (Tesfaye, Lemu, Tareke, Chaka, & Feyissa, 2020). Given the power of contact tracing in

childhood TB case notification (Dodd et al., 2018), these challenges must be adequately addressed to ensure its scale-up in LMICs (Ayakaka et al., 2017).

The results also showed that as part of the treatment protocol, service providers take caregivers through adherence counselling before initiating the treatment regime. In a systematic review and meta-analysis, it was reported that adherence interventions such as education and counselling improve TB treatment outcomes (Alipanah et al., 2018). Adherence counselling has been found to improve clients' knowledge and clarify common misconceptions about TB, thereby resulting in better treatment outcomes (Sajjad et al., 2020). Concerning the theoretical framework, adherence counselling enables both the service provider and the PCG to develop a strong sense of coherence about the treatment regimen. Adherence counselling addresses issues relating to cognitive, behavioural, motivational, and institutional factors as well as fostering relationships (between service providers and primary caregivers) towards successful completion of the treatment regimen.

Summary

This chapter revealed several management practices by the service providers that are consistent with the recommended practices. For instance, the most preferred means of childhood TB diagnosis is the Gene Xpert. Also, intensified case finding, adherence counselling, and contact tracing are all part of the overall management and control of childhood TB in most facilities, albeit with some challenges. Notwithstanding, childhood case notification remains suboptimal in most health facilities. The generally strong sense of coherence

among the service providers provides hope for improvement in childhood TB management and control in Ghana. There is, however, the need for efforts to be intensified towards achieving the overall "End TB Strategy" goal of ending TB in all forms by 2030.

CHAPTER SIX

CHALLENGES OF CHILDHOOD TB MANAGEMENT AND CONTROL: PERSPECTIVES OF SERVICE PROVIDERS

Introduction

The difficulties of childhood TB are widely recognized and constitute national and global health priorities for control programmes. However, the peculiarity of childhood TB continues to present several management challenges for service providers, particularly in many LMICs. These management challenges cut across diagnosis, initiation of appropriate treatment regimen (including monitoring, follow-up), and adherence to the treatment regimen among others. This chapter highlights challenges faced by service providers in the management of childhood TB in the selected health facilities in the study sites. The results are based on the analyses of in-depth interview transcripts of 27 health providers at the point of care in the selected health facilities. Chapter five documents the socio-demographics of the participants.

The data analysis and discussions in this chapter are situated within the remit of the salutogenic theory (ST). Briefly, central to the theory are the concepts; of "coherence" and "generalized resistance resources" (GRR) that help service health care providers effectively manage childhood TB. Generalized resistance resources are concerned with "external and internal resources" that enable service providers to cope with the management of childhood TB amidst the challenges. Coherence on the other hand is determined

by cognitive, behavioural, and institutional factors that create a sense of *meaningfulness, comprehensibility,* and *manageability* of childhood TB. To better understand the challenges that confront service providers in the management of childhood TB, the narratives were situated within the ambit of the theoretical concepts.

Limited generalized resistance resources

Central to the management and control of childhood TB is the availability and adequacy of resources. The narratives of the participants largely point to the general resistance resources (GRRs) being from external sources (the Global Fund through NTP) with limited resources coming from internal sources. The service providers revealed unwillingness on the part of hospital authorities to commit resources to childhood TB management. As state funding for healthcare facilities continue to dwindle, issues of public health (childhood TB management and control in this case) are often seen as not worth financial attention as treatment is free and the units hardly add to the facility's internally generated funds. Nonetheless, the study participants revealed that hospital authorities sometimes provide transport for contact tracing and home visits.

> *I will say the support is on an ad-hoc basis. We had a drug resistance TB case and quickly we had to put our heads together and come up with funds and provide transportation for her to go to the regional audiometry…The rest is for us to ensure that as managers, the human resources are available and the material resources are also available. So, we are doing that. But there's no internal budget for TB care and*

this is a major challenge… (SP_VR_F1_001; Male; 36 years old Public Health Physician with 10 years of working experience and a member of the hospital management team)

Sense of Coherence (SOC)

Sense of meaningfulness

Self-motivation amid challenges is essential for building a sense of coherence. The service providers shared the narrative that even though they are confronted with several challenges in their efforts to manage and control childhood TB, they have also built a strong sense of meaningfulness (a constituent of SOC). The study participants asserted that they are motivated to give their best mainly because of the joy of knowing that they can help a child in distress due to TB infection to regain good health. This sense of meaningfulness is built over time as more and more children overcame the disease through the efforts of the service providers.

Any time I see children [infected with TB] getting better, I just feel accomplished. I don't want to be seeing children suffering from that condition while it is curable. So my motivation is that they will come for the medication and become healthy, and look fine. (SP_VR_F3_001; Female; 32 years Institutional TB coordinator working for 3 years now; District Hospital)

Sense of comprehensibility/understanding

It emerged from the data that service providers have a great deal of comprehensibility or understanding (a component of SOC) regarding childhood/paediatric TB. This strong sense of comprehensibility is achieved as a result of their long professional working experience in the management and control of TB in general. Also, some service providers developed this sense of understanding from training programmes and workshops. As part of efforts by NTPs to ensure effective management of childhood TB, clinical guidelines have been developed based on the Stop TB strategy and made available to all service providers. The narratives and observations point to the observance of these protocols/guidelines in the health facilities. Most importantly, service providers shared the conviction that with early initiation and adherence to the recommended treatment regimen, children should not die from TB, particularly when they are not co-infected with HIV.

> *There is a recommended treatment regimen that is laid out by WHO and NTP; so we are also following it. [The]... They say we should weigh the child before we give the treatment so that is what we do. Some of them will be on treatment for six months, nine months, or twelve months. It [the treatment duration] is based on the form of TB and the specific treatment regimen…* (SP_VR_F2_001; Female; 57 years Principal Nursing Officer with 30 years working experience; District Hospital)

Below is an excerpt that corroborates the observed theme from the data analyses:

TB drugs are all about weight. We are dealing with weight so before the child can be put on treatment, you have to take the weight of the child and calculate the dosage… So all you have to do is to get the weight and then calculate the dosage for the treatment… (SP_BA_F1_002; Female; 35 years Technical Officer with 5 years working experience; Municipal Hospital)

Sense of manageability

Whereas the data point to a strong sense of comprehensibility and meaningfulness, manageability was rather weak among the service providers (see Figure 8). The service providers acknowledged the complexities that are associated with the management of this epidemic, especially among children who are co-infected with HIV and severely malnourished. The study participants highlighted the critical role of nutrition in the treatment outcome of children with TB. Repeatedly, the participants emphasized how the fortified blended foods (FBF), "plumpy'Nut" and other supports provided by NTP through donor funds are critical in addressing malnutrition while the children go through the TB treatment regimen. However, in almost all the study facilities, the service providers expressed frustrations regarding the unavailability and inconsistencies in receiving support and incentives for caregivers to support children on TB treatment.

Sometimes, they bring us fortified blended food from the region as part of the support from NTP…It is limited [Referring to the available resources]! It's not even available for some time now. I think the cushion

[supports and incentives] that caregivers used to get needs to be made available again. (SP_CR_F1_001; Female; 28 years Disease Control Officer with 3 years working experience as institutional TB coordinator; Teaching Hospital)

This frustration regarding the lack of "enablers" and incentives for children with TB was shared across various levels of care. To buttress the above assertion, this is what one of the service providers in a municipal hospital had to say:

We used to receive the enabler's package. Unfortunately, it is out of stock now. They used to give us some Blended Fortified Food for the children but it got finished somewhere in October [6 months ago]... You know that TB is also about nutrition. So these enablers were helping with the recovery of the children. For most clients, when they come and you tell them that it is finished, they will just withdraw back. You see that they enjoyed it… (SP_CR_F3_001; Male; 33 years old Institutional TB coordinator with 4 years working experience; Municipal Hospital)

Study participants shared the assertion that childhood TB requires a great deal of financial and material resources. However, in most of the facilities, resources for TB management and control are very limited, leading to a weak sense of manageability. This weak sense of manageability among the service providers was reflected in the plethora of challenges that the service providers recounted they encounter in their day-to-day service delivery. These challenges are discussed in subsequent paragraphs.

Diagnostic Challenges

Of all the challenges that confront service providers at the various health facilities, diagnosis challenges were frequently mentioned by the study participants. In many resource-limited settings, diagnosing childhood TB continues to pose challenges to "Control Programmes". The service providers were unanimous in their assertion that several childhood TB cases remain undiagnosed because of diagnostic challenges.

Difficulty producing sputum and lack of paediatrician

In most of the facilities, the participants asserted that their most preferred means of diagnosis is the Gene Xpert. However, participants frequently mentioned the difficulties of children producing sputum samples for testing. The study participants expressed a preference for the use of Gene Xpert as the first means of diagnosing childhood TB, as WHO recommends. As such, service providers resorted to gastric lavage procedures to obtain samples for testing. However, a major problem encountered by the service providers in most of the facilities is the absence of paediatricians to undertake the procedure.

Consequently, the service providers accentuated that even though their preference is to use Gene Xpert for diagnosis, the lack of paediatricians to undertake the gastric lavage procedure compelled them to turn to other means such as careful clinical history (including HIV infection, and contact with an infected adult) and the use of chest X-ray. This is what one of the service providers had to say when highlighting the challenges they faced concerning childhood TB management.

At times they [the suspected children] are not able to produce the sputum which is a basic sample for the testing. So they have to go to the extent of using gastric lavage to extract the phlegm [sample] and all that. So if you don't have an experienced doctor [paediatrician] around, it becomes a challenge. (SP_BA_F1_001; Female, 29 years old Institutional TB coordinator with 6 years working experience, Municipal Hospital)

So, for six months or so, we didn't have a paediatrician to do the paediatric TB diagnosis. So, I think in the absence [of a paediatrician], we weren't getting the cases. So, the presence of paediatricians helps in detecting the cases [using gene Xpert]. (SP_BA_F2_002; Male, 33 years with 5 years working experience, Institutional TB coordinator)

Use of X-ray in Childhood TB Diagnosis and associated costs

Despite the recommendation by WHO for the use of Gene Xpert as the most preferred means of TB diagnosis, the use of X-rays in childhood TB diagnosis remains very common. Whereas TB treatment (medication) is free, X-ray services for diagnosis attract fees in almost all the study facilities. Given that TB is a "disease of the poor", clients are often not able to pay for such services. As such, some caregivers exit the facility without their children getting diagnosed and will only return when the condition of the child has deteriorated considerably. The service providers also emphasized that X-ray results may present specificity challenges since other childhood illnesses such as pneumonia

can mimic TB. Thus, the participants fear the possibility of misdiagnosis. The excerpt following reflects this theme.

> *...If the child has any other condition, the x-ray can mimic that of TB. So, you end up treating somebody who is not suffering from it. We don't have a gene expert [in this facility].* (SP_BA_F1_001; Female, 29 years old Institutional TB coordinator with 6 years working experience, Municipal Hospital)

The NTP has made some efforts to address this challenge by providing some facilities with X-ray machines to deliver free TB diagnoses. One of such facilities; the Cape Coast Teaching Hospital (CCTH) has been included in this study. The service providers highlighted that the problem is not solved entirely as the free diagnostic service is only provided once a week due to the absence of a permanent radiographer to provide the service. The NTP provided the X-ray machine with the expectation that the facility will recruit a radiographer to operate the machine.

However, the hospital authorities are reluctant to engage the services of a radiographer due to its seeming economic unviability. As such, the free X-ray service is only available once a week with several clients queuing for the service. According to the service providers, if a child requires an X-ray service on a day other than the designated day and the caregivers cannot pay for the service at the mainstream facility, then they will have to go home and report later for the free service. The participants asserted that this challenge often leads to a missed opportunity for diagnosis as the children are sent home and only

brought back when their health conditions deteriorate considerably. The following excerpt corroborates this narrative.

> *... If we had a radiographer, most of the children could be screened today but we have to wait till Friday. So, if a child has come and then we have suspected TB, the child cannot produce sputum and the mother does not have money for the x-ray then you tell them that they should go and come back on Friday... Most of them go and never come back…So, they will come back when the child's condition has worsened... Even on Friday [designated day], people come to sit here as early as 7 am; the radiographer will come at noon. So, it is a challenge for childhood TB.* (SP_CR_F1_001; Female, 28 years old with 3 years working experience, Disease Control Officer and Institutional TB coordinator; Teaching Hospital)

Delay in getting test results (diagnosis)

Accurate and prompt test results are critical in TB management as undue delays could lead to client anxiety and also delay the initiation of an appropriate treatment regimen. In line with the End TB Strategy, efforts are currently underway to reduce missed TB cases and ensure that all suspected cases have access to advanced diagnostic procedures such as the Gene Xpert. Whereas Gene Xpert produces accurate TB results in a relatively shorter period (Stevens, Scott, Noble, Gous, & Dheha, 2017), it is not available in every health facility across the country. In facilities where the service is not available, service providers have resorted to a Specimen Referral System (SRS) by the NTP to

ensure that clients are not denied access to the required service. Although service providers shared the view that the SRS increases access to accurate diagnosis and removes the cost associated with clients travelling to a referral facility for the test, they highlight delays in getting test results as a major challenge. Also, participants shared their concerns about the limited number of days (twice a week in most facilities) assigned for specimen referrals. One participant shared her frustration in the following excerpt from an in-depth interview.

> *We send the sputum to the regional office and they have days that they usually pick up the sample for testing [Specimen Referral System]. When the result is ready, they will bring it to us. The challenge that we have is that at times the results are delayed… They only come on Tuesdays and Fridays. So if a client comes today, we have to store the samples till Friday then they will come and pick them up. For the specimen sent on Tuesday, we will have to wait till Friday to get them [the results] and because of that, it delays things.* (SP_BA_F1_002; Female, 35 years Senior Technical Officer with 5 years working experience)

Misdiagnosis leading to loss of potential cases

It also emerged from the data analysis that the difficulties associated with diagnosing childhood TB often lead to misdiagnosis as TB among children could mimic other diseases such as pneumonia. Repeatedly, the study participants asserted that the actual burden of childhood TB may be a lot higher as most of the cases are either misdiagnosed or not diagnosed at all. The

participants highlighted that in facilities where advanced means of diagnosis such as gene Xpert are unavailable, coupled with an absence of a paediatrician, childhood TB cases could be missed through misdiagnosis. As such, participants emphasized that, the fact that the burden of paediatric TB in most of the facilities has been relatively low does not necessarily mean childhood TB is not a public health concern. The excerpt below reflects this observation from the narratives:

> *I think the problem is that we are misdiagnosing most of them for pneumonia. So it can be that a lot of the pneumonia cases have been misdiagnosed since we don't have the logistics and experts to diagnose. So childhood TB may be rather common. Not getting them diagnosed doesn't mean it is not there; the problem is how to diagnose them.* (SP_BA_F2_002; Male; 33 years; institutional TB coordinator with 5 years working experience; Municipal Hospital)

Challenges of Treatment Adherence

Adherence to an appropriate TB treatment regimen is the cornerstone to a successful treatment outcome. In effect, the DOT strategy has been put in place to ensure optimum adherence to the anti-TB medication. Nonetheless, the DOT strategy is not applicable across all settings due to challenges relating to linkage care. Consequently, in childhood TB management, service providers heavily rely on mothers or primary caregivers (PCGs) to ensure that the child adheres to the treatment regimen. However, the complexities of childhood TB management make over-reliance on PCGs for adherence to the treatment

regimen a risky endeavour. The narratives highlight non-adherence to the treatment regimen as a major challenge to service providers in the management of childhood TB (see Figure 8 for a summary). This non-adherence is manifested mainly in the form of treatment interruptions due to initial improvement in the health condition of the child.

Treatment interruption following the intensive phase of the regimen

Strict adherence to the recommended treatment regimen is critical in childhood TB management as it has a bearing on the treatment outcome. Treatment interruption could result in worsening health conditions of the child and consequently the development of resistant strains of TB. Participants narrated how some mothers' primary caregivers often interrupted or stopped coming for their medication when they realized that symptoms such as persistent cough, weight loss, and difficulty in breathing have disappeared. According to the participants, the caregivers for the children only report back to the facility after the child's health condition has deteriorated considerably due to the interruption. Most of the participants highlighted that they are often left frustrated when they have to begin the treatment regimen all over again. The following quote by one of the service providers echoes this theme.

> *You know, for TB, if you take your drug very well; maybe in the first two months, the signs and symptoms like the cough and difficulty in breathing will cease. After that, we begin to face challenges because the mothers begin to think that the child is healed so they don't see the need*

to come for the drug. (SP_BA_F1_002; Female, 35 years with 5 years working experience, Senior Technical Officer)

Belief in Herbal Medicine for childhood TB Treatment

Understanding the aetiology of a disease like TB is important to adherence to the recommended treatment regimen. However, the complexities associated with childhood TB often make it difficult for service providers to provide caregivers with a comprehensive understanding of the disease, especially in the case of extra-pulmonary TB. The participants acknowledged that due to the difficulties in diagnosing TB among children, caregivers often visit several facilities before the child is finally diagnosed.

According to the participants, in such cases, primary caregivers approach the treatment regimen with some reservations, especially when the adherence counselling is not properly done. It emerged from the data analyses that due to such reservations, some PCGs resorted to the use of herbal medicines in desperate attempts to help their children recover from their ill conditions. Participants highlighted this as a challenge as it leads to non-adherence to the treatment regimen and possible development of resistant strains of the "*mycobacterium TB"* which is the causative agent of TB. Participants, however, shared the view that this challenge can be addressed through continuous counselling and following-up on clients.

… before they get here, they would have gone to so many places, so the facility [where the diagnosis was done] becomes the last stop. Like the boy from [XXX], after our counselling and everything, the family wanted

to take him to a herbalist but the small boy being intelligent took my number so he called me one evening and told me that the father was planning to take him to some herbalist... So, I quickly called the dad and counselled him until he understood and allowed the child to take the treatment… (SP_VR_F2_002; Female, 32 years old with 11 years working experience, Senior Nursing Officer and Institutional TB Coordinator)

Childhood TB linked to spiritual causes

Service providers also highlighted the belief system where primary caregivers often attribute childhood TB to spiritual causation. According to the participants, this is because of the limited understanding of childhood TB among communities. TB is often not regarded as a disease for children. As such, when a child is diagnosed with TB, caregivers often link it to spiritual causes and therefore embark on seeking spiritual remedies. In such cases, the child is denied the prescribed treatment regimen. The service providers highlighted this as a major challenge for adherence to the treatment regimen.

Parent adherence is a challenge. If the parent happens to be semi-literate by the time you call, they are at the prayer camp. They think the child is being affected by some evil spirits. But for those who understand the disease, the [treatment] outcome is great. (SP_WR_F1_001; Female, 38 years old nurse in-charge at the communicable disease centre with 6 years working experience, Regional Hospital)

Management and Operational Challenges

Management and operational challenges also emerged from the data analyses as some of the major challenges that confront TB services providers across the various levels of health care. The complexities of childhood TB management and control present challenges to service providers, especially in resource-limited settings. In almost all the study facilities, study participants alluded to the numerous management and operational challenges that confront them (see Figure 8). These challenges are highlighted in the subsequent paragraphs.

Contact tracing challenges

One of the main operational challenges that emanated from the data analyses was the lack of contact tracing for childhood TB. Most of the service providers mentioned that they are unable to undertake contact tracing even though they are aware of the critical role it plays in childhood TB control. Even in the few facilities where some form of contact tracing takes place, the participants shared the view that the strategy is not effective due to logistical challenges. Participants frequently mentioned costs associated with transports to communities where clients live, inadequate funds, false or inaccurate residential addresses, and stigma relating to TB (childhood TB) at the community level as major obstacles to effective contact tracing. The excerpts below corroborate this theme from the analyses:

> *For follow-ups and contact tracing, the challenge is with the inaccurate [residential] addresses. When I am not given the proper addresses then I will go to the community and search and not find the house. And as I*

said, stigma; some clients or caregivers don't want other relatives to know that their child has TB. So you have to do everything in seclusion. It is not the best because ideally, everybody [in the household] should be screened… (SP_CR_F2_001; Male; 26 years disease control officer with 3 years working experience as an Institutional TB coordinator; Polyclinic)

Poor linkage care (under DOT strategy)

The DOT strategy has been employed in both adult and paediatric TB management since 1993 and its effectiveness has been documented, especially in LMICs. The Stop TB strategy even highlighted the need to expand DOTS through standardized treatment and proper case management to promote treatment adherence and favourable outcomes. Countries such as Ghana have adopted these strategies in addition to the current "End TB Strategy" which is in operation at various health facilities. The DOT strategy implies that treatment is brought closer to the people. Whereas the service providers shared the view that this strategy mitigates catastrophic costs incurred by clients during the treatment regimen, they also highlighted the challenges that come with this strategy. Study participants shared the concerns that when a child with TB is referred to a lower-level facility such as a health centre or clinic, there is often reluctance on the part of those at the receiving health facility to enrol them. The reluctance is mainly due to the childhood TB management complexities such as monthly reporting and refilling of paediatric anti-TB formulation at the Regional Health Directorate.

Sometimes, the health workers at the lower level of care [first level of primary care] are also part of the problem. Sometimes we would refer a case; these people already don't have money and we refer them to [XXX – name withheld for ethical reasons] with our contact numbers. The client [child] will get there and they will send the child back here because they don't have drugs instead of communicating with us to see how we can get the medicines across… For childhood TB, when you diagnosed the cases that is when you request drugs [paediatric anti-TB formulation]. Our people at the community-based clinic are not helping our course at all. (SP_CR_F1_001; Female; 28 years Disease Control Officer with 3 years working experience as an Institutional TB coordinator; Teaching Hospital)

Long treatment duration

The duration of the treatment regimen also emerged as posing a challenge to service providers across the various levels of care. The study participants stressed that with the long duration of the treatment regimen, children become fatigued with taking daily medications, especially when they "considered" themselves to be in good health. This is even exacerbated when children are co-infected with HIV and have to deal with a co-therapy regimen. The participants shared the view that a lot of tact is required to convince children to continue taking their anti-TB medication for the entire duration of the treatment regimen. This is critical for successful treatment outcomes because most of the children on treatment tend to considerably improve in health after the intensive phase of

the treatment regimen. There is a substantial danger of relapse or even the development of drug-resistant TB if treatment is interrupted or rescinded completely. The participants viewed a possible shorter regimen as the way forward in addressing this challenge.

> *…They understand [the treatment regimen] when they are here [on admission] but they feel reluctant to adhere when they are gone [discharged] home after the intensive phase. So that creates some confusion. They don't understand why they should allow a child to take treatment for six months. So that is the challenge we get… If the regimen can be shortened, that will be fine* (SP_CR_F2_001; Male, 26 years old Disease Control Officer with 3 years working experience as an Institutional TB coordinator; Polyclinic)

To corroborate this perspective, another participant had this to say:

> *Some of the children who can speak and are inquisitive will ask you why they are supposed to take the medicines every day. It takes skilful counselling to make them understand why they have to take the medicines every day. We encounter this, particularly for the retro [co-infected] children. Some of them refuse to take it… If the treatment can be modified and shortened, it will work because most of the caregivers are not really committed.* (SP_VR_F1_002; Female, 29 years old institutional TB coordinator with 4 years working experience; District Hospital)

The control mechanism for the allocation of child anti-TB formulation

As a response to dealing with the problem of wastage of anti-TB medicines, the NTP resorted to keeping paediatric anti-TB medicines at the various regional medical stores. Health providers are expected to make a request for the medicines on a "case-by-case" basis. The study participants acknowledged that this mechanism is geared towards curbing the practice where paediatric anti-TB medicines are left at the health facilities to expire. However, they were unanimous in their assertion that the mechanism presents delays in treatment initiation. Service providers shared the concern that delays in initiating the appropriate treatment regimen may lead to unfavourable treatment outcomes. They highlighted how caregivers often fail to bring back their children when they have to go home and come back on a later day for the commencement of the treatment regimen. The excerpts below corroborate this theme:

> *Our most pressing need now is the paediatric anti-TB medicines that we have to take from the regional hospital anytime we diagnose a case. Before you can get the medicine, you have to get the case first and then make a request. It delays the [initiation] of the treatment.* (SP_BA_F1_002; Female; 35 years old with 5 years working experience; Senior Technical Officer; Municipal Hospital)

Co-therapy regimen for childhood TB and HIV

It emerged from the data analyses that service providers are faced with difficulties regarding monitoring co-therapy administration, especially in facilities that are not fully integrated. However, service providers at the various

DOT centres highlighted the existence of a convivial working relationship with their counterparts at the ART clinics. Notwithstanding, the narratives largely point to service providers not being able to effectively monitor the co-therapy regimen for TB-HIV co-infected children. Service providers shared the view that the high number of clients on ART, coupled with lapses in record-keeping (reliance on paper folders and shelf filing), make it difficult to effectively monitor clients on co-therapy for adherence. Also, the participants shared the concern that co-therapy increases pill burden, thereby presenting adherence challenges. The quote below is a reflection of this observation from the data:

> *The problem is that some of them don't take the HIV medications and when you ask them they will give you flimsy excuses... Initially, most of them were dying and so we decided to look out for why they were dying. That was how we got to know that most of them defaulted for HIV [ART]. And this is not the fault of the HIV unit because close to 1000 patients in* [XXX name of a community] alone... *So they sometimes default without their knowledge.* (SP_BA_F2_002; Male; 33 years Institutional TB coordinator with 5 years working experience; Municipal Hospital)

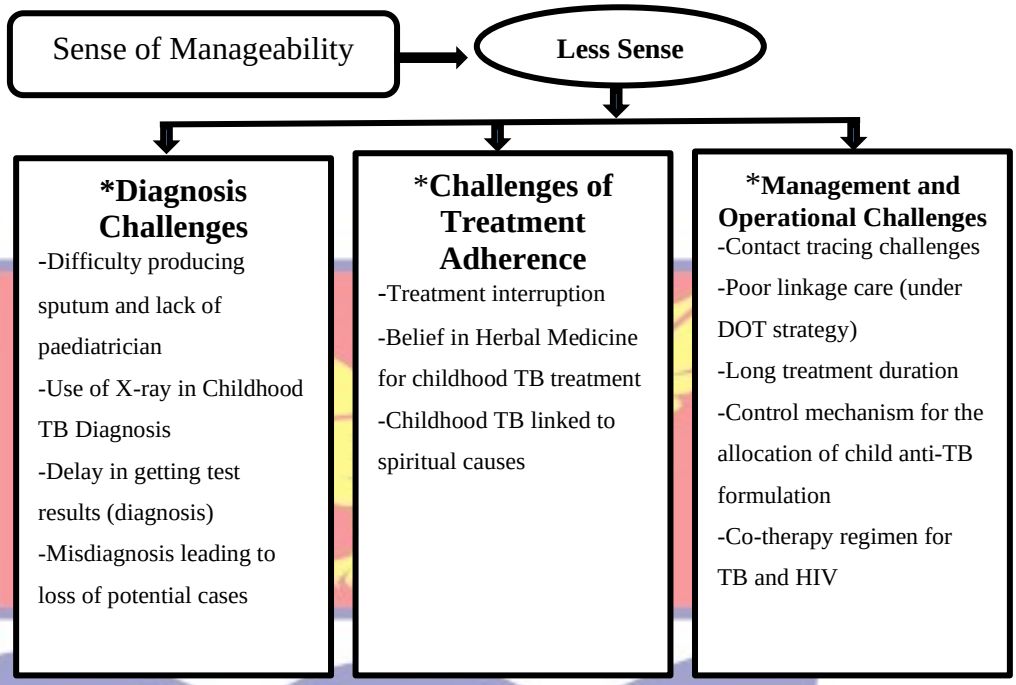

Figure 8: Summary of results using the salutogenic theory framework

Source: Fieldwork, 2021

Discussions

This chapter aims at examining the challenges faced by service providers in the management and control of childhood TB in Ghana using salutogenic theory (ST) as a theoretical framework. There was some evidence of GRR (mainly resources from Global Fund through NTP) which has enabled service providers to continue service delivery regardless of the manageability challenges that confront them. Studies that employed ST have reported how people can overcome or cope amid challenges due to GRRs (Polhuis, Vaandrager, Soedamah-Muthu, & Koelen, 2020; Hovland, Skogvang, Ness, & Langeland, 2021).

In the case of childhood TB management and control, the evidence points to these GRRs being from external sources (mainly Global Fund). Indeed, the Global Fund has been instrumental in TB, HIV, and malaria control in Ghana with a cumulative disbursement of US$ 804 million since 2002 (The Global Fund, 2019). However, there is evidence to show that overreliance on an external source for GRRs for disease-specific programmes such as TB control is a risky one (Shaw, Wang, Kress, & Hovig, 2015). As such, there is a need for governments in LMICs, especially in sub-Saharan Africa to increase their budgetary allocation for health financing (Gautier & Ridde, 2017).

Regarding SOC, there was evidence of a strong sense of meaningfulness among the service providers which is critical in ensuring that service delivery continues despite the manageability challenges. Evidence from a systematic review by Masanotti and colleagues showed the power of meaningfulness in maintaining strong SOC among nurses (Masanotti, Paolucci, Abbafati, Serratore, & Caricato, 2020). Similarly, the power of comprehensibility and manageability in developing adequate SOC in healthcare settings have also been documented (Golembiewski, 2016).

Concerning the sense of comprehensibility, it was evident that service providers at the various facilities understood and have conviction in the management protocol (Stop TB, GHS, 2012) that has been put in place by the Ghana Health Service. Service provision in the various facilities where the weight of the child is given credence is consistent with current recommended practice (WHO, 2016). Unsurprisingly, service providers shared their

conviction that children should not die of TB, especially if not co-infected with HIV since TB is curable and the treatment is free of charge. This is consistent with the vision of international organizations such as the WHO, UNICEF, and the Stop TB Partnership to end TB in all forms and prevent TB-related deaths among children and adolescents (WHO, 2018).

With manageability, the evidence points to a weak sense of manageability among the service providers. Nonetheless, building a positive SOC does not entirely depend on manageability as comprehensibility and meaningfulness also have prominent roles to play (Masanotti, Paolucci, Abbafati, Serratore, & Caricato, 2020). As such, the strong sense of comprehensibility and meaningfulness among service providers ensures continuous efforts aimed at managing and controlling childhood TB in Ghana. The study result shows that service providers are faced with numerous challenges due to the complexities associated with childhood TB management and control. There is documented evidence to show that childhood TB continues to pose challenges to service providers and several controversies still exist that need to be addressed to drive the world towards the elimination of TB (Reuter, Hughes, & Furin, 2019).

Of all the challenges that confront service providers in childhood TB management, diagnosis is considered the most daunting. This is consistent with the existing literature where the diagnosis has been reported to present a major challenge to the global fight against the TB epidemic in children (Trajman & Schwartzman, 2020). Children, especially those less than age 5 find it extremely

difficult to produce sputum, thereby necessitating more invasive procedures such as gastric lavage and sputum induction in diagnosing TB among this population sub-group (Joel et al., 2014). However, in LMICs, modern diagnostics are not yielding results due to challenges relating to skills, competence, provider experience, among other things (Oliwa et al., 2020). It is worth mentioning that invasive procedures such as gastric lavage and sputum induction require highly skilled health personnel such as paediatricians to undertake, yet they are unavailable in many health facilities in resource-limited settings (Baghaei et al., 2011).

The current study also revealed that radiological examination (X-ray) remains prominent in childhood TB diagnosis, despite the rollout of Gene Xpert in the country. Evidence from Mozambique (a resource-limited setting) showed the critical role radiological examination (chest radiograph [CXR]) plays in diagnosing TB among children (García-Basteiro et al., 2015). Nonetheless, relying solely on X-rays for childhood TB diagnosis presents challenges as there are unresolved issues with specificity, thereby affecting accurate diagnosis (WHO, 2016). Besides, X-ray services in most facilities are not free. Evidence suggests that the financial liability of illness is often higher for TB clients in resource-limited settings where healthcare coverage is not universal (Laurence, Griffiths, & Vassall, 2015).

The current study also revealed that efforts are currently underway to improve childhood TB diagnosis by embracing WHO's recommendation for the use of Gene Xpert in childhood TB diagnosis. As part of efforts to improve

access, many facilities have resorted to specimen referral systems (SRS) since the Gene Xpert service is not available in all facilities. Whereas there is documented evidence to show that SRS is feasible and associated with improved diagnostics and infection control in resource-limited settings (Hamilton, Nunes, & Grobusch, 2019), there still exists delays in diagnosis (Bello et al., 2019). Misdiagnosis leading to loss of potential cases has also been documented as a bane in childhood TB control efforts (López Ávalos & Prado Montes de Oca, 2012).

This study also pointed to challenges relating to treatment adherence. Treatment interruption after the intensive phase of the regimen and belief in herbal medicine for childhood TB treatment was evident. A qualitative study conducted in Nepal (a resource-limited setting), reported barriers in access, diagnosis, and treatment adherence. Specifically, the authors highlighted long-distance and travelling costs as barriers. Also, poor awareness of TB and its attendant consequences, coupled with beliefs that childhood TB emanates from the supernatural encouraged people to visit traditional healers for TB treatment (Marahatta et al., 2020).

The findings of the present study are in resonance with existing practice in Ghana where several medicinal plants are used to treat TB (Nguta, Appiah-Opong, Nyarko, Yeboah-Manu, & Addo, 2015). These barriers, especially belief in herbal medicine for the treatment of TB ought to be addressed as a matter of urgency. To date, there is no clinical trial that documents the efficacy of herbal medicine for childhood TB treatment, even though several plant

secondary metabolites have been reported to have anti-tubercular activity comparable to the existing anti-tubercular drugs (Anochie et al., 2018). In Ghana, even though their efficacy has not been proven, the use of medicinal plants for the treatment of TB exists (Nguta et al., 2015). Whereas this may present an alternative source of TB treatment in the future, there is still a long way to go. As such, education on the existing treatment regimen needs to be intensified.

This study also produced evidence of several challenges relating to the management and control of childhood TB. Of key note are contact tracing challenges, poor linkage care under DOT, long treatment duration, the control mechanism for the allocation of child anti-TB formulation, and challenges of co-therapy administration for TB-HIV. With regards to contact tracing, the current study is consistent with documented evidence from Southern Ethiopia where the authors found low TB contact tracing/investigation. Barriers such as "lack of monitoring and supervision, shortage of staff, workload, distance, financial constrain, stigma, and discrimination of household contact tracing of index TB cases", among other barriers were reported as hindering effective contact tracing (Tesfaye, Lemu, Tareke, Chaka, & Feyissa, 2020). Poor linkage care under the DOT strategy reinforces the bottlenecks of this strategy. In a systematic review by Karumbi and Garner (2015), it was evident that DOT did not provide a solution to poor treatment adherence, highlighting the need for considering other options that address financial and logistical barriers to care (Karumbi & Garner, 2015).

Reassuringly, the existing national health insurance scheme can be leveraged to cover all aspects of TB treatment in Ghana. Poor linkage care under DOT was also reported in a study conducted in Ethiopia where reluctance on the part of some health workers was highlighted (Gebreegziabher, Yimer, & Bjune, 2016). Long treatment duration has been documented as posing a challenge to childhood TB management due to the pill burden and the likelihood of treatment fatigue (Thomas, 2017). Gratefully, a new shorter regimen is currently under clinical trial and will be made available if the results turn out to be positive (Chabala et al., 2018). However, it is imperative to note that while shortening treatment duration may result in improved adherence, adult studies showed a high risk of relapse which is occasioned by the drug (Wallis et al., 2016).

The present study also revealed a mechanism that has been put in place to reduce wastage by keeping all paediatric anti-TB medicines at the regional stores and disbursement only made after a request is made following childhood TB case confirmation. Even though this seems like a good strategy, the challenges associated with it should be addressed. Facilities can be given limited doses of the paediatric anti-TB medicines and then request a refill when a case is confirmed. Lessons can be drawn from a study conducted in Pakistan which aimed at strengthening the response to drug-resistance TB management using a practice theory-informed approach to address bottlenecks by focusing on improving the process of care rather than priorities set at the national

programme level as such actions have been found to have negative consequences for the client (Abbas, Kermode, & Kane, 2020).

Concerning TB-HIV co-therapy administration, the literature suggests that drug-drug interaction increases the complexity of both TB cure and viral suppression for HIV with negative outcomes for the client (Mukonzo, Aklillu, Marconi, & Schinazi, 2019). There is evidence to show that several challenges, including adherence, optimal monitoring, and record-keeping still exist in many resource-limited settings with regard to co-therapy despite two decades of co-therapy roll-out (Letang et al., 2020). Therefore, there is a need for assessing the quality of childhood TB care with differentiated service delivery models for children and families affected with TB (Amanullah, Bacha, Fernandez, & Mandalakas, 2019).

Summary

This chapter unravelled the numerous challenges that confront service providers in the management of childhood TB using Salutogenic theory as a framework. Whereas the sense of meaningfulness and comprehensibility were more evident among service providers, the sense of manageability was rather less evident. The challenges of TB management broadly span diagnosis, treatment adherence, management, and operational difficulties. Notwithstanding, general resistance resources from an external source (mainly the Global Fund through NTP) ensured the sustainability of service delivery amidst the numerous manageability challenges.

Given Ghana's commitment to the rather ambitious "End TB Strategy", childhood TB the aforementioned TB management challenges need to be addressed quickly to set the country on the path towards the realization of the ultimate goal of ending TB in all forms by 2030. ST provides a robust analytical framework to comprehensively unravel and understand challenges associated with the management and control of the TB epidemic among this population subgroup which hitherto has not received the needed attention.

CHAPTER SEVEN

INTEGRATION OF CHILDHOOD TB MANAGEMENT INTO CHILD WELFARE CLINIC

Introduction

In many resource-limited settings, there exist limited capacity to identify, diagnose, and manage childhood/paediatric TB, especially at the lower levels of the health care system. The diagnosis and treatment of active paediatric TB are centralized at higher levels of care and often provided in separate TB units referred to as DOT centres. Consequently, there are missed opportunities for childhood TB diagnosis and treatment. As such, integration of childhood TB into child health services such as child welfare clinics (CWCs) has been recommended as part of efforts towards achieving the End TB strategy.

In this chapter, I explored the feasibility of integrating childhood TB management and control into CWC from the perspectives of service providers using the Normalization Process Model (NPM) (a subsidiary of the Normalization Process Theory) as a framework. The power of NPM to study the feasibility, as well as evaluation of complex healthcare interventions, has been demonstrated across various settings (May et al., 2018). The operationalization and contextualisation of the NPT have been provided in chapter two of this thesis.

Operations of CWC

The operations of CWC are virtually the same in all the study facilities. Services at the CWCs are mainly provided by Community Health Nurses (CHNs). These nurses work closely with either a Public Health Physician or a nutritionist at the higher levels of the healthcare system. In all the study facilities, the CHNs provide both static and outreach services. Therefore, the working days are shared between being in the facility (static) and visiting communities (outreach) services. The static services are provided at a designated place at the health facility while the outreach services are provided at the various communities in the sub-districts, especially those without a health facility. In most of the study facilities, the static services are provided twice a week while the remaining three working days are dedicated to community outreach. This is what one of the CHNs said when recounting how the CWC operates:

> *We operate on Mondays and Tuesdays for the weighing and immunization at the facility. On the other days, we operate in our catchment area [communities within the sub-district]. We go for community outreaches and vaccinate the children in the community. We do "weighing and vaccination"…* (CWC_SP_CR_F2_002; Female, 35 years community health nurse with 12 years working experience, District hospital)

The main activities of the CHNs at the CWCs include vaccination, growth monitoring (weighing) and health education. Each mother or primary caregiver (PCG) is provided with either a health record book or maternal and child health

book or the road to health card, depending on the facility. The child's growth is monitored monthly by taking and recording the weight of the child at CWCs. Also, childhood vaccines such as BCG, pentavalent, measles, RTS, S among others are given to children at different growth milestones. Each child is expected to receive various vaccines and his/her growth is monitored until the child is 5 years old. Considering how the CWC operates, it offers opportunities for service providers to regularly be in contact with children and their PCGs.

> *They run the clinic (CWC) almost every day. But they have the days they go to the communities to provide health services. They go with their vaccines, growth monitoring and do a bit of nutrition, family planning and post-natal care. So they are generally in touch with the kids. They are supposed to be in touch with the kids.* (SP_VR_F1_001; Male, 36 years Public Health Physician with 10 years working experience, Municipal hospital)

Interactional workability: Opportunities for childhood TB diagnosis

Missed opportunities for diagnosis remain one of the main challenges confronting childhood TB. National control programmes and health providers in resource-limited settings continue to explore ways to enhance the intensified case finding (ICF) strategy that has been adopted to address the missed opportunities for diagnosis. CWC offers a good avenue for childhood TB diagnosis as service providers at the unit meet children under-5 every month for growth monitoring and childhood vaccination under the Expanded Programme for Immunization (EPI) (see Figure 9). This is critical for childhood TB control

as children under 5 have the highest risk of developing active TB compared to other childhood age categories (Luzzati et al., 2017).

Besides, children under 5 present the greatest diagnostic challenge and show lower rates of treatment success (Ramos et al., 2019). Participants unanimously shared the view that integrating childhood TB into CWC will lead to an increase in the number of children that get diagnosed and help address the situation where children missed the opportunity to be diagnosed. The study participants also highlighted that due to the high level of interactions that take place between PCGs and service providers during CWC, integration could yield favourable results. The quotes below reflect this dominant theme from the data:

> *They [Service Providers at CWC] can help with case detection because every month mothers bring their children to CWC. Maybe the child might have been coughing but the mother would not take it seriously. If the mother brings the child to the CWC, the health worker can carry out an assessment… you suspect that the child may be suffering from TB so you will go further and screen the child for TB.* (SP_BA_F1_002; Female, 35 years old Senior Technical Officer with 5 years working experience; Municipal Hospital)

> *I think that when it is integrated, it will help with diagnosing because they must probe further when the child is not gaining weight [growth monitoring]. So when they probe further [screen], they can get to diagnose TB if it is present.* (SP_ER_F1_001; Male, 29 years old

Institutional TB coordinator with 4 years working experience; District Hospital under CHAG)

Not only did the service providers highlight how the frequent interaction with children at CWC offers opportunities for childhood TB diagnosis, but they also shared the conviction that the regular community outreach will also offer an opportunity for diagnosis at the community level. Also, the narratives point to the possibility of the service providers using their weekly community outreach services to carry out childhood TB contact tracing to reach out and diagnose the many undiagnosed childhood TB cases in the community. Besides, the added advantage to the household contact tracing is that, it will offer an opportunity to screen and possibly diagnose children outside the 5 years cut-off age for CWC.

I think it is a good course because they mostly see the kids. So if they set out to find TB and they know the signs and symptoms they can do it. I think it will be cool… With this [case-finding during outreach], we will be able to diagnose most of the cases because some people will not go to the hospital and so when you bring the services to their doorsteps, they will take the opportunity [advantage] of that since they are not going to pay. With the home visits and all that, it will help. They work with kids so it is not going to be a big problem. (SP_CR_F1_002; Female, 29 years old Disease Control Technical Officer with 5 years working experience; Teaching Hospital)

A community health nurse working at the CWC at a district hospital corroborated this assertion:

> *It will be good. You know the community health nurses are the ones who go for outreaches. So, when we go for outreaches, we can be looking out for such things [childhood TB]. We can also do contact tracing to screen members of the household…* (CWC_SP_BA_F3_002; Female 28, Community Health Nurse with 4 years working experience at the CWC)

Relational integration: Expertise and practices at CWC

The extent to which knowledge and practice regarding a new policy or intervention are mediated is critical for successful integration and subsequent normalization. Whereas the study participants were almost unanimous in their assertion that integration will result in improved case-finding, they however expressed some reservations regarding the management of the disease by the CWC service providers. Many of the participants shared the view that service providers at the CWC do not possess the requisite expertise to manage the disease. According to the participants, the work of community health nurses at the CWC is more of preventive health where vaccination and growth monitoring of children form the core of their activities.

TB management is a complex one and includes a range of activities such as screening, diagnosis, initiation of the treatment regimen, giving out medications over a long duration, contact tracing, follow-up, and monitoring for successful completion of the regimen. Consequently, the study participants

shared the view that community health nurses at the CWC may not be in the position to add total management of childhood TB to their existing CWC activities (see Figure 9). As such, they advocated for partial integration where CWC health providers would just limit their involvement to case-finding and then refer the cases to the TB unit for management. The excerpt below reflects this thematic observation from the data:

> *... but their focus is on children under five years for CWC. But, generally speaking, I think that health professionals, irrespective of where they find themselves, should be willing to save lives. If you are at the OPD and you are trained to screen and diagnose TB, it will help. So I think case search can be encouraged at all levels. However, for the management of TB, you need to appreciate the other things... I think it will be too much of a burden for them. However, at the community level, there are various aspects of the management that they can perform.* (SP_VR_F1_001; Male, 36 years old Public Health Physician with 10 years working experience; District Hospital)

Reservations regarding full integration

Scepticism about full integration of childhood TB management into CWC also emanated from the fact that TB control is programmatic. The programmatic nature of TB management and control in Ghana requires service providers to keep records and report to the NTP periodically. As such, participants highlighted that, the programmatic nature of TB management will not allow for full integration of childhood TB into CWC. Of key concerns expressed by the

participants are issues relating to record-keeping and accountability which are critical requirements under the TB control programme. The vertical nature of the control programme, coupled with the accountability structures put in place means that service providers at the TB clinics lend higher accountability obligations to the NTP than their health facilities.

> *... But you know that the TB drug is a programme drug and then this place is the designated area for taking the drug; those at the other facilities and units have to refer them to this place because it is only this place that they can get the drug for them. So, they cannot do the treatment there [at the CWC]. We have to keep records well and report to the region regularly.* (SP_BA_F1_002; Female, 35 years Senior Technical Officer [Disease Control] with 5 years working experience in TB; Municipal Hospital)

Skill-set workability: Preference for partial integration

It emerged from the data that allocation of tasks and setting of boundaries will be critical in ensuring successful integration and normalization of childhood TB management at the CWC. Repeatedly, the study participants emphasized that the work of the health providers at the CWC should be limited to case-finding and diagnoses. The actual management (initiation and monitoring of the treatment regimen) of childhood TB should be left in the hands of the health providers at the various chest clinics (DOT centres or TB Units) of the health facilities. According to the study participants, partial integration where CWC health providers will screen, diagnose children with TB and then refer them to

the TB unit for actual management present a viable option. Thus, the study participants advocated for close linkage care or a collaborative model (partial integration) of care for children infected with TB.

> *… For case detection, yes, they can help with the case search and be involved in it but for the management, I don't support it. That one should be exclusively left for us [service providers at the TB unit]. We should work closely with them to monitor the child during treatment.* (SP_BA_F1_001; Female, 29 years old Institutional TB coordinator with 6 years working experience; Municipal Hospital)

Possible role conflicts and extra workload

The narratives pointed to the need for a clear definition and allocation of tasks as critical in ensuring the successful integration of childhood TB into CWC. The study participants envisaged possible disputes, especially at the initial stages of the policy. Complaints relating to extra workload and role conflicts were highlighted as possible challenges that might impede successful integration, especially for full integration (see Figure 9). Nonetheless, most of the study participants expressed optimism that with the right engagements among agents (health providers at the CWC and the TB unit), coupled with appropriate training, integration can be successful, albeit a partial model.

> *Well, I think some providers will find it awkward at the beginning that they are receiving a lab request from a community health nurse… Maybe it will be awkward when they start prescribing anti-tubercular drugs or medications. So, that may have to be reserved. The pharmacy people*

may not be too pleased about it. But I don't think that will be too much of a problem because we will do the planning and part of the planning will mean engaging other units… Most of them [CWC health providers] think that their role in TB is just by giving the BCG. So, we would have to ask them if they will want to do it. All they need is to be trained. ((SP_VR_F1_001; Male, 36 years old Public Health Physician with 10 years working experience; District Hospital)

Possible complaints about workload featured prominently in the narratives as a major reason for expressing reservations about the full integration of childhood TB management into CWC. According to service providers at the DOT centres (TB Units), full integration could be misinterpreted by their colleagues at the CWC as shifting their responsibility to them. Consequently, community health nurses may kick against the idea of integration. As such, the study participants expressed the view that partial integration rather presents a viable option for service providers and could benefit the client, especially children under 5 years. The quote below is a testament to this observation.

Well, it can be integrated but we cannot take it in isolation and say that it should be integrated completely… They [health providers at the CWC] will tell you there is too much workload on them, so we cannot put the drugs there for them to give it out. So, I prefer this place [the TB unit] to be a good place for the actual treatment. Maybe we may have to sync their weighing date with the treatment date for the TB. After everything, they will just come here for the TB drugs and then go. (SP_VR_F2_001;

Female, 57 years old Principal Nursing Officer with over 30 years of experience in TB, District hospital).

To corroborate the above assertion, this is what another participant who works at the CWC had to say:

> *... It will increase our workload because we are few. So, we can assist with the screening and early detection and then refer the cases to them so that they can take it from there like the way we refer the pregnant woman to them [for testing].* (CWC_SP_ER_F1_002; Female, 27 years old Community Health Nurse with 3 years working experience; District Hospital)

Contextual integration: Availability of institutional structure and personnel

There was no debate about the ownership and control of the management of TB at the various health facilities. The study participants were unanimous in their assertion that TB management and control remain the prerogative of the institutional TB coordinator under the NTP. Most of the study participants shared the view that the facilities already have the personnel and the institutional structures in place to successfully integrate childhood TB management into CWC activities. According to them, health providers will only require training on how to screen and obtain samples for diagnosis since the facilities already have clinicians to help with the diagnosis. Thus, most of the study participants shared the conviction that such a policy shift will not require many changes to incorporate into the daily healthcare delivery.

If the CHPs compounds are diagnosing and treating TB, then why can't it be done here [referring to the CWC]? [She quizzed]. So for me, I think it is possible. What we need to do is to change our mindset and be committed to the course because the other logistics like the drugs are already available. So it is just a matter of them being trained... I don't think it needs extra hands or something. (SP_WR_F1_001; Female, 38 years old nurse in-charge at the communicable disease centre with 6 years working experience, Regional Hospital)

Yes, I think they have the personnel to do case finding because that will not be an extra duty. It is part of our day-to-day duties so the staff or personnel available can add it to their work. The CWC is done throughout the week so it [active case-finding] can be done. (SP_BA_F1_001; Female, 29 years institutional TB coordinator with 6 years working experience; Municipal Hospital)

Whereas most of the participants shared the view that integration of childhood TB into CWC will not require any major infrastructural commitments or logistics, a few participants were rather adamant in their assertion about the need for improved infrastructure for such an initiative. They highlighted space as the major obstacle that will need to be addressed to ensure smooth integration. This is how one of the service providers put it:

The only problem will be the space. Their space is too small and you know that for TB you have to get proper ventilation and those things.

They are joined with ANC [antenatal care]; the pregnant women. So, space will be a problem. I also think they don't have the capacity because they are not trained like us so the only thing that can help is to train them to render the services. (SP_ER_F1_002; Female, 27 years old staff nurse with 3 years working experience; District Hospital)

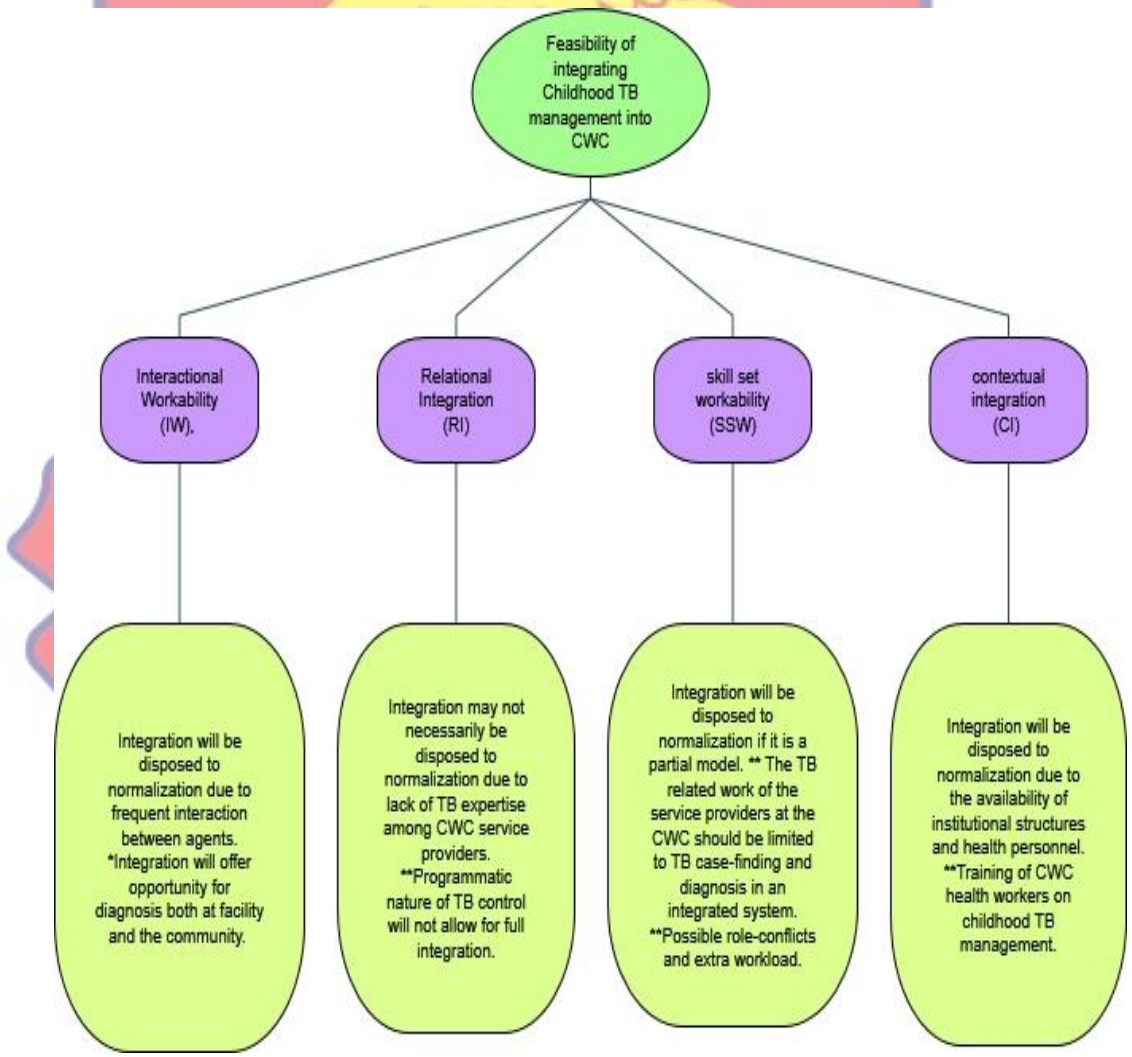

Figure 9: Summary of the study results based on NPM tenets

Source: Field Survey, 2021

Discussion

This chapter explores the perspectives of the service providers (both at the CWCs and the DOT centres] on the feasibility of integrating childhood TB management into CWCs using the normalization process model as a framework. There was evidence of perceived interactional workability based on the narratives of the study participants. This interactional workability stems from the frequent interactions that CWC service providers have with children under 5 years (the most vulnerable group for childhood TB). There is documented evidence about the critical role that multiple and flexible opportunities for communication (a component of interactional workability) play in ensuring the successful integration of an intervention or policy (Holtrop, Potworowski, Fitzpatrick, Kowalk, & Green, 2016). The need for linking childhood TB prevention and care to maternal and child health services/programmes have been documented and the promotion of integrated approaches to diagnosis are being encouraged (Getahun et al., 2012; Marais et al., 2013).

Evidence suggests that children with undiagnosed TB (with or without HIV co-infection) often do not present to TB or HIV clinics (Graham, Sismanidis, Menzies, Detjen, & Black, 2014). Such children are rather found with acute malnutrition or pneumonia with a history of not responding to antibiotic treatment at community and primary healthcare facilities in resource-limited settings (Oliwa, Karumbi, Marais, Madhi, & Graham, 2015). This makes integration of childhood TB case-finding into CWC a very good strategy in an effort toward addressing undiagnosed childhood TB. In a retrospective

study carried out in India, it was reported that intensified TB case finding among children at a Nutritional Rehabilitation Centre is feasible and appropriate since most TB-infected children enter the health facility as malnourished children seeking nutritional care rather than care for TB at a separate TB unit within the facility (Pathak et al., 2016). Similarly, a study carried out in Ethiopia demonstrated the feasibility of intensive screening of children under 5 years in a Maternal, Neonatal, and Child Healthcare (MNCH) clinic, highlighting opportunities for integration as part of efforts to address missed childhood TB cases (Kebede, 2016).

Given the multiple entry points for childhood TB, control programmes can leverage the interactional workability of MNCH services, including CWC to diagnose more children and address the persistent problem of missed paediatric TB cases (Detjen, Essajee, Grzemska, & Marais, 2019; Dubois et al., 2020). This is important as children under 5 years present the greatest diagnostic challenge and have been found to have lower rates of treatment success (Ramos et al., 2019). Besides, it has been estimated that as much as 80 per cent of child mortality due to TB occurred among children below 5 years old (Dodd et al., 2017).

The present study also revealed some reservations about the expertise of CHNs to fully manage childhood TB. Thus, concerns were raised regarding the *relational integration* of childhood TB management into CWCs. This is in contrast to documented evidence which showed that integrated case management of multiple diseases by well-trained community health nurses is

feasible and will lead to better care-seeking and a reduction in all-cause mortality among under-5 children (Miller et al., 2014). It is however important to note that childhood TB management is not like any other childhood disease. As such, childhood TB management will require expertise to undertake (WHO, 2018). Another major reason put forward by the service providers for expressing reservation regarding a complete integration of childhood TB management into CWC is the programmatic nature of TB control. Indeed, Marais et al., (2013) cautioned that integrated programming ought to support, not erode the essential functionality of NTPs such as policy direction, disease surveillance, drug supply, and keeping of records (Marais et al., 2013).

Concerning *skill set workability*, there was evidence of preference for partial integration where the work of the health providers at the CWC will be limited to case-finding (diagnosis) and referrals while the actual management is done by the DOT unit. Currently, there is limited documented evidence on the operational feasibility and the form (either partial or full) for integrating childhood TB management into child health services such as CWC. Also, the impact of such intervention on childhood TB case detection, a cascade of care, and treatment outcomes has not been scientifically established.

Reassuringly, there is a "cluster-randomized stepped wedge trial" currently underway that will ascertain the appropriateness and impact of integrating paediatric TB services into other child healthcare services in Africa (Ndam-Denoeud et al., 2020). This will help inform policy direction and efforts towards better management of paediatric TB. Notwithstanding, some studies

have provided pointers to suggest that integration of childhood TB into other child health services such as malnutrition care (Pathak et al., 2016), MNCH clinics (Kebede, 2016), and paediatric outpatient departments (Malik et al., 2018) is feasible and will result in better childhood TB case-finding.

A major reason put forward by the study participants for their reservation about full integration is the possibility of role conflicts and extra workload on service providers at the CWCs. A study conducted in Malawi highlighted the importance of managing workload in ensuring the successful integration of childhood TB into maternal and child health services where nutrition and HIV services are also provided (Verkuijl et al., 2016). Regardless of whether partial or full integration of childhood TB into child health services, system challenges such as "limited human resources, inadequate training and supervision, poor data management, dysfunctional referral mechanisms, and poor infrastructure" need to be addressed (Detjen, Essajee, Grzemska, & Marais, 2019). With the right training and definition of boundaries (a critical condition for skill-set workability), CHNs can easily integrate childhood TB into their routine services.

Regarding *contextual integration*, the evidence points to the availability of institutional structures and personnel to allow for integration. Since 1994, the management and control of TB in Ghana have been under the NTP (NTP, 2019). Currently, there are about 9,380 DOT centres in 260 districts across the 16 regions of Ghana under the National TB control programme. The various DOT centres in the country are under the leadership of institutional TB coordinators

who are supported by other health workers such as disease control officers and nurses (NTP, 2019). The CWCs are mainly manned by community health nurses (CHNs) who work closely with nutritional officers in some facilities. In higher levels of care, both the CWCs and DOT centres are part of the larger Public Health Department which is usually headed by a public health physician.

Services by both units are free in all public facilities. As such, the existing institutional structures could easily allow for service integration in various forms (WHO, 2018). It is however noteworthy that even when childhood TB is fully integrated into CWC or other MNCH services, the ultimate responsibility lies with the institutional TB coordinator due to the programmatic nature of TB control (Marais et al., 2013). Also, integration of childhood TB management into MNCH services like CWC will require that all critical health system challenges, including inadequate and inappropriate infrastructure, are addressed (Detjen, Essajee, Grzemska, & Marais, 2019).

Summary

This study revealed that both TB and CWC service providers are open to the integration of childhood TB management into CWC, albeit in a partial form. Whereas interactional workability and contextual integration domains provide strong optimism for childhood TB integration into CWC, relational integration and skill-set workability present grounds for caution regarding the model of integration. Evidently, the balance of preference is tilted towards partial integration where CHNs will screen and diagnose children with TB while the

actual management is done by the service providers at the DOT centres in a collaborative manner.

The implication of partial integration of childhood TB management and control into CWC is that many children will get the opportunity to be diagnosed early and primary caregivers may be more disposed to adhere to the treatment regimen. This is because partial integration will safeguard against potential stigma and delays in accessing care as was put forward by the participants with regards to full integration model. This study provides meaningful insight into the possible pathways (models) for integration as well as the requirements to make integration possible within the existing child health system. The use of NPM as a theoretical framework enabled a focus on conceptual issues that are critical for possible integration as well as offering a valuable ambit for the discussion of such issues.

CHAPTER EIGHT

TOWARDS IMPROVING THE MANAGEMENT AND CONTROL OF CHILDHOOD TUBERCULOSIS: PERSPECTIVES OF SERVICE PROVIDERS

Introduction

Children infected with TB can experience a considerable number of difficulties. Yet, childhood TB is less prioritized in respect of research and health innovations as means of lessening the difficulties of children living with TB (Hummel, Ahamed, & Amanullah, 2020). However, with the current recognition of the significant contribution of childhood TB to the global burden of the epidemic, increasing attention is now being directed to it (Dodd, Yuen, Sismanidis, Seddon, & Jenkins, 2017; WHO, 2021). Children are a vulnerable group and should be afforded priority in efforts towards enhancing diagnosis, treatment, and prevention of TB, especially in resource-limited settings. Childhood TB is crucial in meeting "the End TB strategy" goal of zero TB deaths and targets aimed at ending TB by 2035 (WHO, 2014; WHO, 2020).

Notwithstanding, there exist challenges and gaps in practice regarding childhood TB management and control. The roadmap toward ending TB in children and adolescents emphasises the urgent need for more basic and implementation science research to inform practical solutions to address gaps in diagnosis, treatment, and prevention (WHO, 2018). Often, policy-related studies only consider the views and opinions of experts and programme

managers, thereby missing out on the perspectives of service providers at the point of care even though they could offer meaningful insights into practice. In this chapter, I explored the perspectives of service providers on how to improve the management and control of childhood TB as part of efforts toward achieving the End TB strategy. Given their experience in managing TB over the years, it was envisaged that their perspectives could offer valuable insight on how to improve the management and control of childhood TB. Several issues emerged from the data worth considering; these issues revolved around priority setting, policy-driven service delivery strategy, re-organization of the care delivery system, and better disease control strategies.

Getting childhood TB firmly on the public health agenda

The "End TB Strategy", which seeks to end TB in all forms by 2035, recommends the need to direct more attention to childhood/paediatric TB. In this study, the participants asserted that childhood TB has not received the necessary attention in the fight against TB. Our participants expressed the view that getting childhood TB on the priority agenda is an important step towards this goal. According to them, there is a need to create awareness among the general public that children can also be infected with TB just like adults. They highlighted how efforts by the NTP aimed at awareness creation often ignore children. As such, they called for commensurate attention to childhood TB through awareness creation and public education about childhood TB. The following excerpts represent this view:

> *[Just] as they do with the adults, they [NTP] can also design posters to educate or emphasize childhood TB. But, here lies the case that they have made the whole thing about only adults. Look at all the posters that we have here; not even a single poster portrays TB among children. So even if there is a child at home coughing, they will think it is a normal cough and then go and buy a normal cough mixture almost every month and the child will be suffering... So, if we can highlight more and educate the public that children too can get TB, it will help; so NTP should do massive campaigns.* (SP_WR_F1_002; Female, 32 years old, Deputy in-charge at the Infectious Disease Unit with 3 years working experience; Regional Hospital)

The narratives also point to the conviction that not only will awareness creation benefit clients who may not be aware of childhood TB, but health providers as well in their ability to identify and diagnose childhood TB. Many of the study participants made references to how training programmes and workshops often ignore childhood TB. However, they acknowledged that the situation is gradually improving. Notwithstanding, service providers were also of the view that there is a lot that needs to be done to ensure that childhood TB receive the necessary attention. Participants asserted that health care providers will benefit from regular workshops and training that focus on childhood TB. They shared the view that awareness creation among health workers will lead to opportunities for more children to be diagnosed and treated.

… Training should be organized under the NTP. Participants [service providers] should be reminded about childhood TB. That is, how we can be able to get hold of it. When we are constantly reminded of it, we will be on the lookout for it… management of childhood TB should be added to our in-service training and health providers will start searching for it. (SP_BA_F1_001; Female, 29 years old, Institutional TB coordinator with 6 years working experience; Municipal Hospital)

Improve childhood TB active case finding (ACF)

Case-finding remained a major challenge in the battle against childhood TB. The study participants shared the view that there are many children out there with TB who remained undiagnosed due to the difficulties in reaching them. As such, they held the view that in order to reach, diagnose, and treat the majority of childhood TB cases, there should be an improved childhood TB active case-finding strategy. Several of the study participants shared the view that a passive case-finding strategy where service providers wait at the facility for opportunities to make a diagnosis may not yield optimum results. Most of the study facilities rely on a passive case-finding strategy, although few facilities do engage in contact tracing which is largely ineffective due to the associated funding challenges. As such, they advocated for an active case-finding strategy where service providers will regularly embark on contact tracing and screening to identify and diagnose children with TB.

I think effective contact tracing will help us. When you get your index case, you can use contact tracing to get others. Maybe for the index case,

there might be another child in the house also suffering from TB but because the person is a child, they will not pay attention to the child as possibly suffering from TB... So, through contact tracing, even if the index case is an adult when you get to the house, you can screen and then put the child on treatment [including IPT] if it's suggestive, especially if the child has been in close contact with the index case… (SP_BA_F1_002; Female, 35 years old Senior Technical Officer with 5 years working experience; Municipal Hospital)

Another participant corroborated:

I think we should continue to put pressure on them [referring to the NTP and hospital authorities] for the resources that we need… contact tracing will be a nice way of getting these undiagnosed cases. I told you [earlier] of a case where we treated two other kids who slept in the same room with the index child. So, if you don't go to their houses, they won't tell you. In that house, for instance, the mother didn't want her son to take the medicines. They found it difficult to come to terms with the fact that they have TB and their child also has it. So, contact tracing is very important! (SP_CR_F1_001; Female, 28 years Disease Control Officer and Institutional TB coordinator with 3 years working experience; Teaching Hospital)

Addressing loss to follow-up and ensuring treatment adherence

Loss to follow-up during treatment has been recognised as a major challenge in

the management of childhood TB. The study participants unanimously asserted that in order to ensure effective management and control of childhood TB, the challenges associated with loss to follow-up needed to be addressed. The narratives revealed that even though efforts have been put in place to ensure that clients receive treatment at their local facilities or those very close to them as stipulated under the DOT strategy, some clients preferred having treatment far away from their localities due to stigma.

The study participants frequently mentioned the difficulties in following up on clients during treatment since most of them live outside the catchment areas of their service providers. Whereas phone calls could have mitigated this challenge, the study participants highlighted how attempts to reach defaulting clients in the past via phone calls have proved futile as clients either do not pick up their calls or provide phone numbers that are difficult to reach. In effect, they suggested that service providers should only register clients who live within their catchment areas and refer those outside their catchment areas to their respective health facilities. The excerpts below represent this theme:

> *I will want to only register people that are in my jurisdiction that I can go to; I can boldly walk to* [XXX - suburbs of the city where the facility is located] *to follow a case up… But in a situation where you register people far from your jurisdiction, it is very difficult to follow up. If the person defaults and you call, you won't get any proper feedback; that's even if they pick up at all! But if you know their houses, then you can easily follow up, ... So, the adherence will come when you can follow*

them to their homes and talk to them about the need for them to take the medication because if they don't understand the treatment regimen; like the one you came to meet, I would be here only to realize that she has defaulted… (SP_CR_F1_001; Female, 28 years old Disease Control Officer; Institutional TB coordinator with 3 years working experience)

The above assertion was a common narrative in the data. To substantiate, this is what another participant had to say:

… The catchment areas and easy access to the facility will help. If the place is close, they will come for the medication. But if it is further from them, they will tell you they don't have money for transportation so they won't come and there is nothing you can do. But if the person is right here within my catchment area, I can easily go there with the medication. (SP_ER_F2_001; Female, 27 years old, DOT Nurse with 4 years working experience; District Hospital)

Treatment adherence is at the core of childhood TB management; successful treatment outcome depends largely on adherence to the regimen. The participants highlighted the challenges that they faced with adherence to the treatment regimen, partly due to the long treatment duration. The narratives of the service providers revealed how they have to deal with some caregivers who tend to relent on their efforts after the intensive phase when the child experienced remarkable improvement in health condition. The participants shared the view that as part of the way forward, the NTP through donor

organisations such as the Global Fund should pursue a shorter treatment regimen for children if possible. According to them, a shorter treatment regimen will increase adherence and reduce loss-to-follow-up. The following excerpt is a reflection of this theme in the data.

> *If the treatment can be modified and shortened, it will work because most of the caregivers are not really committed. So if the medicine can be modified so that the treatment will be shorter than six months, that will help and adherence will improve. I don't know if it is possible, but if it can be shortened, it will help. The reason why I am saying this is that for most of them, when they start and the child begins to feel better, they think the child is cured and so you find it difficult to get them to come for the medicine. By the time you realized the child has retrogressed and that brings a bad outcome.* (SP_WR_F1_001; Female, 37 years old, Nurse In-charge with 6 years working experience; Communicable Disease Unit; Regional Hospital)

Prioritizing continuous counselling and monitoring

The study participants also shared the view that in order to improve the management and control of paediatric TB, service providers should help ensure that primary caregivers adhere to the treatment regimen for their children. The narratives point to an acknowledgement of the complexities associated with long-term treatment regimens like childhood TB where adherence depended largely on the primary caregiver's commitment to the welfare of the child. The service providers narrated how some primary caregivers (PCGs) sometimes

relent on their commitment when they observed improvement in the child's health condition, following the intensive phase of the treatment regimen.

They also highlighted how some mothers deliberately interrupt the treatment regimen due to pill burden (the children getting fed up with taking several medicines daily), particularly with children who were on TB-HIV co-therapy. Therefore, the service providers suggested prioritizing continuous counselling and monitoring as part of efforts toward ensuring adherence. Participants shared the view that making PCGs appreciate the need that interrupted treatment could result in the development of resistant strains and in turn longer treatment duration could help PCGs to commit to ensuring treatment adherence for the children. This is how one of the service providers put it:

> *For me, it is not the children that default; it is the caregivers that default. If you take your time to do the counselling well and explain to them why they should receive the treatment for the entire 6 months, then they will keep up with the treatment [regimen]. Also, continuous monitoring through phone calls and home visits to check whether the child is taking the medicines is the way to go and can help to prevent treatment interruption.* (SP_CR_F3_001; Male, 33 years old nurse, Institutional TB coordinator with 4 years working experience; Metro Hospital)

To substantiate the above, this is what another participant had to say when sharing her view on ways to ensure adherence to childhood TB treatment regimen:

> *You may have a very good counselling session initially, but you must know that counselling must be continuous. Sometimes you may start on a very good note but they go home and someone will distort everything. After the first 2 months and the child starts doing well, they think that is all. So the counselling must continue throughout the period...* (SP_VR_F1_001; Male, 36 years old Public Health Physician with 10 years working experience; District Hospital)

Policy implementation reforms

The need for policy implementation reforms emerged from the narratives of the study participants as important in improving the management and control of childhood TB in a resource-limited setting like Ghana. Many of the participants referred to how TB control policies are implemented at the various facilities. These policy-related issues are presented thematically in this section.

Facility custody of the paediatric formulation

Whereas some service providers revealed that paediatric formulation for TB treatment is not available to them, others indicated its availability, albeit with some accessibility challenges. As part of efforts by NTP to reduce wastage in the supply chain, paediatric formulations (child-friendly anti-TB medications) are kept at the various regional medical stores and service providers can only request them after a child is diagnosed. While the intention of this policy was endorsed by the service providers, its implementation comes with a considerable challenge to the service providers.

According to the participants, delaying the initiation of the treatment regimen due to the unavailability of drugs may not inure to the benefit of the child as most of them are critically ill at the time of diagnosis. They also highlighted that asking clients to go and return on another day to commence treatment often leads to clients not coming back. The caregivers only return to the facility when the child's health condition has considerably worsened. As such, they suggested that a buffer stock of at least two intensive-phase paediatric formulations should be kept at the facility at all times to promptly initiate treatment for critically ill children.

> The unavailability of the paediatrics formulation is the problem. Here, in the Eastern region, for you to get a paediatric anti-TB medicine, you have to diagnose the child, send the weight of the child and the diagnosis, age and height to the regional medical store before they can calculate and give you the medicine. It is frustrating! But it is not their fault. I heard last year that a whole stock of paediatric anti-TB medicines got expired; in the whole nation. Some facilities were hoarding them while some did not have them at all… At least, they should let us keep one pack at the facility so that always there will be reserved medicine for one client. (SP_ER_F3_001; Female, 34 years old Institutional TB coordinator with 12 years working experience; District Hospital)

The need for a review of the policy on custody of paediatric formulation featured prominently in the narratives of the study participants. Another participant had this to say:

Maybe bringing back the policy of us keeping the paediatric drugs. They changed the policy to when we diagnose a case, then you send the weight of the child to the regional [medical] store then they give you the medication. But if the child is coming from a far distance, you cannot tell the child to wait for some days so it will prolong the start of treatment… (SP_BA_F1_001; Female, 29 years Institutional TB coordinator with 6 years working experience; Municipal Hospital)

Financial and Nutritional Support for Children on TB Treatment

Financial and nutritional support for children who are on anti-TB treatment emerged from the data as critical in improving childhood TB management in resource-limited settings like Ghana. Service providers highlighted that even though childhood TB diagnosis (excluding X-ray services) and treatment are free of charge, caregivers incur a substantial cost and face financial hardship from non-medical and indirect costs associated with childhood TB. As such, service providers suggested a scheme where financial assistance is provided to caregivers of children with TB to help successfully navigate through the treatment regimen. The following quote is a reflection of this theme that emerged from the data view:

… Also, supporting the mothers [caregivers] can help them to bring the child to the clinic [adherence to the regime] because sometimes they may want to bring the child, but transportation may deny them from doing so. But if there is little financial support, it will help the mother to bring the child on appointment dates. That fund will also help with the

child's feeding during the treatment. (SP_BA_F1_002; Female, 35 years old Senior Technical Officer with 5 years working experience; Municipal Hospital)

Aside from financial assistance, the study participants also advocated for nutritional support for children who are on anti-TB treatment. The narratives point to nutritional support where children are given fortified blended flour (FBF) and Plumpy'Nuts being important in meeting the nutritional needs of infected children, especially those co-infected with HIV. Also, the service providers emphasized that such support will serve as a motivation for caregivers to navigate the treatment regimen. However, they lamented how enablers' package from NTP has dwindled in recent times. According to the participants, this has affected caregivers negatively, especially those who largely depend on this support for their child's upkeep during the treatment. The study participants asserted the need for uninterrupted nutritional support for children on anti-TB treatment throughout the regimen. According to them, this will go a long way to ensuring treatment adherence and favourable outcome. The following excerpts highlighted this observation.

They will need financial and nutritional assistance. The enablers must be brought back because most of them are coming from a low economic background and they will need that support during treatment. For the child that died yesterday, if the support was there, it may have gone a long way to keep him alive. (SP_WR_F1_001; Female, 37 years old,

Nurse In-charge with 6 years working experience; Communicable Disease Unit; Regional Hospital)

Another participant from a different region and a lower-level health facility had this to say:

Sometimes they [the caregivers] come expecting the enabler's package so if they come once, twice, thrice and they don't get the enablers then they stop coming… For the enabler's package, at first, we were getting, but for close to two years now, we have not had anything of that sort. The fortified blended flour and the "plumpy'Nuts" should be made available regularly… (SP_CR_F2_001; Male, 26 years old Institutional TB coordinator, Disease Control Officer with 3 years working experience; Polyclinic)

Sensitization and training of clinicians on childhood TB

Due to the peculiarities of childhood TB, many children often remain undiagnosed since the disease can mimic other conditions such as pneumonia. The study participants highlighted the need for paediatricians and other clinicians at the various facilities to be trained and sensitized on the identification and diagnosis of childhood TB cases.

I talked about the fact that there is a deficit when it comes to training; particularly in paediatric TB. I think that should be looked at very well. As it stands, none of my prescribers has had the chance to be part of any childhood TB training in the last 2 years. So everything they are doing

> *is based on what they learnt from school. We all know how medicine is dynamic, especially diseases that are designed as programmes; things change very often.* (SP_VR_F1_001; Male, 36 years old Public Health Physician and a Medical Director with 10 years working experience; Municipal Hospital)

To buttress the above, this is what another participant had to say:

> *… Also, the provision of in-service training for our physicians will help going forward. For every case, we will need to make a diagnosis before we can treat it. I have observed that diagnosing extra-pulmonary TB in children is even more difficult. It is the doctors who diagnose and then we do our part [manage the disease]. So if our physicians are more vest in TB detection in children, it will help…* (SP_CR_F2_001; Male, 26 years old Disease Control Officer and Institutional TB coordinator, with 3 years working experience; Polyclinic)

Making X-ray services for childhood TB diagnosis free of charge

Whereas childhood TB diagnosis is free of charge under the national TB control programme, when a chest X-ray (CXR) is required (as is the case in most facilities), the cost is borne by the client. According to the study participants, this presents a barrier to most clients. Due to the paucibacillary (smaller number of bacterial in the sputum to confirm TB) nature of childhood TB, most clinicians and service providers rely on CXR to make a diagnosis. As such, it is one of the critical requirements in arriving at a diagnosis. However, the participants indicated that the cost of this service (GHC 55 ~ $10) has been a

bane in their efforts as some caregivers either secretly leave the facility without the child having the X-ray or delay it for several days. In effect, the study participants suggested the need to make this service free of charge to make their work easier and also save families from catastrophic costs due to children suffering from TB.

> *... For the chest X-ray, we need it to be able to make a diagnosis. When they go, they have to pay for it. Some of them, when you ask them to send the child for a chest X-ray, they will tell you that they don't have money so they will go and never come back. So you just imagine if the child is suffering from TB. They will go and come back worse. So I think they can help by making it free of charge for children.* (SP_VR_F1_002; Female, 29 years old Institutional TB coordinator with 4 years working experience; District Hospital)

Adequate Community Engagement

Community engagement has been recommended by the WHO as part of efforts toward achieving the End TB Strategy. However, it emerged from the data that only a few of the facilities currently undertake community engagement. Participants narrated that even with little community engagement, positive results have been achieved with regard to case-finding and preventive therapy. Therefore, they shared the view that improvement in this strategy and scaling-up same will yield favourable outcomes and help in the drive towards achieving the End TB strategy. This is what one of the study participants had to say:

.... We have the TB champions – people who have been cured of TB. Their work is to look out for TB in the community. They bring in potential cases or refer them here for testing…They also do contact tracing and defaulter tracing in the community for us. Before their introduction, we the coordinators were doing it by ourselves but not regularly because combining the community visit with the office work was burdensome. We know TB is not in the office but in the community. But we could only do little. So, they coming on board is facilitating things. This should be scaled up across the country… (SP_CR_F2_001; Male, 26 years old Disease Control Officer and Institutional TB coordinator, with 3 years working experience; Polyclinic)

To validate the above, this is what another participant had to say when suggesting ways to improve childhood TB management and control.

… Then we have to partner with the community for them to know the key role they can play in helping others to understand the disease and how much it takes from us. Opinion leaders can champion the effort to deal with the issue of stigma, and perceived spiritual causation of TB… (SP_VR_F1_001; Male, 36 years old Public Health Physician and a Medical Director with 10 years working experience; Municipal Hospital)

Partial Integration of Childhood TB into Child Welfare Clinic

Partial integration of childhood TB into child welfare clinics was also put forward by the study participants as a strategy for improving childhood TB management and control. The service providers emphasized the difficulties associated with childhood TB case finding and diagnosis. In their narratives, the participants mentioned how some children with TB go through the healthcare system without getting diagnosed. It is not common for caregivers to send their children to the "Chest Clinic" for them to get tested for TB even if they have a persistent cough. For children under 5 years, the CWC serves as the first point of contact with the health workers as they attend the clinic monthly. Therefore, the study participant shared the view that integrating childhood TB into CWC will present a valuable opportunity for diagnosis. According to the study participants, this should form part of the strategy towards addressing childhood TB as part of the general TB control effort towards achieving the End TB strategy.

> *Integrating childhood TB into CWC will be good in the sense that they deal with children under five [years]. So with that, they can monitor them very well for us... Because they often see the children, they can diagnose more. So it will lead to early detection of the cases. In some cases, if it is not detected early, they die.* (SP_WR_F1_002; Female, 32 years old, Deputy in-charge at the Infectious Disease Unit with 3 years working experience; Regional Hospital)

Discussion

This chapter explored the views of service providers on how to advance the management and control of childhood TB. It was evident from the narratives of the study participants that to achieve this goal, childhood TB needs to be put firmly on the public health agenda. This is in resonance with the calls by global health advocates for countries to pay equal attention to childhood TB (The Union, 2018). Whereas childhood TB screening and treatment have considerably improved in the developed world, it remains one of the neglected aspects of the fight against TB, particularly in sub-Saharan Africa (Kalu et al., 2015; Thomas, 2017). With timely diagnosis and treatment regimen, the prognosis of childhood TB is highly positive. However, an estimated "90 per cent of children who die from TB globally" remained undiagnosed and so untreated (Dodd, Yuen, Sismanidis, Seddon, & Jenkins, 2017; The Union, 2018).

Evidence shows that children with TB have been neglected by health systems and TB control programmes over the years due to the notion that childhood TB is less contagious and complicated by challenges in diagnosis (Reuter, Hughes, & Furin, 2019). The continuous neglect of childhood TB, leading to avoidable child mortality constitutes an abuse of children's rights (Hummel, Ahamed, & Amanullah, 2020). Hopefully, the strategic plan by the Ghana NTP to roll out extra screening equipment such as digital CXR and Gene Xpert for testing, together with appropriate training/workshops for service

providers, early and accurate diagnosis and treatment of childhood TB will become a priority (MOH, 2014).

The study results also showed the need for improvement in active case-finding and treatment for children with TB. This call is timely and needs to be considered as part of current efforts to address childhood TB in Ghana. Evidence from Guinea-Bissau reveals that even in resource-limited settings, active case-finding that is targeted at high-risk groups like children households of critically ill TB clients on admission can successfully be implemented (Bosa et al., 2017). Screening children as contacts is the general recommendation for national TB control programs globally (WHO, 2013). Despite this recommendation, screening children is often not done in many LMICs (Triasih et al., 2012; Belgaumkar et al., 2018).

Challenges such as lack/shortage of tuberculin, unavailability of chest X-ray (CXR) machines (even when available, its associated cost), transport and time costs for clients and their families, record keeping/documentation, lack of skilled staff to interpret diagnostic results, and excess workload on healthcare workers have all been documented as inhibiting screening across various settings (Amisi, Carter, Masini, & Szkwarko, 2021; Emerson et al., 2019; Hill, Rutherford, Audas, van Crevel, & Graham, 2011; Rutherford et al., 2012). Therefore, it is important to address these pertinent challenges, including the passive nature of the existing case-finding strategy to ensure improvement in management and control (Laghari et al., 2019).

The literature, however, points to divergent views on the best approach to case-finding. Whereas some experts support a household-based approach where all children are screened anytime a member of the household is diagnosed with TB (Szkwarko et al., 2017), evidence proved that most children with TB are not exposed in the household, highlighting the need for broader screening approach that extends beyond the household (Said et al., 2019). Consequently, others advocate for targeted, non-household screening in the malnutrition unit and the general paediatric/children's wards, especially among children diagnosed with malnutrition or pneumonia (Munthali et al., 2017). Whatever the case may be, control programmes need to identify an active case-finding strategy that is appropriate for a specific setting.

Addressing loss to follow-up was also put forward by the service providers as worth considering. Loss to follow-up has been a bane of TB control programmes over the years, especially in resource-limited settings. For instance, studies from Malawi, Nigeria, and Ethiopia have all reported a high loss to follow during childhood TB treatment (Flick et al., 2016; Adejumo et al., 2016; Ramos et al., 2019). Childhood TB, even if not considered a public health threat, is an important control indicator of transmission rates as it represents a sentinel event. Critically, when children enter adolescence and TB infection becomes more adult-type, the risk of transmission to others increases significantly (Thomas, 2017; WHO, 2018).

Childhood TB prevention and treatment offers significant benefits to the affected child, their families, and the general population. As such, there is a need

to ensure that children who are on treatment are not lost to follow-up (Selgelid & Reichman, 2011). Nurse-led follow-up during the treatment regimen has been found to increase treatment adherence and better treatment outcome (Guix-Comellas et al., 2018). This study also brought to the fore the need for a shorter treatment regimen to ensure adherence and safeguard against loss to follow-up. The extended spell of the treatment regimen is a challenge to childhood TB treatment adherence due to the pill burden (Thomas, 2017). Reassuringly, a new shorter regimen is currently under clinical trial and will be made available if the results are favourable (Chabala et al., 2018).

Another area that was highlighted in this study is continuous counselling and monitoring to ensure treatment adherence. Treatment adherence in children can be more cumbersome and relies on a multiplicity of factors, including the relationship between the child, the primary caregiver, and the service providers. This advocacy for continuous counselling in the present study is in character with the call by Guix-Comellas et al., (2018) who similarly put forward the need for age-appropriate counselling, provision of enablers, and monitoring of children undergoing anti-TB treatment regimen as they were found to be associated with treatment adherence. Counselling efforts aimed at adherence should therefore take into consideration the life aspirations and plans of children of various age groups (Weaver, Lönnroth, Howard, Roter, & Lam, 2015). With evidence demonstrating the feasibility and acceptability of decentralization of TB care, service providers under the NTP can leverage community health nurses to help with "continuous" counselling and monitoring of children during the

treatment (Rachlis et al., 2016). Models of decentralized paediatric care have been developed in the field of HIV and their effectiveness has been demonstrated. Such models can be adapted for use in childhood TB care (Kanters et al., 2017).

This study also underscored the need for several policy implementation reforms. One of the policy reforms that emerged from the data is the non-custody of paediatric anti-TB medication at the facilities. The policy aimed at reducing wastage and ensuring an even distribution of already scarce paediatric TB formulation. Whereas the intention of this policy is commendable, its operationalization needs to be revisited as delay in treatment initiation could lead to missed opportunities (Valvi et al., 2019). Availability of child-friendly formulation is critical in the management of childhood TB as it is acceptable and likely to increase adherence to the treatment regimen as compared to breaking of adult anti-TB medication to be used by children based on weight and age (Wademan et al., 2019). Therefore, identifying and addressing barriers to treatment initiation for paediatric TB is critical. Both patient- and system-level barriers must be addressed to ensure better treatment outcomes for children (Sullivan, Esmaili, & Cunningham, 2017).

Financial and nutritional support for children during the treatment regimen was also put forward for consideration as part of the way forward in childhood TB management and control. Müller et al. (2018), in a systematic review and meta-analysis, found that financial and nutritional support (food incentives) reduce treatment default (loss to follow-up). It is however

noteworthy that just supporting adherence with interventions targeted at mitigating only direct impacts and challenges of receiving TB treatment may not be adequate. Families of children with TB can face catastrophic costs and long-term socio-economic impacts from TB which emanate from both direct and indirect costs of childhood TB (Muttamba et al., 2020; Muniyandi et al., 2020). Eliminating catastrophic costs associated with TB treatment is one of the goals of the End TB strategy (WHO, 2014). Achieving this goal will mean providing financial support for TB-infected children through their PCGs. The role of nutrition in pulmonary tuberculosis treatment has been documented (Kant, Gupta, & Ahluwalia, 2015). Strengthening the enabler's package to address malnutrition among TB-infected children is, thus, critical for adherence to the treatment regimen and better outcomes.

This study also brought to the fore the need for sensitization and training of health providers, including clinicians on the essentials of childhood TB. This call is consistent with the strategic plan for the NTP of Ghana which among other things sought to train health providers on childhood TB (MOH, 2014). The peculiarity of childhood TB presents service providers, including clinicians with diagnostic and management challenges. Even though advancements have been made in childhood TB (including diagnosis, treatment regimen, and control), gaps remain in practice regarding the provision of preventive therapy and case detection (Marais et al., 2021). An undiagnosed child will probably not get treatment opportunities until the disease progressed, even though treatment

can be initiated based on suggestive symptoms, history of contact with a confirmed adult with TB, and physical examinations (WHO, 2014).

With children co-infected with HIV, diagnosis becomes even more difficult due to decreased specificity of TB symptoms (i.e. childhood TB mimicking other diseases) and the commonality in clinical features of HIV infection and childhood TB (WHO, 2014; Naidoo, Mahomed, & Moodley, 2017). Timely diagnosis is thus critical in reducing the risk of progression to active TB, severe clinical presentations, and even death. The key to minimizing the chances of missing childhood TB cases is the training of health personnel (both clinicians and nurses) both in school and regularly in-service. This will improve the depth of suspicion and ensure early diagnosis, appropriate clinical decision-making, and the adoption of new evidence and emerging recommendations into practice (WHO, 2018). As part of the way forward, it is important to ensure adequate staffing of well-trained healthcare workers to close the persistent gap between policy and practice.

The study results also revealed a call to make X-ray services for childhood TB diagnosis free of charge as the associated costs continue to present a challenge to childhood TB diagnosis. This call for the provision of free X-ray service in childhood TB diagnosis is consistent with the current WHO recommendation (WHO, 2016). Indeed, the national TB control program of Ghana as part of its strategic plan for 2015-2020 indicated intentions to support health facilities with x-ray films and equipment (see MOH, 2014). Notwithstanding, it was evident from this study that in almost all the study

facilities (with exception of one where NTP provided a digital X-ray machine for diagnosis), clients are required to pay for the X-ray services. As part of the way forward, the national TB control programme in Ghana can leverage the existing national health insurance scheme to cover x-ray costs for TB diagnosis while the program bears the cost of X-rays for those without health insurance coverage.

The participants also put forward adequate community engagement as one of the critical areas of childhood TB management that need special attention going forward. With consistent evidence that TB infection in children often happens soon after exposure to an infected adult, the role of preventive therapy in childhood TB control has become even more essential (Martinez, Cords, Horsburgh, Andrews, & Pediatric TB Contact Studies Consortium, 2020). However, preventive therapy cannot work in isolation. Therefore, there is a need for quick identification and management of exposed children through community engagement and contact tracing. In Ghana, community engagement in contact tracing and TB care remained sub-optimal (Addy et al., 2019).

Even though contact screening and preventive therapy have been part of TB control recommendations over the years, they have been poorly implemented in several LMICs. Barriers such as difficulty accessing services, lack of education around TB, and health system challenges have been reported as inhibiting the implementation of IPT for TB prevention in children (Grace, 2019; Zegarra-Chapoñan, Bonadonna, Yuen, Martina-Chávez, & Zeladita-Huaman, 2021). Contact tracing through community engagement thus provides

an opportunity for early case detection, treatment, and preventive therapy. Indeed, evidence from Ethiopia showed that community IPT delivery together with community-based TB interventions through contact tracing resulted in better acceptance and improved treatment outcomes for children (Datiko, Yassin, Theobald, & Cuevas, 2017). As such, the call by the study participants for adequate community engagement as part of efforts towards improvement in childhood TB could be in the right direction.

Partial integration of childhood TB into child welfare clinic (CWC) was also put forward by the service providers in this study. This call is consistent with the line of action by the WHO which seeks to improve childhood TB case-finding through the integration of service (WHO, 2018). Child care services such as regular TB screening among acutely malnourished children have been identified as feasible and have the potential for enhancing childhood TB case-finding, especially in resource-limited settings (Pathak et al., 2016; Patel & Detjen, 2017).

More importantly, there is a "cluster-randomized stepped wedge trial" currently underway that will ascertain the appropriateness and impact of integrating paediatric TB services into child healthcare services in Africa (Ndam-Denoeud et al., 2020). Results from that trial will help inform policy directions in resource-limited settings of Africa. Going by the operations of CWC in Ghana, there is no doubt that integration (if done properly using the context-specific appropriate model) will significantly enhance childhood TB management and control efforts. The routine outreach activities by service

providers at various CWCs will provide opportunities for contact tracing, monitoring, and diagnosis of children, including those outside the under-5 age bracket.

Summary

This chapter highlights the perspectives of service providers on the way forward in childhood TB management and control in Ghana as part of efforts toward achieving the End TB Strategy. The insights shared by the service providers could be valuable in efforts aimed at improving childhood TB in Ghana. Issues such as getting and sustaining childhood TB on the public health agenda, improving childhood TB active case finding, addressing loss to follow-up and ensuring treatment adherence, prioritizing continuous counselling, and monitoring could form an integral part of future improvement efforts.

Policy reforms such as free chest X-ray services, adequate community engagement, and partial integration of childhood TB into child welfare clinics among others could improve childhood TB management and control in Ghana. A comprehensive child and family-friendly approach are required to improve childhood TB management and control in Ghana. The issues highlighted in this study could inform a new roadmap towards achieving the paediatric component of the "End TB Strategy" in Ghana with the overall goal of eliminating TB in all forms by 2035.

CHAPTER NINE

HEALTHCARE-SEEKING AND PSYCHOSOCIAL EXPERIENCES OF CHILDHOOD TB MANAGEMENT

Introduction

Childhood TB can be treated and cured with timely initiation and completion of an appropriate anti-TB regimen (Ohene, Fordah, & Boni, 2019). However, adherence to the treatment regimen among children can be more complex compared to adults; it relies on the interplay of the relationships among the child, the primary caregiver (PCG), the service providers, and the health providers. The "End TB Strategy" calls for client-centred care and support that is sensitive and responsive to the client's educational, emotional, and material needs (WHO, 2014).

Notwithstanding, the impacts of childhood TB treatment regimen on children, their primary caregivers, broader families, and their psychosocial contexts remain less understood (Hoddinott & Hesseling, 2018). This chapter explores healthcare-seeking/clinical, household and psychosocial contexts of the treatment regimen based on the experiences of the primary caregivers. The results are discussed within the ambit of the salutogenic theory.

Background of the study participants

A total of 35 primary caregivers for children with various forms of TB participated in the study. In terms of sex, 29 of the primary caregivers were female while 6 were males. There were not many variations regarding the age

categories of the study participants. Age categories 30-34 years and 35-39 years accounted for 9 participants each while the 14-19 years category only had one participant.

Table 3: Background characteristics of the primary caregivers

Background Characteristics	Frequency (N=35)	Percent (%)
Sex		
Male	6	17.1
Female	29	82.9
Age		
14-19 years	1	2.9
20-24 years	1	2.9
25-29 years	2	5.7
30-34 years	9	25.7
35-39 years	9	25.7
40-44 years	5	14.3
45-49 years	5	14.3
50-54 years	3	8.6
Level of Education		
No Education	6	17.1
Primary	4	11.4
JHS	18	51.4
SHS	5	14.3
Tertiary	2	5.7
Religion		
Christian	33	94.3
Islam	2	5.7

Table 3, Continued

Occupation		
Formal Sector	3	8.6
Informal Sector	24	68.6
Unemployed	8	22.9
Marital Status		
Never Married	5	14.3
Married	21	60.0
Divorced	1	2.9
Widowed	3	8.6
Separated	5	14.3
Relationship with child		
Mother	21	60.0
Father	4	11.4
Caregiver (Relative)	10	28.6

Source: Field Survey, 2020

Most of the participants – 24 of them work in the informal sector as traders and seamstresses while 8 of them were unemployed. Only 3 of the primary caregivers work in the formal sector. Concerning marital status, 21 of the participants were married while 5 of them were never married. In terms of PCGs' relationship with the child, 21 were mothers of the TB-infected child while 10 were family relatives who assumed caregiving responsibilities due to the absence (either by death or ill-health) of the biological mother. The remaining 4 of them were the fathers of the TB-infected child.

Table 4: Background characteristics of the children

Background Characteristics	Frequency (35)	Percent (%)
Sex		
Male	19	54.3
Female	16	45.7
Age		
0-4 years	3	8.6
5-9 years	10	28.6
10-14 years	22	62.9
Education		
No education	10	28.6
Pre-school	9	25.7
Primary	12	34.3
JHS	4	11.4
Period of Regimen Covered		
Less than 2 months	7	20.0
2-4 months	11	31.4
5-6 months	11	31.4
Above 6 months	6	17.1
TB-HIV Status		
TB-HIV Co-infection	22	62.9
TB only	13	37.1
Type of TB		
Pulmonary TB	25	71.4
Extra-Pulmonary	6	17.1
Pulmonary MDR-TB	4	11.4

Table 4, Continued

Schooling Status		
Currently schooling	16	45.7
Currently not schooling	19	54.3

Source: Field Survey, 2020

There were 19 male and 16 female children under the care of the study participants. In terms of age, 10 of the children were in the age category 5-9 years, 22 of them were in the age category 10-14 years while only 3 of the children were in the age group 0-4 years (the most vulnerable group of children with TB, yet most difficult to diagnose). With regards to formal education, 10 of the children have no education while 4 attained a Junior High School education at the time of the study. However, the schooling status of the children at the time of the study showed that 19 of the children were not in school while 16 of them were schooling.

In terms of the period of the treatment regimen covered, 7 of the children were in the first two months (intensive phase) while the rest were in the continuation phase with 6 of the children receiving treatment for more than 6 months (mainly MDR-TB and extra-pulmonary TB). Whereas 22 of the children were TB-HIV co-infected, 13 were only TB infected. Concerning the type of TB, pulmonary TB accounted for 25 while 6 had extra-pulmonary TB and the remaining 4 were pulmonary MDR-TB.

Healthcare seeking context

Complex diagnostic journey

The diagnostic procedure of childhood TB can be very challenging due to the presentation of the disease (childhood TB mimicking other diseases) and the lack of access to advance means of diagnosis in many resource-limited settings (Tsai et al., 2013). The primary caregivers (PCGs) recounted how difficult it was for their children to be diagnosed. The narratives point to most PCGs and their children having to visit several health facilities before they were finally diagnosed after a chest X-ray was carried out. In most cases, a definite diagnosis of childhood TB was only done upon reaching a higher level of care after earlier reporting at lower-level health facilities. Despite persistent cough being an obvious symptom of TB, almost all the study participants recounted how they did not suspect that their children could be suffering from TB.

> *She was coughing seriously and the cough refused to go. We were giving her medications and visited different hospitals but still, she wasn't responding to treatment. Then we came here [a Regional Hospital]; where she was admitted. On our third day of admission, the child was then diagnosed with TB. When she was admitted, they ran a series of tests on her because although they were giving her drugs to take to minimize the cough, it wasn't working. They did an HIV test, and a coughing test [gene Xpert]. When they realized how severe the cough was, that was when they made us go for an X-ray test…* (PCG_WR_F1_001; Female, 39 years old, Married. – Female child, 6

months old; pulmonary TB with no HIV infection; 3 months on treatment)

This difficult diagnostic experience was exacerbated in the case of childhood extra-pulmonary TB. Several participants recounted the unpleasant experience of going to health facilities frequently. In one of such cases, the caregiver narrated how she had given up all hopes before the child was finally diagnosed by chance. She recounted in the following excerpts:

> *… Soon after she started walking, we realised that the abdomen became tender and started protruding and she started to lose weight. So we kept moving from one hospital to the other…* [Narratives about different diagnoses and the need for referral to Korle-Bu]… *We spent over a month at the Volta Regional Hospital at Ho. It was one day that a certain doctor who wasn't even part of the medical team that was attending to us chanced on us and had some conversation with our doctor. After that, he came to us and said to me that there is one last test that we would need to carry out on the child... It was not until the following day that the result was made available. The doctor then came and told me that the child has abdominal TB… The child wasn't coughing, but I know usually TB comes with a severe cough. So I was confused! So telling us about abdominal TB was so strange to us [sigh].* (PCG_VR_F2_003; Female; 30 years old caregiver; Trader. – Female child, 4 years old; Extra-pulmonary TB with no HIV infection; 6 months on treatment)

Delay in diagnosis due to spiritual connotation attached to childhood TB

It also emerged from the data that some primary caregivers linked the child's deteriorating health condition to spiritual causes. As such, they initially sought spiritual solutions from different places. This action by the primary caregivers often creates unnecessary delays in diagnosing the child and initiating an appropriate treatment regimen. The longer the delay in making a diagnosis, the more TB-infected children suffer from harm caused by the disease.

> *... all this while, no one knew it was TB; not even the doctors. It took us about 4 years to finally confirm that the child was indeed suffering from TB. We had to visit different places, including Shrines until the Prophet from the church [XXX] finally confirmed it was a spiritual problem. So, after dealing with the spiritual aspect, he then told us to go to the hospital for the medical aspect to be looked at. Initially, he was diagnosed with rheumatism which was treated before he was later diagnosed with TB which we are still treating.* (PCG_VR_F2_002; 30 years old female caregiver; House Wife. – Male child; 5 years old; More than 1 year of the regimen covered; Extra-pulmonary TB with no HIV)

Adherence counselling and initiation of the treatment regimen

Health education and adherence counselling are important aspects of childhood TB management. Most of the caregivers mentioned that providers counselled and educated them on adherence before the initiation of the treatment regimen. Information on dosage and treatment duration were the common content of counselling and education. However, a few of the narratives seem to point to

the counselling not being comprehensive enough to offer the caregivers a better understanding of the disease and its attendant treatment regimen. Several participants felt they should have been given education on childhood TB as a disease in addition to education on the available treatment.

> *They told me that the treatment will be taken on a monthly basis. Every day, I have to give the child two doses of the medication and they also give me a yellow card to mark each time I give the drug to the child. They also told me that I shouldn't wait for the medicine to be finished; when it is left with about three doses, I should come for a refill.* (PCG_BA_F3_002; 36 years old female caregiver; Trader. – Female child; 3 years old; 2 months of the treatment regimen covered; Pulmonary TB with HIV co-infection)

Given that most people perceive TB to be a disease of the aged or the elderly, most of the participants felt they should be given education on childhood TB which according to them was lacking in the counselling they received. A participant who felt she was not given enough counselling had this to say:

> *They didn't explain the child's disease to me but they gave me the treatment and told me the time for giving the medicine to the child. They also told me that when they see any negative changes [adverse reaction], they will change the medicines.* (PCG_CR_F1_004; 52 years old female caregiver; grandmother. – Female child; 14 years old; 2 months of the regimen covered; Pulmonary TB with HIV co-infection)

Early initiation of the childhood TB treatment regimen is critical for successful treatment outcomes. Treatment initiation is dependent on a conclusive diagnosis of the disease. Whereas the narratives point to late diagnosis because of the peculiarities of childhood TB and its attendant diagnostic difficulties, treatment was largely initiated early. Most of the participants revealed that the child was put on the treatment regimen within about three days following the diagnosis. One PCG recalled:

> *... I didn't know that was the disease [TB] affecting my child. I took her to so many health facilities, but no avail. So after they finally diagnosed the child here, they started the treatment immediately; on that same day because the child's condition was very bad.* (PCG_BA_F2_002; 50 years old female caregiver; Mother. – Female child, 14 years old, 5 months of TB treatment regimen covered; Pulmonary TB with no HIV infection)

Support for partial integration of childhood TB into CWC

Whereas the participants support the idea of testing children suspected of TB during routine child welfare clinics (CWCs), they however expressed reservations about receiving treatment for childhood TB at CWC. The narratives of the study participants gave credence to the idea that CWC offers a good opportunity for childhood TB diagnosis due to the frequent meetings between clients and service providers. Nonetheless, the primary caregivers emphasized the risk of spreading the diseases to other children; having to spend longer time

during a scheduled visit at CWC due to overwhelming numbers; children above 5 years old not admitted to CWC; and possible stigma from fellow mothers/caregivers as reasons for been opposed to full integration of childhood TB management into CWC. The excerpt below from one of the study participants is a reflection of this theme.

> *... They [CWC health workers] didn't test my child even though I was attending CWC regularly. So, if it can be integrated for the nurses there to be able to diagnose children with TB, it will be fine…For me, I think that integration into the CWC where TB treatment is provided will not help because when you go there they don't have time for you. Here [referring to the TB Unit], the nurses are receptive and I don't spend a lot of time; you won't get this at the CWC. If it is integrated and you take your child there, other parents will discriminate against you; they wouldn't like to sit by you when they see that the child is coughing. So I am not in favour of it.* (PCG_BA_F1_003; 32 years old female caregiver; Mother – Male child, 7 years old; 2 months of TB treatment covered; Pulmonary TB with HIV co-infection)

Psychosocial context of childhood TB treatment

Management of childhood TB goes beyond just making treatment available and scheduling primary caregivers to come for them (biomedical perspective). The complex nature of childhood TB treatment makes primary caregivers' appreciation of the regimen critical in ensuring adherence. This position is advanced by the salutogenic theory. The theory has a starting point of viewing

treatment adherence in this case as the result of continuous interactions between the individual and the prevailing "social, economic, cultural, mental, and biochemical stressors" (see, Antonovsky, 1996).

When faced with live challenges (child's TB diagnosis and the attendant long-term treatment regimen), primary caregivers want to be motivated to follow the treatment regimen (*meaningfulness*), to believe that the disease, as well as the treatment regimen, can be understood (*comprehensibility*), and to recognize that resources are available to help them adhere to the treatment regimen (*manageability*), leading to the development of a sense of coherence (SOC). I explored caregivers' perspectives on childhood TB, including the treatment experience using the main tenets of the salutogenic theory.

Comprehensibility: Understanding of childhood TB

Primary caregivers' understanding of childhood TB and the attendant treatment regimen is critical in ensuring that the child adheres to the regimen. The narratives point to a somewhat deficit in caregivers' understanding of issues relating to childhood TB. Whereas the study participants highlighted aspects of the treatment regimen such as the duration, dosage, and record-keeping, little or no reference was made to the disease itself. Thus, the narrative points to some level of understanding or sense of comprehensibility of the treatment regimen, but not the aetiology of childhood TB. Several participants indicated that they have a limited understanding of childhood TB itself.

… They didn't give me an education about the disease itself. What they said was that the treatment will cause the child to have a high appetite

for food and so I should feed the child well. They also said that the child will take the treatment for 6 months. So, they gave us a card for us to mark whenever the child takes the medication. So I mark it; sometimes it is the child who marks it himself… I know that it is adults who get TB. So I don't understand it [how a child can get TB]. When they told me that the child had TB, I was disturbed and couldn't believe it. It was difficult for me to believe… (PCG_BA_F3_001; 40 years old female caregiver; Mother. – Male child, 13 years old; 4 months of the treatment covered; Pulmonary TB with HIV co-infection)

This seeming lack of understanding about childhood TB is even more pronounced among primary caregivers for children with extra-pulmonary TB. Several of the participants frequently mentioned that TB is a "cough disease" and a disease of the adult and aged. They narrated how it was difficult for them to come to terms with the diagnosis (i.e. *comprehensibility* of childhood TB) even after the initial counselling by the service providers.

...After the doctor said it was TB, I was shaken because I have only heard of TB, I didn't know what it was actually. People say that it is a coughing disease that affects older people. So, I was confused when they said it is TB that has affected his back [spine] and caused him not to be able to stand or walk… I didn't really know about TB. The doctor explained several types of TBs to me on the day. But I am still confused [sigh]. (PCG_VR_F2_001; 35 year old male caregiver; Uncle. – Male child, 12

years old; 4 months of the treatment covered; Extra-pulmonary TB of the spine)

Meaningfulness: Motivation to follow the regimen

Remaining motivated amid life challenges or difficulties is important in building a strong sense of coherence. Childhood TB management is a complex endeavour that requires commitment. In the course of the treatment regimen, primary caregivers actively evaluate the prevailing health condition of the child and develop a perception of the possible outcome(s) of the treatment. This perception has the potential to influence caregivers' attitudes toward the treatment regimen for their children. It emerged from the data that caregivers were much more motivated to continue the treatment regimen and remain committed if there are observed improvements in the health condition of the child. The reverse also holds. Many of the participants shared the view that they remained committed to the treatment regimen because they want the child to be cured and get back to normal life so that they could also revert to their usual activities. This is how one of them put it:

Before we started this treatment, the cough was very serious. She can't even sit here because she will be coughing continuously. But because of the treatment, the cough has reduced considerably now. So, it has given me the motivation to continue so that she can be cured… I have to see to it that she takes the treatment because I believe she will be cured... (PCG_VR_F3_001; 39 years old female caregiver; Aunt. – Female child; 4 years old; 5 months of the treatment covered; Pulmonary TB)

Whereas the narratives point to a seemingly strong sense of meaningfulness among caregivers for children with TB without HIV coinfection, the reverse was observed among PCGs for children with TB-HIV co-infection. Some of the participants expressed frustration and feeling of hopelessness due to children being on antiretroviral therapy (ART) for a long time and the addition of anti-TB medication has taken a toll on the caregivers. The excerpt below is from a participant who had assumed caregiving roles for her younger half-brother following the demised of both parents.

> *I had the feeling the drugs were not making him feel any better so I wanted to stop giving him the drugs and if he would pass away [die], then so be it. Honestly, I wanted to stop giving him the drugs because I have become so fed up. I am tired! But then I had a second thought which was considering the reaction and the assistance of [name – the Head of ART unit]… So, that is what made me continue the treatment regimen.* (PCG_VR_F1_002; 27 years old female caregiver; Sister – Male child, 7 years old; 5 months of the TB treatment covered; Pulmonary TB with HIV co-infection, Being on ART for 4 years)

Sense of Manageability: Resources for managing childhood TB

Manageability is also critical in developing a strong sense of coherence necessary for life challenges such as navigating the treatment regimen for children with TB. Issues such as; access to a healthcare facility, health insurance, finance, and enabler's package emerged from the data as influencing the development of either a weak or strong sense of manageability of childhood

TB treatment regimen. These issues are discussed within the ambit of a sense of manageability in the subsequent subheadings.

Access to health facilities and free anti-TB medications

Participants unanimously viewed geographical access to health facilities and the availability of free anti-TB medication as reassuring in the sense that the children will be able to deal with the disease. Similarly, most of the participants also asserted that enrolment in the national health insurance (NHIS) made the burden and stress associated with childhood TB somewhat less. The narratives point to these two critical issues as important in primary caregivers' view of the treatment regimen as manageable.

> *Once I got to know that the child's condition can be treated here and the fact that the medicines are free of charge, I was relieved because I am the only person responsible for the child. The father is dead and I don't receive help from anywhere. But, I know that when my child takes the treatment he would be cured of the disease. So, even if I am facing challenges, I would still find ways to get to the facility so that I can get the medicines for him... He has health insurance [NHIS] and it is helpful. When he gets sick and they are to give him a drip [IV fluid], the insurance covers it.* (PCG_BA_F3_001; 40 years old female caregiver; Mother – Male child; 13 years old; 6 months of TB treatment covered; Pulmonary MDR-TB with HIV co-infection)

Whereas access to health facilities and free anti-TB medications suggest a positive sense of manageability, several issues emerged from the data that highlight the negative sense of manageability by the primary caregivers. These issues are discussed in the subsequent subsections.

Financial stress

Even though the study participants reported not incurring direct costs from medications because the medication is free, they highlighted other associated costs. Most of the participants emphasised direct costs incurred in the diagnosis journey as well as transportation to health facilities for scheduled treatment appointments. Due to the difficulties in case detection, children often go through treatments for the wrong diagnoses before TB diagnosis, thereby compounding the household financial difficulties. Several of the study participants recounted having to purchase medicines, including over-the-counter medicines in an attempt to find a solution to the child's problem. For most PCGs, this cycle continued with the associated financial costs until the child was finally diagnosed with TB and the actual treatment regimen was initiated. The study participants also emphasised costs associated with transport for scheduled clinical appointments as posing a challenge to them. Transportation costs were perceived to be higher among caregivers of children with TB-HIV co-infection as they had to make separate clinic appointments.

> *When we didn't know what was wrong with the child, we took him to several places, including different hospitals; so that greatly affected our finances. Now, we are even in debt [sigh]… We haven't paid for any of*

the [anti]TB medicines. But, it is the cost of transportation that is seriously affecting our finances because we live far away. Because we come here twice every month [two separate clinic appointments for TB and HIV] for medication, when the time is due and I don't have money, I have to go and borrow money from someone. (PCG_BA_F1_003; 32 years old female caregiver; Mother; Unemployed – Male child; 7 years old; 2 months of the treatment covered; Pulmonary TB with HIV co-infection).

Loss of earnings and savings

Some caregivers also recounted having to endure loss in earnings and savings due to childhood TB. Some participants narrated how they have to stop working due to their caregiving responsibilities. According to the PCGs, this interruption in work resulted in the loss of earnings as almost all the caregivers were engaged in the informal sector. The loss of earnings compelled the household to fall on their savings, thereby increasing their financial vulnerability. In a few of the cases, caregivers even had to sell some property of the household to offset the difficult financial situation brought about by childhood TB.

… Caring for the child affected my work greatly. I no longer work, so I don't get money. I have to use all my savings. I even had to sell my mother's plot of land to get some money to support the child's treatment and the family. It makes me feel very sad… Now, the only thing we have left is the machine used for grinding corn [corn mill]. So, we were thinking if we could get someone to buy it at a cheaper price so that we

use the money to support the family. So, our problem is big and no one will listen to us. [sigh] It is difficult ooh. (PCG_CR_F1_002; 46 years old female caregiver; Trader; Mother – Female child, 14 years old, 2 months of TB treatment covered; Extra-pulmonary TB)

Absence of enabler's package

Caregivers also highlighted the absence of an enabler's package (nutritional support) for the children. The caregivers acknowledged the important role of the enabler's package in the treatment regimen. As such, they shared their unhappiness about the unavailability of the enabler's package in recent times. For many caregivers, they only received the enabler's package once, even though it was very helpful.

… I borrow things from people to take care of the child [sigh]… They [service providers] use to give us tom brown, but it has been a long time since they gave us some. I wish we could get it every month. That is what she takes in the morning – 30 minutes after she has taken the medicines before she goes to school. It helps a lot. But we were only given once when she started the treatment. (PCG_CR_F1_004; 52 years old female caregiver; Grandmother – Female child, 14 years old, 3 months of TB treatment covered; Pulmonary TB with HIV co-infection)

Psychological impacts of childhood TB on caregivers

Anxiety, guilt, and helplessness of primary caregivers

The data shows that childhood TB and the attendant treatment regimen have enormous psychological impacts on both the primary caregiver and the infected children. The study participants narrated having to deal with the anxiety that comes with childhood TB and the long-term treatment regimen for the children.

> *… Just when we thought everything was okay then the child also got TB. So it was quite disheartening and worrisome. To be frank, I worry a lot. Sometimes I worry so much that they even admitted me to the hospital for about 3 weeks. So it is [XX – The TB coordinator] who has been encouraging me not to give up.* (PCG_BA_F2_002; 50 years old female caregiver; Mother. – Female child, 14 years old, 5 months of TB treatment regimen covered; Pulmonary TB with no HIV infection)

This psychological impact is even more pronounced among mothers of TB-HIV co-infected children who themselves are also infected with HIV. The narratives show that these mothers were going through considerable stress and psychological instability as they have to deal with their own conditions and that of the child at the same time. These mothers conveyed a feeling of guilt for being responsible for their children's condition. A young mother narrated her ordeal in the excerpt below.

> *I am very worried because I don't know how things will turn out. I am always thinking about the situation. I got to know not long ago that I have HIV and now my child has both HIV and TB; I am very worried. I*

think about it a lot because the child is very young and has not even started walking; it disturbs me a lot. Sometimes, I'm not able to sleep at night, just thinking about the child. I see other children around his age who are walking, but he cannot walk because of the disease. Sad I'm putting my child through this ***[Participants broke into tears]***. (PCG_CR_F2_001; 19-year-old female caregiver; Mother – Male child, 1 year + 10 months; 3 months of TB treatment covered; Pulmonary TB with HIV co-infection)

Non-Disclosure of status due to shame and fear of stigmatisation

Status disclosure is regarded as important in TB control efforts. However, almost all the study participants indicated not disclosing the child's TB infection and the treatment regimen, preferring to keep it a secret. In some instances, participants revealed that not even close family members, including the fathers of the children are aware. Most of the study participants revealed that the children are not aware of their disease and they intend to keep it away from them for as long as possible. The participants frequently mentioned fear of stigma and discrimination as the reason behind their non-disclosure. However, some participants indicated that they will disclose the child's status to close family members and possibly their teachers if they are convinced that they will not stigmatize and discriminate against them. The following quote sums up this observation from the data.

It is only me and the father who knows about it. For the others, they know that the child is sick but they don't know the actual sickness…

People are afraid of TB so if I tell them that the child has TB, then they will not get close to him. Even his friends will not come close to him. Because of this, I have not told anyone. It is between me and his father. Even the child doesn't know what is called TB. (PCG_VR_F2_001; 35 years old male caregiver; Uncle – Male child, 12 years old; 4 months of the treatment covered; Extra-pulmonary TB)

Stigma against TB-infected children

Not only did the primary caregivers narrate having suffered psychologically, but also highlighted how TB infection and treatment have had considerable psychological impacts on the infected children. Participants highlighted that the inability of the TB-infected children to engage in basic activities with other children has taken a psychological toll on the children. The narrative from one of the PCGs highlighted how the TB-infected child is often shunned [possible stigma] by other children because their mothers probably have warned them to stay away from the child due to his condition.

For [name withheld], most of the time he is quiet, especially in recent times. When other kids are playing, he will just be looking at them. I could imagine the trauma he goes through. So, when it happens like that, I just tell him to stand up and go inside. He looks at the other kids when they are playing in a really weird way and it appears to me that he wishes to be there but there is no chance for him to be with the others due to his condition… Even if I allow him to join them, once he gets there, the other children will just disperse and start running away from

him. I believe their parents have told them to keep away from him. Imagine how you will feel seeing your only brother in such an awkward situation [PCG **Crying – counsellor called to come and help**]. (PCG_VR_F1_002; 27 years old female caregiver; Sister – Male child, 7 years old; 5 months of TB treatment covered; Pulmonary TB with HIV co-infection, Being on ART for 4 years)

Social impact of childhood TB on caregivers and infected children

Lack of social support due to negative societal perceptions about TB

The study participants highlighted the societal perception of TB as a dangerous disease with spiritual connotation as means by which they are denied social support. According to them, many of their community members regard TB as an incurable disease. The disease is often associated with death. As such, when someone gets infected, people stay away from the infected person as much as possible as means of protecting themselves. This is how one of the participants put it:

They see it as a dangerous and bad disease. They translate it [TB] as a disease that will take you to your grave. No one will want to come close to you. Sometimes they say that it may be caused by spiritual forces. Even for me, I also agree that it is a very bad disease because of how my child was coughing. He would cough all the time and not be able to eat properly. My child was virtually at the point of death. (PCG_BA_F2_003; 32 years old female caregiver; Mother – Male child;

7 years old; 3 months of TB treatment covered; Pulmonary TB with HIV co-infection)

Reduced involvement in social activities by caregivers

Childhood TB and the associated complexities come with social consequences. Primary caregivers narrated how the children's TB infection and the associated caregiving responsibilities meant that they became less involved in social activities. Participants frequently mentioned funerals, markets, and church services among others as social/community-based activities that they were either unable to attend or have had to reduce involvement due to their child's TB status. According to the PCGs, their actions and inactions were necessitated to prevent possible stigma, discrimination, and having to face uncomfortable questions from people about the child's health condition. Also, they reported that since there is no one to take over the caregiving responsibility in their absence, they had no option other than to skip social activities.

… People will be asking why my child is sick and they wouldn't want to get close to me. It would be too much stress for me psychologically. I no longer go to funerals, unless it is very necessary. Even with that, I don't go with him [the TB-infected child]. When the sickness got intense, I don't even go to church at all. It is as if I am no longer part of society. (PCG_ER_F1_001; 37 years old female caregiver, Mother – Male child, 5 years old; 5 months of TB treatment covered; Pulmonary MDR-TB with HIV co-infection)

Disruption of infected children's education

The social impact of childhood TB on children was mainly in the area of education. The participants reported how TB infection and subsequent treatment regimens have resulted in the disruption of the infected children's education. Several of the study participants narrated having to withdraw their children from school due to childhood TB. The complex diagnostic journey and subsequent treatment regimen meant that most of the children spent about 6 months out of school, returning only after completing the treatment or when their health condition was deemed by their primary caregivers to have improved. For children who were not enrolled in school before the onset of TB, their school enrolment was delayed substantially. In the case of a few of the TB-HIV co-infected children, they have been out of school entirely as their condition worsened. Almost all the primary caregivers indicated that their decisions to withdraw the child from school were not based on professional medical advice, but rather on personal decisions.

> *…By then I was teaching so by the time she was just 4 months old I got her enrolled in a pre-school. But she had to stop when the sickness started… It was based on a personal decision because of how people were talking and asking me questions regarding the child. I was no longer feeling comfortable and so we decided that she should stop going to school. There was also the issue of us moving from one hospital to the other which greatly interrupted her schooling. Look, she is now 4 years old and has to be in nursery 2, but because of the sickness I'm about to*

send her to nursery 1. (PCG_VR_F2_003; 30 years old female caregiver, Mother – Female child, 4 years old; 6 months of TB treatment covered; Extra-pulmonary TB [Abdominal]; currently not in school)

Discussion

This chapter offers insights into how caregivers for children with TB navigate the treatment regimen. The experiences of the caregivers were contextualised – clinical/health-seeking, household, and psychosocial contexts were specifically explored. The primary caregivers for children with TB were mostly women – either mothers or female relatives who assumed caregiving responsibilities following the death of the child's biological mother. With most of the caregivers engaged in the informal sector with a low and often unstable income, childhood TB could increase the household's financial vulnerability (Batista Lacerda et al., 2014). The background characteristics of the TB-infected children revealed that TB-HIV co-infection has been common, with several children not in school due to the disease. The close association between childhood TB and HIV has been documented across various settings (Fry, Barnabas, & Cotton, 2019).

With regards to the clinic/health-seeking context of childhood TB, it was evident that caregivers were faced with a complex diagnostic journey. Late diagnosis has been a bane in childhood TB management and control in many resource-limited settings (Trajman & Schwartzman, 2020). The clinical and radiographic presentations of TB are less specific in children and often mimic bacterial pneumonia, thereby contributing to the delay in diagnosis (Thomas, 2017). Besides, advanced procedures such as gastric lavage and sputum

induction for obtaining samples for gene Xpert are limited in many LMICs (Oliwa et al., 2020). The difficulties with diagnosing childhood TB are even exacerbated when it comes to extra-pulmonary TB as symptoms are not specific and clinicians hardly suspect TB infection (Santiago-García et al., 2016).

The present study revealed that consistent with good practice, adherence counselling and education are usually provided to caregivers before the initiation of the treatment regimen. Adherence counselling and patient education are important aspects of childhood TB management/control and often play a key role in treatment completion (Alipanah et al., 2018). Adoption of a client-centred approach to providing comprehensive childhood TB counselling and education, not only about the treatment regimen but also about the aetiology of the disease is essential (Guix-Comellas et al., 2018). As part of efforts toward achieving the "End TB Strategy", service integration has been recommended, especially in resource-limited settings (Petersen, Blumberg, Wilson, & Zumla, 2017).

It was evident in this study that primary caregivers support integration, albeit a preference for partial integration of childhood TB into child welfare clinics where the diagnosis can be undertaken, but the actual management is referred to the DOT centre of the facility. Whereas there is no implementation scientific evidence to suggest the form (either full or partial) of integration, the prospects of integration in childhood TB management appear promising (Kebede, 2016). Fortunately, there is a "cluster-randomized stepped wedge trial" that is currently underway to determine the impact and appropriateness

(including the form of integration) of integrating childhood TB services into child healthcare services in Africa (Ndam-Denoeud et al., 2020).

This study also delivers some insight into the psychosocial context of childhood TB management. Given the complexities associated with childhood TB, caregivers need to develop a strong sense of coherence (SOC) based on their sense of comprehensibility (understanding); sense of meaningfulness (motivation); and sense of manageability (resources) about childhood TB. Eriksson and Mittelmark, (2017) noted that as a requirement for handling a stressful situation like childhood TB with a long-term treatment regimen, it is important to understand the situation to a very large in detail. A sense of coherence by an individual develops throughout the life-course, and it is largely influenced by consistent experiences in life, load balance, decision-making capabilities, and emotional stability (Eriksson & Mettelmark, 2017). Sense of coherence is usually enhanced by experiencing the right challenges – "a balance between under- and overload in daily life" (Antonovsky, 1996; Langeland & Vinje, 2017).

Antonovsky (1987) highlighted that although a strong sense of manageability is contingent on a strong sense of comprehensibility, it appears as if the motivation element within the meaningfulness component of the sense of coherence is the most vital component (Antonovsky, 1987). In the present study, we found a relatively weak sense of manageability among the study participants due to the numerous challenges that confront them as primary caregivers. Notwithstanding, there was evidence of a strong sense of

meaningfulness among participants, especially caregivers for children with pulmonary TB without HIV co-infection. It is however noteworthy that the same was not observed among caregivers for TB-HIV co-infected children as they conveyed a rather weak sense of meaningfulness.

Also, the evidence suggests some form of a sense of comprehensibility among the study participants. These results reinforce the idea that the "one-size-fits-all" approach to TB management and control might not be the best for children (Szkwarko & Hirsch-Moverman, 2019). Therefore, there is a need for a client-centred approach to providing childhood TB counselling, education, and management (Guix-Comellas et al., 2018). Also, counselling services and health education about the disease and the recommended treatment regimen have to be sustained throughout the treatment regimen. This is important for the development and maintenance of a strong sense of coherence which is essential for successful navigation of the treatment regimen.

In addition to SOC, access to and use of various resistance resources are important in the salutogenic theory (Antonovsky, 1996). General resistance resources (GRRs) may comprise such things as social support, material resources, coping strategies, access to a healthcare facility, access to anti-TB medications and ARTs, and financial sources, among other things. The inadequacy or lack of these resources is termed generalized resistance deficits (GRDs). Whereas GRRs help to strengthen and preserve a strong sense of coherence, GRDs work in the opposite direction to weaken an individual's sense of coherence (Antonovsky, 1987). The present study provides some useful

insights into the manageability and generalized resistance resources of caregivers for children with TB.

Whereas easy access to health facilities and free anti-TB medications serves as GRRs for caregivers, financial stress; loss of earnings and savings; and absence of enabler's package emerged as generalized resistance deficits. This has potential repercussions on the formation of a "sense of coherence" necessary for adherence to the treatment regimen. Indeed, the result of the relatively weak "sense of coherence" among the study participants manifested within the psychosocial contexts of their lived experiences about childhood TB (and in some cases HIV co-infection) and the attendant treatment regimen.

Psychological issues such as anxiety, guilt, and feeling of helplessness; non-disclosure of status; and stigma against TB-infected children were evident in the present study. In the same vein, social impacts of TB were felt by the participants in various ways, including; lack of social support due to negative societal perceptions about TB, reduced involvement in social activities by the primary caregivers, and disruption in the formal education of the infected children, among others, were all evident in the present study. These findings are in resonance with Loveday et al., (2018) study on childhood MDR-TB in KwaZulu-Natal, South Africa where it was reported that caregivers were often anxious and concerned about their children's prospects while at the same time the cost incurred due to childhood TB has increased the vulnerability of the affected households (Loveday et al., 2018).

Often, children with TB get admitted to the hospital for treatment because of unjustified fear regarding its spread (van Custem, Issakidis, & Farley, 2016). Also, households, though not based on medical advice, prevent their children from attending school during the treatment regimen as a way of protection against stigma and discrimination. Amo-Adjei, (2016) noted that women are more disposed to keep TB in the family a secret due to fear of stigma and discrimination. Given that most of the caregivers in this study were women, it was therefore not surprising that non-disclosure was evident. There is also documented evidence of myths and misconceptions about TB in Ghana with people sometimes associating TB with spiritual causation (Amo-Adjei & Kumi-Kyereme, 2013; Tabong, Akweongo, Adongo, & Shiri, 2021).

The evidence from this study emphasises the need for psychosocial support for households affected with childhood TB. Indeed, pillar 1 of the "End TB Strategy" calls for patient-centred care and support that is sensitive and appropriate to the emotional, educational and material needs of clients (WHO, 2014). Tuberculosis – whether paediatric or adult-type has both direct and indirect effects on the household (Meghji et al., 2020). Children, caregivers, and the affected households are in urgent need of age-appropriate counselling, health education based on specific needs (i.e. type of TB, TB-HIV co-therapy), assistance to cope with a long-term treatment regimen, financial, nutritional, and psychosocial support regarding stigma and feeling of guilt (Treatment Action Group, 2013; Paz-Soldan, Alban, Jones, & Oberhelman, 2013). Also,

material support for TB-affected households is vital to improving the management and control of childhood TB.

Whereas there was no direct cost from medication due to anti-TB medication being free under the NTP, there were other direct and indirect costs incurred by the household due to childhood TB. For instance, costs of transportation to the health facility every month, loss of earnings, or the need to sell personal or family property to support TB treatment have all been documented (Getahun, Wubie, Dejenu, & Manyazewal, 2016). Both the SDGs and the End TB Strategy aim at protecting TB-affected households from catastrophic costs associated with the disease as a matter of urgency (see, WHO, 2014; UN, 2015). To achieve this goal, urgent actions are required in terms of support for childhood TB-affected households. Support is necessary if for instance the primary caregiver is the only one responsible for the child but is no longer able to work because of the caregiving responsibilities of the TB-infected child.

Summary

Childhood TB diagnosis and the attendant treatment regimen exert considerable psychosocial impacts on primary caregivers, infected children, and their household at large. With a complex diagnostic journey and subsequent long-term treatment regimen, childhood TB exerts enormous psychosocial stress on primary caregivers, the infected children, and their households. The psychosocial stresses are mainly the result of the manageability challenges that confront caregivers. To develop and sustain a strong "sense of coherence"

needed for successful navigation of the treatment regimen, the manageability challenges highlighted in this study need to be addressed by the NTP of Ghana.

Psychosocial and financial supports for childhood TB-affected households are urgently needed. Client-centred counselling and health education must be sustained throughout the treatment regimen, especially for caregivers of children with TB-HIV coinfection. NTP should prioritize child-friendly policies and an integrated family-based approach to childhood TB management, address the vulnerabilities faced by TB-infected children, support caregivers, particularly women and young people, and provide the needed social protection for households.

CHAPTER TEN

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Introduction

With the recent appreciation of the substantial contribution of childhood TB to the overall burden of the disease, there has been a growing consensus for the needed policy and programmatic attention. This chapter addresses some key issues in the thesis – a summary of the study, a summary of the major findings, conclusions, recommendations, contribution to knowledge, reflections on the theoretical frameworks, limitations and opportunities for further studies.

Summary of the study

Children and their caregivers suffer a great deal from TB infections. The peculiar challenges that confront childhood TB require thoughtful attempts to understand programme-related contexts to inform policies toward better treatment outcomes for children. This thesis, therefore, explored the management and control of childhood TB in Ghana. Specifically, the study seeks to: (1) Assess how childhood TB is managed in the selected health facilities; (2) Examine the challenges faced by service providers in the management of childhood TB; (3) Explore the perspective of service providers on the integration of childhood TB management into child welfare clinics (CWCs); (4) Explore the views of service providers on ways to improve the management of childhood TB in Ghana; (5) Investigate how primary caregivers

follow the treatment regimen for children with TB (healthcare-seeking and psychosocial contexts).

Various theories of infectious disease management were reviewed and synthesized into broader theoretical perspectives to understand how these theories explain management and adherence to a long-term treatment regimen for childhood tuberculosis. After the review, the study was situated within the social-ecological perspectives as it offers a better understanding of the issues surrounding the management and control of childhood TB. The social-ecological perspective acknowledges the complexities associated with a long-term treatment regimen and emphasizes the need to situate adherence within a broader context of personal beliefs, social experience, healthcare environment as well as organizing structures and social norms. Within this perspective, two micro-level theories – the normalization process model (NPM) a subsidiary of the larger normalization process theory and the salutogenic theory (ST) were utilized.

The nature of the issues under investigation led to the adoption of interpretivist philosophy and its attendant qualitative methods of inquiry. A total of 66 study participants – 31 service providers and 35 primary caregivers for TB-infected children were interviewed in 15 different health facilities across five regions of Ghana. The data were managed and analysed with QSR Nvivo 12 plus computer software. Both inductive and deductive coding approaches were used.

In this chapter, a summary of the results of the study, the conclusions, contribution to knowledge, and recommendations are presented. It also put forward possible areas for additional research in the field of childhood TB management and control.

Summary of Main Findings

Generally, childhood TB case notification was less frequent in most of the study facilities, highlighting the difficulties in childhood TB diagnosis. Participants however acknowledged that the relatively less frequent case notification for childhood TB is a concern as they suspected that several children remained undiagnosed. Service providers are aware of the synergy between childhood TB and HIV resulting in co-morbidity, especially among children with pulmonary TB. This study also found that the modalities of childhood TB management in the study facilities are largely consistent with the recommended practices, albeit with some challenges. For instance, clinical investigation/diagnosis of childhood TB in all the study facilities follow a similar algorithm where clinical history is combined with modern means of diagnosis, including X-ray and Gene Xpert. Childhood TB management and control strategies like adherence counselling, intensified case finding (ICF) and contact tracing were being undertaken at the various facilities, amidst challenges.

Even though the study found evidence of generalized resistance resource (GRR) mainly from the Global Fund, several manageability challenges were unravelled. These challenges cover diagnosis, treatment adherence, management/control, and operational difficulties. Specific diagnostic

challenges that emerged included; difficulty producing sputum and the absence of paediatricians to conduct sputum induction procedures such as gastric lavage, the use of X-rays for childhood TB diagnosis and the attendant costs, delay in getting test results (diagnosis), and misdiagnosis leading to missed cases. With regards to treatment adherence, interruptions were common after the intensive phase. Concerning management/control and operational efforts, challenges relating to contact tracing, weak linkage care under DOT, long treatment duration, the control mechanism for the dispensing of child anti-TB formulation, and co-therapy regimen for childhood TB and HIV were often cited.

Using the normalization process model (NPM), I examined the feasibility of integrating childhood TB into child welfare clinics. The evidence shows that in terms of interactional workability, service integration will be disposed to normalization due to frequent interactions between agents within the healthcare system. Thus, service integration will offer an opportunity for diagnosis both at the facility and community levels. Concerning relational integration, service integration may not necessarily be disposed to normalization due to the perceived lack of expertise among child welfare clinic service providers. Also, the structure of TB control currently operated in the country may not allow for full integration.

Regarding skill-set workability, service integration will only be disposed to normalization if it is a partial model. Thus, childhood TB-related work of service providers at the child welfare clinic should be limited to case-

finding and diagnosis in a partially integrated system. Concerning contextual integration, service integration will be disposed to normalization due to the availability of institutional structures and health personnel. However, there will be a need for training of child welfare clinic service providers on childhood TB management, especially on recognition of symptoms and the recommended testing protocols. Overall, some form of partial integration seems feasible.

As part of efforts towards improving the management and control of childhood TB, service providers recommended among other things; getting childhood TB firmly on the public health agenda, improving childhood TB active case finding (ACF), addressing loss to follow-up and ensuring treatment adherence, and prioritizing continuous counselling and monitoring. Policy implementation reforms such as facility custody of the paediatric formulation, financial and nutritional support for children on TB treatment, sensitization and training of clinicians on childhood TB, making X-ray services for childhood TB diagnosis free of charge, adequate community engagement, and partial integration of childhood TB into child health services could form an integral part of the way forward.

The salutogenic theory was used to explore the healthcare-seeking and psychosocial experiences of childhood TB management. The evidence point to a complex diagnostic "journey" by the primary caregivers, usually beginning from a lower level of the healthcare system before ending at a tertiary level of care. Concerning the psychosocial contexts of the treatment regimen, there was varied understanding (*comprehensibility*) of childhood TB among the primary

caregivers. Of key notice is the confusion among primary caregivers for children with extra-pulmonary TB as they found it difficult to comprehend (even after counselling) how a child can be said to be having TB without coughs. Whereas a seemingly strong sense of *meaningfulness* was observed among primary caregivers for TB-infected children with no HIV co-infection, a rather lesser sense of meaningfulness was evident among those caring for TB-HIV co-infected children.

A sense of *manageability* is important for the development of a strong "sense of coherence" necessary for navigating the treatment regimen for childhood TB. Easy access to a health facility and free anti-TB medications were found to be helpful in the formation of a strong sense of manageability. However, several manageability challenges such as financial stress, loss of earnings and savings, and absence of enabler's package were all found to have contributed to the development of a weak sense of manageability among primary caregivers. Anxiety, guilt, and feeling of helplessness, coupled with non-disclosure of status due to shame and fear of being discriminated against, and stigma against TB-infected children were some of the psychological impacts childhood TB exerted on primary caregivers. Social impacts of childhood TB were evident in terms of lack of social support due to negative societal perception about TB, reduced involvement in social activities by caregivers, and disruption of infected children's education.

Conclusions

Guided by the research questions and based on the main findings from the study, the following conclusions are made:

Childhood TB management and control practices/strategies by the service providers in the selected health care facilities are largely consistent with the recommended practices, although some challenges and disparities exist. For instance, Gene Xpert and X-ray are the two most preferred means of childhood TB diagnosis, even though some lower-level facilities lack these services. Notwithstanding, childhood TB case notification remained sub-optimum in most of the health facilities.

Numerous challenges confront service providers in the management and control of childhood TB. The study found that whereas a sense of meaningfulness and comprehensibility were more evident among service providers, a sense of manageability was rather less evident due to the numerous challenges that confront them. Nonetheless, general resistance resources from an external source (the Global Fund through NTP) ensured the continuity of service delivery amidst the numerous manageability challenges.

Service providers across the various levels of care are open to the integration of childhood TB into child welfare clinics, albeit partially. Whereas interactional workability and contextual integration domains provide strong optimism for the appropriateness of integrating childhood TB into child welfare clinics, relational integration and skill-set workability present bases for caution regarding the model of integration. The evidence point to a preference for a

collaborative model where service providers for CWC will screen and test children for TB and the confirmed cases are then referred to the Chest Clinic/TB unit for management.

Despite recent progress, the management and control of childhood TB in most of the study facilities remain sub-optimal. As such, a lot more effort is required in terms of policy reforms to set Ghana on the path toward achieving the "End TB Strategy". For instance, childhood TB needs to be firmly on the public health agenda and policy reforms such as free chest X-ray services, adequate community engagement, and integration of childhood TB into various maternal and child health services such as child welfare clinics are urgently needed.

Childhood TB diagnosis and subsequent treatment regimen exert enormous negative psychosocial impacts on primary caregivers, infected children, and their households at large. Psychological stresses manifest mainly as a result of the manageability challenges that confront primary caregivers. Navigating childhood TB treatment regimen is a daily struggle for primary caregivers, especially those caring for TB-HIV co-infected children. Financial stress, loss of earnings and savings, anxiety, guilt, and feeling of helplessness are part of the daily psychosocial struggles of primary caregivers for children with TB.

Recommendations and Policy Implications

The following recommendations are put forward for consideration based on the major findings and conclusions;

1. The Ghana Health Service (GHS) and the National Tuberculosis Control Programme (NTP) should ensure that the management and control practices/strategies at the various facilities are sustained and enhanced through regular monitoring and supervision of chest clinics/TB units by the various regional and district TB coordinators. Strategies for case notification urgently need to be improved.

2. Given Ghana's commitment to the ambitious "End TB Strategy", the numerous manageability challenges, including those related to childhood TB diagnosis, treatment adherence, and management/control policy implementations need to be addressed urgently by the various stakeholders, including the Ministry of Health (MoH), NTP, hospital authorities, and donor organizations to set the country on the path towards the realization of the ultimate goal of ending TB in all forms by 2030.

3. The NTP and GHS should consider partial integration (possibly a collaborative model) of childhood TB into child welfare clinics as it presents a viable option for both service providers and primary caregivers for children with TB. Partial integration will provide an opportunity for improved childhood TB case notification while ensuring

early initiation of the treatment, adherence to the treatment regimen, and a favourable treatment outcome as it offers opportunities for continuous monitoring of children during community outreach activities.

4. The GHS, the NTP, hospital authorities, and donor organizations should give commensurate attention to childhood TB just like adult TB. Comprehensive child-friendly approaches are required to improve childhood TB management and control efforts. The views expressed by the services providers on the way forward in childhood TB management (e.g. improving active case finding for childhood TB, addressing loss to follow-up, ensuring treatment adherence, prioritizing continuous counselling and monitoring, sensitization and training of clinicians on childhood TB, making X-ray services free of charge, adequate community engagement etc) could inform a country-specific roadmap towards the realisation of the paediatric component of the "End TB Strategy" in Ghana.

5. Psychosocial and financial support for childhood TB-affected households are urgently needed. Client-focused counselling and health education must be sustained throughout the treatment regimen, especially for caregivers of TB-HIV co-morbid children to put them in the right frame of mind to follow the treatment regimen. The NTP and GHS should prioritize child-friendly policies and an integrated family-based approach to childhood TB management, address the

vulnerabilities faced by TB-infected children, support primary caregivers, and provide the required social protection for TB-affected households.

Contributions to knowledge

In recent times, there have been amplified calls for adequate attention to childhood TB, including an understanding of how children follow the treatment regimen. To the best of my knowledge, this study is one of the few studies to explore the healthcare-seeking and psychosocial contexts of childhood TB treatment in Ghana. By considering the various forms of childhood TB – pulmonary childhood TB without HIV infection, childhood TB-HIV coinfection, childhood MDR-TB, and childhood extra-pulmonary TB, this study has unravelled the dynamics of childhood TB and provides an in-depth understanding of critical contextual issues.

The study also adds to the growing body of evidence on programme-related context which could be leveraged for better management and treatment outcomes among children. For instance, part of this thesis explored the feasibility of integrating childhood TB management into child welfare clinics. The results showed that integration is feasible, albeit with a preference for a partial model. Also, the study brought to light some challenges that confront service providers in the management and control of childhood TB. Addressing these challenges could result in better management and control of childhood TB in a resource-limited setting like Ghana.

In terms of methods, drawing evidence from both service providers and primary caregivers offers an opportunity for in-depth analyses and a comprehensive understanding of the issues. The study also offers an insight into how various qualitative techniques can be combined in one study to enhance the quality and trustworthiness of qualitative evidence. For instance, both inductive and deductive coding techniques were employed in the data analyses, with inductive coding taking precedence over deductive coding.

The principle of "bracketing" was employed during the inductive coding stage as a measure to avoid forcing the theoretical framework on the data. Also, an inter-rater coding process was employed to code the data at all levels. In addition, this study demonstrated practical ways to assess saturation as applied to sampling and sample size determination. These methodological efforts add to the growing contribution to the contemporary qualitative scientific inquiry literature.

Reflections on the theoretical framework

Situating this study within the Social-Ecological Perspective (SEP) was fit for purpose. This is because the pieces of evidence from this study point to the complex nature of childhood TB management and control. Childhood TB management and control involve a continuous interaction between the infected child and the primary caregiver on one hand and their ecosystem/social web on the other hand. This complex social web/ecosystem involves their family, community, social norms, and most importantly the healthcare facility and the service providers for childhood TB. The two micro-level theories – the

normalization process model and salutogenic theory that guided this study were important in offering a comprehensive understanding of the issues surrounding childhood TB management and control.

The exploration of the challenges that confront the service providers was situated within the remit of the salutogenic theory. In the same vein, the chapter that explored the healthcare-seeking and psychosocial contexts of the treatment regimen was also framed around the salutogenic theory. The tenets of the theory offered a framework for the second stage of the data analysis which involved a deductive coding process. This provided us with the opportunity to interpret the data, rather than just summarize it (Broom, 2021). For instance, the tenets of "sense of coherence (SOC)" as posited by the salutogenic theory were critical in unravelling how caregivers navigate through the treatment daily and how that can be leveraged for ensuring adherence to the treatment regimen. Largely, the salutogenic theory was appropriate for this study as the tenets of the theory allowed for broader insights into the issues under investigation.

Despite the enormous strength of the salutogenic theory, there is an inherent limitation. The theory assumed linearity where a strong sense of coherence will automatically translate into positive behaviour (primary caregiver's treatment adherence for their children in this case) which will then result in a favourable treatment outcome. However, the evidence from this study revealed that whereas this largely holds, it may not always be the case. For most primary caregivers for TB-HIV co-infected children, the "sense of coherence" (SOC) changes in the course of the treatment regimen, depending on observed

health improvements or otherwise. Some primary caregivers developed a strong sense of coherence at the beginning of the regimen but soon become demoralized. Conversely, some caregivers with a weak sense of coherence at the beginning of the treatment regimen quickly developed a strong "sense of coherence" in the course of the regimen, especially after the intensive phase of the treatment.

The normalization process model which was used to explore the feasibility of integrating childhood TB management into child welfare clinics provided an analytical framework that offers a broader and better understanding of the perspectives that were expressed by the study participants. The model helped to gain a broader understanding of the possible pathway(s) of integration and the conditions necessary for the existing healthcare system to make integration possible. From an analytical point of view, the theoretical framework ensured that the data analysis process went beyond mere coding and sorting interview data, to encompass a more iterative process where coders were in constant interaction with the tenets of the normalization process model. Consequently, the theoretical framework (i.e. the NPM) allowed for both abstraction and (re)embedding in data which enhanced the robustness of the evidence.

Given the importance and scope of childhood TB as a public health concern (childhood TB spanning across several resource-limited settings), programmatic solutions need to be applicable across space. Situating this study within appropriate micro-level theories (i.e. the NPM and the Salutogenic

theory) offered bases for transferability of the study results in the sense that theoretical conceptualization and its attendant framework analyses aid the demonstration of the meaning of the data at a broader level. As such, the findings can be transferred across sites, settings, and contexts. Also, situating this study within the remits of the two micro-level theories allowed the coders to interpret the data at a broader level, thus satisfying the philosophical requirement of interpretivism which requires offering meanings (interpretative leap) to the data.

Limitations and opportunities for further studies

Despite the contributions made by this study to the field of childhood TB management and control, there are some inherent limitations. Nonetheless, these limitations do not in any way diminish the validity and worth of this study since the scientific enterprise is generally concerned about making contributions to knowledge rather than consummating knowledge. In effect, the limitations highlighted in this study will serve as pointers for future studies to advance knowledge and understanding of the complexities of childhood/paediatric TB.

Firstly, the exploration of the management of childhood TB in the selected health facilities was done mainly by relying on verbal accounts provided by the service providers during interviews. There was no review of medical records to assess the burden of childhood TB and treatment outcomes in the various health facilities. There is therefore a need for epidemiological studies that will estimate the burden of childhood TB and assess treatment outcomes across the various levels and models of care.

Secondly, the assessment of the feasibility of integrating childhood TB into child welfare clinics was only explored from the perspectives/views shared by the service providers and primary caregivers. Whereas the evidence provides meaningful insight into the possible pathway(s) for integrating childhood TB management into child welfare clinics, caution must be taken as the impact of such policy reform on childhood TB case notification, the cascade of care, and treatment outcomes are not currently known. Therefore, there is a need for implementation science research that will ascertain the appropriateness of integration and its impact on childhood TB management and control. Fortunately, there is a cluster-randomized stepped wedge trial currently underway in some African countries to address this gap. More such studies are needed to address the pertinent contextual issues and provide a shred of robust evidence in support or otherwise for the integration of childhood TB into child health services such as child welfare clinics. Notwithstanding, the insights shared in this study are valuable as they emanated from actual providers and users of TB and CWC services.

Whereas this study explored the healthcare-seeking and psychosocial contexts of childhood TB treatment and provided meaningful insights into how primary caregivers navigate the treatment regimen, some pertinent issues require further investigation. For instance, it was revealed that childhood TB exerts substantial financial stress on primary caregivers and the household at large. However, the actual costs incurred by childhood TB-affected household was not estimated in this study. Mitigating catastrophic costs due to tuberculosis

is at the core of the current global TB control efforts as outlined in the "End TB Strategy" (see WHO, 2014). It will be insightful for future studies to consider the magnitude and drivers of childhood TB-affected household costs to inform policies on cost mitigation and to determine the proportion of households experiencing catastrophic costs.

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APPENDICES

APPENDIX A

A: CONSENT FORM FOR SERVICE PROVIDERS

Study Title: Management and Control of Childhood Tuberculosis in Ghana

PARTICIPANT STATEMENT AND SIGNATURE

"I acknowledge that I have read the purpose and contents of the Participants' Information Sheet and that all questions have been satisfactorily explained to me in a language I understand (English). I fully understand the contents and any potential implications as well as my right to change my mind (i.e. withdraw from the research) even after I have signed this form".

I voluntarily agree to be part of this research.

Name or Initials of Participant…….. ID Code ……

Participants' Signature …… Date: ……

CONSENT FOR AUDIO RECORDING OF INTERVIEWS

"I certify that the interviewer/PI has explained to me the ethics regarding the recording of interviews and I agree for the interview to be audio-recorded. ***(Tick the appropriate box below)"***

Yes ☐ **No** ☐

…… Date: ……
(Signature of participant)

INVESTIGATOR STATEMENT AND SIGNATURE

"I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed".

Researcher's name……. Signature……

Date……

APPENDIX B

B: CONSENT FORM FOR PARENT/CAREGIVERS

Study Title: Management and Control of Childhood Tuberculosis in Ghana

PARTICIPANT STATEMENT AND SIGNATURE

"I acknowledge that I have read or have had the purpose and contents of the Participants' Information Sheet read and that all questions have been satisfactorily explained to me in a language I understand (English □ / Twi □ / Ewe □). I fully understand the contents and any potential implications as well as my right to change my mind (i.e. withdraw from the research) even after I have signed this form".

I voluntarily agree to be part of this research.

Name or Initials of Participant…….. ID Code ……

Participants' Signature ……. OR Thumb Print……

Date: ……

INTERPRETERS' STATEMENT

"I interpreted the purpose and contents of the Participants' Information Sheet to the afore named participant to the best of my ability in the (Twi □ / Ewe □) language to his/her proper understanding".

"All questions, appropriate clarifications sort by the participant and answers were also duly interpreted to his/her satisfaction".

Name of Interpreter……

Signature of Interpreter……. Date:……

Contact Address……

Mobile:…….

STATEMENT OF WITNESS

"I was present when the purpose and contents of the Participant Information Sheet were read and explained satisfactorily to the participant in the language he/she understood (English □ /Twi □ / Ewe □)".

"I confirm that he/she was given the opportunity to ask questions/seek clarifications and the same were duly answered to his/her satisfaction before voluntarily agreeing to be part of the research".

Name: …….

Signature…… OR Thumb Print …….....

Date: ……

CONSENT FOR AUDIO RECORDING OF INTERVIEWS

"I certify that the interviewer/PI has explained to me the ethics regarding the recording of interviews and I agree for the interview to be audio-recorded. ***(Tick the appropriate box below)"***

Yes ☐ **No** ☐

…… Date:…….
(Signature or Thumb Print of participant)

INVESTIGATOR STATEMENT AND SIGNATURE

"I certify that the participant has been given ample time to read and learn about the study. All questions and clarifications raised by the participant have been addressed".

Researcher's name…….Signature……

Date……

APPENDIX C

C: In-Depth Interview Guide for Childhood TB Service Providers

UNIVERSITY OF CAPE COAST
COLLEGE OF HUMANITIES AND LEGAL STUDIES
FACULTY OF SOCIAL SCIENCES
DEPARTMENT OF POPULATION AND HEALTH

In-Depth Interview Guide for Childhood TB Service Providers

A. BACKGROUND INFORMATION

- Sex
- Age.....
- Type of facility: 1= Regional hospital 2= District Hospital 3= Polyclinic 4= Clinic 5= Other [specify].....
- Programme affiliation.....
- Current Position.....
- How many years altogether have you been working in your current position?
- Have you ever had any in-service training, seminar or workshop on childhood TB management? **Probe:** When was the last time? What were the issues covered? Was the training relevant? How relevant?

B. Management of Childhood TB

Preamble: I will like us to talk about childhood TB. By this, I mean TB among persons between ages 0-14 years.

1. Can you please tell me about the frequency of childhood TB in this facility?
   - Who are the children that usually get infected with TB? Probe for details, including parents' characteristics. How easy or difficult is it for you to diagnose children with TB?
2. I will like you to tell me about how you manage and control childhood TB in this facility.

- Probe for diagnosis procedure, intensified case finding, community engagement/participation for case finding and surveillance.
- *Probe but don't prompt for* ***adult/child contact tracing*** *after childhood TB has been diagnosed.*

3. What can you say about the importance of contact tracing in childhood TB management?
   - Describe to me how you carry out contact tracing/management for children with TB.
   - Tell me about some of the challenges that you face in contact tracing for childhood TB.
   - How can these challenges be addressed to ensure effective and efficient contact tracing?
4. What are the guidelines for delivering services for children with TB, with and without HIV co-infection?
   - Probe: Specific roles by NACP and NTP official/facility coordinators and other service providers in terms of diagnosis, initiation of the treatment regimen, and, follow-up on clients.
   - Describe to me the kind of working relationship between TB clinics and HIV clinics **(Ask in relation to the team members in case of full integration model and *relationship between the paediatric unit*).**

   Probe: - What good things can you say about the two units?
   - What are some of the things you don't like about how they work?
5. What can you say about the relevance/importance of providing TB services for children taking into account HIV?
   - Probe but don't prompt! E.g.: Early initiation of treatment for both infections.
6. Tell me about your experiences with service delivery for children with TB. ***Probe:***

- *Understanding/Comprehensibility*: What is your understanding of childhood TB and the recommended treatment regimen?

- *Meaningfulness*: Tell me about your motivation for getting involved in childhood TB management and ensuring that mothers adhere to the treatment regimen for their children.
- *Manageability*: What resources do/did you have to help you deliver childhood TB services and also help caregivers to adhere to the treatment regimen? (Resources include; support from hospital authorities, **support from NTP**, enabler's package, etc).

C: Challenges faced in the management of Childhood TB

7. Recount to me some of the challenges you face in your day-to-day management and control of childhood TB. ***Probe for***
   - Challenges relating to diagnosis, Recommendation of the appropriate treatment regimen, Adherence to the treatment regimen and or loss to follow-up.
8. Tell me about some of your current pressing needs in this facility regarding childhood TB management and control.
   - Why are these most pressing needs?
9. What are some of the barriers to providing childhood TB services taking into account HIV in this facility? Probe for what makes each an issue of concern; e.g.: Recordkeeping, Inadequate staff, limited capacity (infrastructure) of the facility to provide integrated service, nosocomial infection, funding, and role conflicts between NACP and NTP officials.
10. In your view, how do these barriers affect or hinder service delivery?
11. How can these barriers be overcome?

D: Integration of Childhood TB management into Child Welfare Clinic (CWCs)/ Maternal and Child Health (MCH) care?

12. Can you please tell me how the CWC/MCH operates in this facility?
    - Probe for detailed accounts

13. There is currently a call for service integration (horizontal healthcare delivery). It has been suggested that childhood TB management should be integrated with the CWCs. What is your view about this call? ***Ask for reasons for the views expressed***

14. What is your view about the available resources (personnel, organizational structure, facility, and other resources) of this facility to integrate childhood TB management into CWC/MCH care?

15. What is your general assessment of childhood TB and HIV service delivery in this facility?

    - What are some of the benefits associated with how you provide Childhood TB and HIV services? **(Benefits to both services providers and caregivers**)

    - Can you tell me about some of the challenges you face in the way you provide childhood TB and HIV services?

    - What can you say about how *satisfied* or *unsatisfied* your clients are in accessing care under your way of service delivery? Probe for reasons.

16. If you were put in authority, how would you want childhood TB and HIV services delivered in this facility or country?

    - (Try to tease out the ***integration*** of childhood TB services into CWCs/MCH and ***decentralization*** into the primary/community healthcare system)

    - [***Probe:*** *viability, appropriateness and perceived benefits*]

17. What is your preferred model (strategy) of childhood TB management?

    - Reasons for the preferred model of integration.

E: Towards improving the management of Childhood TB in Ghana

18. Childhood TB has been considered a neglected aspect of the global fight against TB, especially in resource-limited like Ghana. In your opinion, what do you think can be done to ensure that childhood TB remains firmly on the health agenda?
    - Probe the role of government, GHS, donor partners, and NTP at the facility level.
19. We know that WHO and other organizations concerned about health are now talking more about paying attention to childhood (e.g. enhanced means of diagnosis, safe and improved treatment regimen, treatment adherence etc). What is your opinion about this current call for attention to childhood TB?
20. In your opinion, how can we reach, detect and treat the majority of children with undiagnosed TB cases? ***Ask in relation to:***
    - National level interventions
    - Community-level interventions
    - Facility-level interventions (Try to probe for contact tracing for adults diagnosed with TB who has been in contact with children)
21. Loss to follow-up during treatment has been identified as a major challenge in the fight against childhood TB in Ghana. In your opinion, how can we ensure that children who are on treatment are not lost to follow-up (adherence to the regimen)?
22. Childhood TB is considered a neglected aspect in the fight against TB. In your view, what can be done to improve the management of childhood TB in your facility specifically and Ghana as a whole?
23. Do you have anything else to say generally about childhood TB and HIV management and the way forward in Ghana?

Thanks for your time and cooperation.

APPENDIX D

D: In-Depth Interview Guide for Parents/Caregivers for childhood TB

UNIVERSITY OF CAPE COAST
COLLEGE OF HUMANITIES AND LEGAL STUDIES
FACULTY OF SOCIAL SCIENCES
DEPARTMENT OF POPULATION AND HEALTH

In-Depth Interview Guide for Parents/Caregivers for childhood TB

A. BACKGROUND INFORMATION

Parent/Caregivers background characteristics

- Sex
- Age.....
- Highest Level of Education attained.....
- Religion.....
- Occupation.....
- Marital status

Child's background characteristics

- Sex of the child……
- Age…….
- Level of education…….
- How long has the child been on the TB treatment?
- Is the child co-infected with HIV?

B. Experiences with childhood TB treatment regimen:

Clinical/healthcare context

1. Can you please recount to me how your child's condition was diagnosed?
    - Probe for recognition of signs and symptoms – who did; how long it took for the confirmation of diagnosis.
    - Where was the child diagnosed?

- How easy/difficult was the diagnostic procedure?

2. How long did it take from when the child was diagnosed with TB to being placed on treatment?
3. How will you describe your experience with the adherence counselling session for the treatment regimen for your child? – How did it help you?
4. What is your assessment of the treatment regimen experience so far? From the start of the treatment regimen until now. *Probe for details!*
    - *Understanding/Comprehensibility*: Did/Do you understand your child's condition (childhood TB) and the recommended treatment regimen?
    - *Meaningfulness*: Tell me about your motivation for helping the child adhere or not with the treatment regimen.
    - *Manageability*: What resources do/did you have to help you cope, manage, and adhere to the treatment regimen? (Resources include; social support, access to a health facility, finance, enabler's package, health insurance etc).
5. What do you think the outcome of the treatment will be?
    - Why do you say so? (*Encourage the participant to provide a detailed account*).
6. It has been suggested that childhood TB management should be integrated with the CWCs/MCH, Paediatric care. What is your view

about this call? ***Ask for reasons for the views expressed***. Probe for, if not already mentioned!

- **Acceptability,** and **Viability** based on the current service delivery model or system.

C: Disclosure and Community Experiences

7. Have you disclosed your child's TB status to your family? *Probe for detailed accounts of events*
   - What about disclosure to others/neighbours within your community?
   - Probe for why. If the status is not disclosed, ask if the caregiver will be willing to disclose the child's status or will like to keep it secret. *Probe for reasons*.
8. What is the community's perception of a child with TB? ***Probe for details***
   - Misconceptions regarding childhood TB
9. Have you noticed any changes in attitude towards you and or your child since the disclosure of TB status? Probe for a detailed account of the participant's experience.
   - Do you feel stigmatized and discriminated against?

D: Household burden of TB, household finances, and impact of child's TB on the household

10. Apart from your child, does anyone else (child or adult) have TB in your household?

- If yes, have they gone through the treatment regimen or currently undergoing the treatment?
- – Probe for the relationship of the infected adult with the child.
- If treatment was completed, what was the outcome of the treatment?

11. How will you describe the result of TB treatment of your child on your finances?
    – Probe if the parent/caregiver was made to pay for the treatment and services.
    - Probe for effects on earnings; effects on savings; sale of properties etc.
    - What effect does your travelling cost for the treatment have on your finances?
12. How will you describe the financial support that you received for your child's TB treatment?
13. What psychological effect do your child's TB diagnosis and subsequent treatment have had on you? – What about the child? Probe for *how* and *why*.
14. Describe for me the social effects that your child's TB diagnosis and treatment had on you. – Probe: reduced involvement in social/community-based activities e.g. church/mosque/market – ***ASK FOR REASONS***.
15. What can you say about the child too? Probe for: school, church, & outdoors play etc.
    - Is this based on medical advice or personal decisions?

Thanks so much for your time!

APPENDIX E

E: ETHICAL CLEARANCE

GHANA HEALTH SERVICE ETHICS REVIEW COMMITTEE

In case of reply the number and date of this Letter should be quoted.

MyRef. GHS/RDD/ERC/Admin/App/19/299
Your Ref. No.

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9th July, 2019

Prince Justin Anku
University of Cape Coast
PMB, University Post Office
Cape Coast

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

GHS-ERC Number	**GHS-ERC 006/05/19**
Project Title	Management and Control of Childhood Tuberculosis in Ghana
Approval Date	9th July, 2019
Expiry Date	8th July, 2020
GHS-ERC Decision	**Approved**

This approval requires the following from the Principal Investigator

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 12 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing.
- Submission of a final report after completion of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.
- Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED.....
DR. CYNTHIA BANNERMAN
(GHS-ERC CHAIRPERSON)

Cc: The Director, Research & Development Division, Ghana Health Service, Accra

APPENDIX F

F: Word cloud for current management and control of childhood TB

Nvivo word cloud for the exploration of current management and control of childhood TB in the selected facilities. Chapter 5. This was concerning objective 1. Codes were developed based on the most frequently used words:

Tb; treatment, children, HIV, contact tracing, difficult, management, start, sputum, diagnosis/diagnose etc.

APPENDIX G

G: Word clouds for challenges faced by service providers

Nvivo word cloud to examine the challenges faced by the service providers in the management and control of childhood TB. Chapter 6. This was geared towards objective 2. Codes were developed based on the most frequently used words. Word trees were used to match the context in which the words were used. Dominant words include; TB, come, treatment, funding, drug, childhood, challenges/challenge, diagnosis, regimen, infrastructure, medication adherence etc.

APPENDIX H

H: Word cloud for integration of childhood TB into CWC

Nvivo word cloud to explore the perspective of service providers on the integration of childhood TB management into child welfare clinics (CWCs) – Chapter 7. Frequently used words around which themes were developed include TB, HIV, childhood, facility, integration, CWC, services, management, community, benefits, resources, screen, drugs, delivery etc. Trees were developed for the various words and mapping was done to assess the contexts of usage.

APPENDIX I

I: Word clouds for ways to improve childhood TB management

Nvivo word cloud to explore the views of service providers on ways to improve the management of childhood TB in Ghana; - Chapter 8. Words that appeared frequently include TB, childhood, children, treatment, community, management, tracing, screening, cases, follow, education, support, training, diagnosis, and government. Trees were developed to assess contextual issues based on the words.

APPENDIX J

J: Word clouds for healthcare-seeking and psychosocial contexts

Word clouds for investigating how primary caregivers follow the treatment regimen for children with TB (healthcare-seeking and psychosocial contexts). Chapter 9; Objective 5. Aside from child, treatment, and TB which were dominant in the data, critical words include; finances, household, money, school, diagnosis, effect, psychological, support, church, earnings, travelling, etc. Tress were developed for each of these words and their contexts of usage were assessed. Codes were developed from the word trees.