Navigating Asthma—The Immigrant Child in a Tug-of-War: A Constructivist Grounded Theory

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Indu Sudarsan

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Abstract

Indians constitute the second-largest immigrant group in New Zealand. Asthma symptoms are often underestimated among Indian immigrants in New Zealand and other Western countries, resulting in increased morbidity and avoidable hospitalisations. Indian immigrant children's asthma has received little attention in the literature. Furthermore, research rarely includes children's voices, despite Article 12 of the *United Nations Convention on the Rights of the Child*, which guarantees their freedom of expression. The current study addresses these gaps by exploring the asthma experiences of Indian immigrant children and their family caregivers.

I adopted a constructivist grounded theory design, with social constructionism as its theoretical framework. Children (8–17 years of age) and their family carers were recruited through general practices, schools, and various Indian cultural associations in the Greater Wellington region. Intensive, semi-structured interviews were conducted with participants in a setting of their choice. The interviewing of children under 14 years of age was facilitated by drawing and photography. Concurrent data collection and analysis took place, accompanied by memoing.

“Navigating asthma—The immigrant child in a tug-of-war” was the resultant grounded theory, in which the tug-of-war was the basic social process. Two types of tug-of-war were observed: one between the Indian and New Zealand cultures, and another between children’s and their family carers’ preferences. The three major categories in this theory, which corresponded to the three phases of the child's asthma journey, included *being fearful, seeking support, and clashing cultures*. These phases followed a cyclic pattern. During their asthma battle, participants often reflected on their own experiences and modified their plans as they learnt more from their own lives and social networks. This helped them cope with varying levels of fear in different situations.

The theory explains the complex interaction of multiple influences, such as sociocultural factors and acculturation, which may determine the participants' shared values, beliefs, and priorities. Importantly, the study reveals numerous tensions regarding children's participation in their asthma-care decision-making. The study results add to scholarly knowledge by providing a comprehensive picture of Indian immigrant children's asthma and highlighting the barriers and facilitators for providing culturally safe healthcare to this group.

Publications and Presentations

Publications

Sudarsan, I., Hoare, K., Sheridan, N., & Roberts, J. (2022). Positioning the researcher for studying Indian immigrant children's asthma in New Zealand: A reflective account. *Qualitative Research Journal*, *22*(3), 378–390. https://doi.org/10.1108/qrj-08-2021-0091

Sudarsan, I., Hoare, K., Sheridan, N., & Roberts, J. (2022). South Asian immigrants' and their family carers' beliefs, practices, and experiences of childhood long-term conditions: An integrative review. *Journal of Advanced Nursing*, *78*(7), 1897–1908. https://doi.org/10.1111/jan.15217

Sudarsan, I., Hoare, K., Sheridan, N., & Roberts, J. (2022). Giving voice to children in research: The power of child-centered constructivist grounded theory methodology. *Research in Nursing & Health*, *45*(4), 488–497. https://doi.org/10.1002/nur.22231

Sudarsan, I., Hoare, K., Sheridan, N., & Roberts, J. (2022). Navigating asthma—The immigrant child in a tug-of-war: A constructivist grounded theory. *Journal of Clinical Nursing*. [Online ahead of print]. https:// doi: 10.1111/jocn.16521

Conference Proceedings

Sudarsan, I. (2022, June 7–9). *Navigating asthma—The immigrant child in a tug-of-war* [Paper presentation]. Health Workforce Academy Virtual Conference 2022, Central Queensland University, Brisbane, Queensland, Australia.

Sudarsan, I. (2022, September 15–16). *Navigating asthma—The immigrant child in a tug-of-war: A constructivist grounded theory* [Paper presentation]. International Grounded Theory Alliance Virtual Conference 2022, University of Sheffield, South Yorkshire, United Kingdom. https://groundedtheoryconference.com/wp-content/uploads/2022/09/Recalibrating-society-IGTA-Conference-2022-Abstract-Booklet.pdf

Presentations

Sudarsan, I. (2022, September 28). *Navigating asthma—The Indian immigrant child in a tug-of-war* [Oral presentation]. Massey University Doctoral School 2022, Massey University, Palmerston North, New Zealand.

Sudarsan, I. (2021, June 26). *Indian immigrant children's and their family carers' beliefs, practices, and experiences on asthma: A constructivist grounded theory study* [Oral presentation]. Massey University Doctoral School 2021, Massey University, Palmerston North, New Zealand.

Sudarsan, I. (2022, August 23). *Navigating asthma: The Indian immigrant child in a tug-of-war* [Oral presentation]. Massey University 3 MT Thesis Competition, Massey University, Wellington, New Zealand.

Preface to the Thesis Structure

This thesis follows a *PhD with publications* format, consisting of chapters with and without published articles. Chapters 1 to 5 include four research articles that are published in peer-reviewed journals. The thesis is presented as a coherent whole; publications included in the thesis are integrated through the effective use of linking passages. The thesis has been edited to eliminate unnecessary repetition. However, repetition was sometimes necessary to ensure logical flow or to adhere to journal guidelines. Most journals, for example, require an ethical approval statement as well as a description of the research context.

I have presented the journal articles in the same format as the remainder of the thesis, but they may differ slightly from how they appear in the published version. For example, I have numbered pages, figures, and tables consecutively, followed APA referencing style throughout the thesis for consistency, and listed all the references at the end of the thesis. I have formatted my thesis according to APA guidelines. Despite this, APA formatting rules are not adhered to in some areas to ensure consistency. Some participant quotations, for instance, are written in a different format based on the journal article formatting pattern, as converting these quotations to APA format would necessitate substantial alterations to the published journal article. In the appendices, I have included all the relevant supplementary documentation from the journal articles.

I have written this thesis in the first person, from my own viewpoint, for clarity and self-reference. This decision recognises my role as an insider researcher with personal experience in the research area. It also acknowledges the philosophical paradigm I have employed, i.e., social constructionism.

Dedication

A loving tribute to my late father, Mr. Sudarsan. S (1958–2022)

Acknowledgements

My first and foremost gratitude extends out to my parents (Sudarsan and Uma Devi), husband (Vipin Raj), and children (Krithika, Kaniha, and Krish), who have been by my side every day, supporting me as I followed this calling, and holding space for me when it all seemed too challenging. Next, I am immensely grateful to my supervisors. You granted me the autonomy to conduct the study while providing appropriate guidance and direction as needed. To my primary supervisor, Prof. Karen Hoare, I thank you for believing in my potential. It was your tireless enthusiasm and timely feedback that enabled me to succeed throughout my study. Your knowledge of grounded theory methodology is invaluable, and I appreciate the opportunity to learn from your expertise at our meetings. To my impeccable adviser, Prof. Nicolette Sheridan, it was your unwavering guidance that helped me begin my doctoral study. Thank you for your ongoing mentoring, support, and leadership. Also, I would like to acknowledge DR. Jennifer Roberts, who stepped in midway through my PhD journey to provide me with additional support since the COVID-19 pandemic. Your guidance and advice were instrumental in enabling me to cross the finish line.

Many other people contributed to the conduct of this PhD study. Most importantly, a huge thank you to all the participants in this study who generously shared their knowledge, experience, and wisdom with me. To my dear peer PhD scholars, DR. Shilpa Saseendran Nair (also my sister-in-law), Jayakrishnan Sreekumar, and Amy Sarah, thank you for always listening to me and reaffirming my strengths. Thank you, Dr. Hari Sudarsan, for being more than my brother by inspiring me to achieve excellence in all my endeavours. Also, I would like to extend my appreciation to my beloved sister-in-law (Arathy Vimal) and brothers-in-law (Prem Raj and Vimal Raj), and all other friends for always being there for me and bringing joy into my life. Finally, I owe my deepest gratitude to Massey University for providing me with a doctoral scholarship during my studies.

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Key Terminologies and Operational Definitions

Indians: For the purposes of this study, Indians refer to *Asian Indians*, i.e., people from the country of India. This does not include people of Indian descent whose ancestors migrated to Fiji, South Africa, or any other parts of the world. Though they may share some similarities in language, religion, and diet, their experiences and cultures are different from the present-day cultures of Indian ethnic minorities (Ramesh, 2017).

Immigrant: The terms *immigrant* and *migrant* are frequently used synonymously (Anderson & Blinder, 2019). According to the Oxford University Press (2022), immigrants are people who intend to settle permanently in their new country, while migrants are people who move from one place to another temporarily in search of better employment or living conditions. Furthermore, the term migrant is occasionally used by some scholars to refer to people who relocate within their own country. The term immigrant, rather than migrant, is used in this study to refer to non-nationals who moved to New Zealand for permanent settlement (Gimeno-Feliu et al., 2019).

Children: The United Nations Convention on the Rights of the Child (UNCRC) defines a child as anyone under 18 years of age (United Nations Children’s Emergency Fund [UNICEF], 1989). In this thesis, *children* refer to children (8–17 years old) with a diagnosis of asthma. They include both first-generation immigrant children (those who immigrated from India) as well as second-generation immigrant children (children who were born in New Zealand and who identify with their ethnic heritage as Indians).

Family carer: In this study, a *family carer* is defined as the family member who mostly manages the day-to-day care of the child, more frequently accompanies the child to inpatient hospitalisations and clinic appointments, and therefore, may have higher levels of direct exposure to potentially stressful illness events and experiences, higher levels of distress, and greater caregiver burden (Fedele et al., 2014). All family carers who participated in this study were the parents of the participant children.

List of Abbreviations

AAM	Author Accepted Manuscript
ACC	Accident Compensation Committee
ACT	Asthma Control Test
AIR	Anti-Inflammatory Reliever
BA-pMDI	Breath actuated-pressurised Metered Dose Inhaler
BSP	Basic Social Process
CALD	Culturally and Linguistically Diverse
CAM	Complementary and Alternative Medicine
CHC	Community Health Centre
CFCC	Child and Family Centred Care
CGT	Constructivist Grounded Theory
COREQ	Consolidated Criteria for Reporting Qualitative Research
CYP	Children and Young Person
DA	Dimensional Analysis
DALY	Disability Adjusted Life Years
DHB	District Health Board
DPI	Dry Powder Inhaler
ED	Emergency Department
EM	Explanatory Model
GAN	Global Asthma Network
GINA	Global Initiative for Asthma Network
GP	General Practitioner
GT	Grounded Theory
HCP	Healthcare Professional

HrQOL	Health related Quality of Life
ICS	Inhaled Corticosteroid
IPA	Interpretive Phenomenological Analysis
IS	Indu Sudarsan
JAN	Journal of Advanced Nursing
JCN	Journal of Clinical Nursing
JR	Jennifer Roberts
KH	Karen Hoare
LABA	Long-Acting Inhaled β2- Agonist
LTC	Long Term Condition
MBIE	Ministry of Business, Innovation and Employment
MOH	Ministry of Health
MSN	Medical Surgical Nursing
NCNZ	Nursing Council of New Zealand
NP	Nurse Practitioner
NS	Nicolette Sheridan
NZ	New Zealand
PAH	Potentially Avoidable Hospitalisation
PHC	Primary Health Centre
pMDI	pressurised-Metered Dose Inhalers
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
QRJ	Qualitative Research Journal
RINAH	Research in Nursing and Health
RN	Registered Nurse
SA	South Asian

SABA	Short-Acting Inhaled β2- Agonist
SI	Symbolic Interactionism
SMART	Single Maintenance and Reliever Therapy
SMI	Soft Mist Inhaler
TOW	Treaty of Waitangi
UK	United Kingdom
UNCRC	United Nation Convention on the Rights of the Child
UNICEF	United Nations International Children’s Emergency Fund
USA	United States of America
WHO	World Health Organisation

Chapter 1–The Beginning and Before

Not I, some child, born in a marvellous year,
Will learn the trick of standing upright here

—*Allen Curnow*

DeSouza (2004) interprets the above passage from Allen Curnow's poem as a metaphor for the struggles experienced by Indian immigrants in adapting to change, whether as members of the host society or immigrants. The “trick of standing upright here” involves balancing the native and host cultures successfully.

Few studies have articulated Indian immigrant children’s and their family carers’ beliefs, practices, and experiences regarding asthma. This study utilised a *constructivist grounded theory* (CGT) approach to explain the adaptation process of Indian immigrant children and their family carers in managing their children’s asthma in New Zealand (NZ). I begin this chapter by describing my background and providing a brief overview of the events that led to my decision to pursue a PhD. In the section that follows, the research question and objectives are listed. Next, I present a journal article published in the *Qualitative Research Journal* (QRJ), in which I discuss my philosophical position in relation to this study and introduce the impetus for choosing the study topic. Furthermore, this chapter provides an overview of the context, illustrating the significance of the study. This is followed by a brief note on the study’s theoretical framework of *social constructionism*. Finally, the chapter concludes by highlighting the impact of the COVID-19 pandemic on the study and outlining the synopsis of the thesis.

My PhD Journey

How did I Become a Nurse?

I have largely adhered to my parents’ wishes in all facets of my life. This is not uncommon for children in India, where most parents expect their children to behave in accordance with their parents' wishes. Once I completed my secondary school education, I intended to pursue further studies in Chemistry and eventually become a Chemistry teacher. However, my parents wanted me to enrol in a medical school since the trend at that time was to become a doctor as a way to gain social status. Moreover, as my family has a strong medical background, I found myself compelled to follow in their footsteps, even though I had no desire to become a doctor. In Indian society, children are regarded as the key to enhancing family pride, and education serves as the most effective means of sustaining and advancing social class. Parents may feel ashamed if their children are unable to fulfil their academic expectations (Chandra et al., 2016).

Initially, my parents agreed to my request to not attend medical school. They were, however, forced to reconsider their decision due to pressure from my extended family members, including my uncles, aunts, and grandparents. As a result, my parents helped me secure a placement at one of the country's best medical-entrance exam-training centres, where students were prepared to get through the highly competitive exam required for admission to medical school. However, I did not commit fully to the training as I was not interested. In the end, I did not achieve the score required for admission to medical school. I was happy in my mind that I could fulfil my wish and go forward in the desired direction.

Against my expectations, my parents urged me to retake the exam since I scored just below the required score to be considered for admission to medical school. Nevertheless, I was qualified for admission to the nursing programme based on my scores. Following the recommendations of my close family members, my parents strongly encouraged me to pursue nursing as a profession, as there is a greater possibility of obtaining employment anywhere in the world. While I did not know what nursing was about, I went into nursing with the goal of never having to take the medical entrance exam again.

Before enrolling in nursing school, I was the kind of person who was unable to tolerate other people's distress or suffering. Still, I am the same person to some extent, except for a minor change in my attitude brought about by the nursing profession. I found it extremely difficult to deal with the emotional impact of seeing people in distress. My first clinical placement was in the neurosurgical ward, where we were trained in caregiving. It took me a while to overcome compassion fatigue. At that point, I even thought of quitting the course. Meanwhile, I enjoyed acute nursing, where patients are expected to recover or improve within a short period. Having a great desire to work with children, I realised that paediatric nursing was my area of interest. Above all, I was fascinated by the what, how, and why of nursing. My primary interests were teaching patients and taking part in clinical presentations. I was praised for my presentation skills, which motivated me to undertake part-time tutoring jobs during my nursing studies.

At the end of the course, I was assigned to work in an intensive care unit as a part of the mandatory one-year internship. Since I could not deal with the ongoing compassion fatigue, I quit the internship. To fulfil my ambition to become a paediatric nurse, I applied for a voluntary position as an intern at a hospital near my house. Eventually, I was hired and worked in the paediatric ward for a year. After one year, I decided to follow my dream of becoming a teacher. I enrolled in the Masters programme to achieve this goal.

For my Masters programme, I decided to specialise in *Child Health Nursing*. The Indian post-graduate nursing programme offers five specialisations: *Medical-Surgical Nursing* (MSN), *Child Health Nursing, Obstetric* and *Gynecological Nursing, Psychiatry Nursing*, and *Community health nursing*. Nonetheless, I was forced to follow the advice of my parents and other family members to obtain a specialisation in MSN, since my parents believed that MSN offered greater employment opportunities than child health nursing. Thus, I gave up my dream of getting a teaching job in child health nursing and completed my

Masters in MSN with a sub-specialisation in *Oncology Nursing*. Oncology nursing was a field in which I did not want to specialise because of the compassion fatigue involved. However, I did not have any other choice, as oncology nursing was the only sub-specialisation offered by my college.

PhD–A pathway to my dream of becoming an academic

When I immigrated to NZ, my dream to pursue a career in academia was lost. Despite their extensive training and experience overseas, many newly immigrated professionals find themselves unemployed in NZ because their overseas qualifications or experiences are not recognised. Consequently, their hopes for a better life are shattered. I was in a similar situation. Despite my postgraduate degree in nursing, I did not possess enough clinical experience to be registered with the Nursing Council of New Zealand (NCNZ). I became deeply depressed, but I was reluctant to express my feelings to others for fear of further humiliation. To obtain my NCNZ registration, I had to redo the graduation course.

After gaining registration, I was keen to enter academia based on my overseas post-graduate qualification. However, many of my colleague migrant nurses discouraged me, saying that overseas post-graduate qualifications would not be recognised in NZ and that I would need to retake the Masters papers. My sister-in-law, who was doing her PhD in Molecular Medicine at the University of Auckland at that time, motivated me to pursue a PhD as a pathway to enter academia. Although getting a PhD was one of my dreams, it was not my short-term goal. At the same time, my sister-in-law warned me about the challenges involved in undertaking a PhD. In general, a PhD requires three to six years of study, depending on whether it is pursued part-time or full-time. In this time frame, people's circumstances may change, and it may be difficult to balance PhD study with family life, careers, and life events. Additionally, a PhD may present financial challenges, particularly if the study is self-funded.

Despite all of this, I was still determined to apply for a PhD, and I waited for my residency to be approved.

Meanwhile, I started working as an aged-care registered nurse (RN) as it was the easiest pathway to get NZ residency. I initially felt frustrated and disappointed by my inability to practise in academia. I applied for my Masters degree to be assessed against NZ standards with the NZ Qualification Authority as a trial step, believing that this would make a difference while employers consider my applications. I kept applying for academic jobs despite repeated rejections. Eventually, I came to realise that if I were to progress further in academia, I would have to pursue a PhD. Furthermore, I wanted to show others that the training I had while I was in India could be expanded on. I began applying for a PhD once I received my residency. Although I did not have a clue how I would manage full-time studies, two children, and the enormous costs associated with completing a PhD, I was determined. I did not intend to do the programme part-time as I wanted to see the outcome as soon as possible, even though part-time was the most realistic choice for me. I self-funded my studies for the first year, after which I was awarded a three-year doctoral scholarship.

An integral part of the PhD application was the preparation of a research proposal based on my previous research experience. As my Masters project was focused on the effectiveness of electric scalp cooling caps on chemotherapy-induced alopecia, I prepared a research proposal based on this topic. I cannot adequately express how excited and happy I was when I received my PhD offer letter. A few days later, after accepting the offer letter, Prof. Nicolette Sheridan, one of my PhD supervisors, contacted me to discuss my research background and areas of interest. Since I was working as an aged-care nurse at that time, we planned to choose a topic in the aged-care field. I initially decided to look into Indian immigrants' palliative care experiences in aged-care residential settings. As I assumed that I would not be able to work on a project outside of my current field of employment, I did not disclose my passion for paediatric nursing to Prof. Nicolette. Moreover, I expected that it would not be acknowledged given that I was employed in aged-care. A co-supervisor was assigned to me, with whom I met to discuss and confirm the study topic. However, she resigned from the university, and Prof. Karen Hoare was assigned to me as my supervisor in her place.

As Nicolette talked about Karen's expertise in child health, I unknowingly revealed my interest in this area and how I had been unable to pursue it previously. I still recall Nicolette's words:

> I also agree with you. If you are passionate about child health, take up a topic related to child health. With two young children, and being in your late twenties, this is a better option for you than engaging with topics such as end-of-life care, where you can become emotionally exhausted. (N. Sheridan, personal communication, November 4, 2018)

Nicolette supported me in changing the topic to my area of interest, and she assigned Prof. Karen as my primary supervisor. For the first time in my academic life, I felt allowed to follow my true passion. Since I was seeking a career in academia, Prof. Nicolette suggested that I do a PhD with publications.

My Profession

While undertaking my PhD, which was a full-time endeavour, I worked part-time as an aged-care RN. At the beginning of my PhD, I attempted to secure jobs as a nursing tutor or as a paediatric RN. As I had restrictions regarding the number of hours I could work because of the doctoral scholarship, I was not able to commit to either of these jobs as they required more hours than I had been allowed. Therefore, I worked as an aged-care RN while pursuing my PhD.

My Research Background

My passion for research comes mainly from the professor who taught a research paper in my Masters programme. I am a relatively novice qualitative researcher. Before enrolling in the PhD program, my background was in quantitative research. Moreover, I did not have any extensive quantitative research experience; my only research experience was my Masters project. After completing a quantitative project for my Masters programme, I wished to engage in qualitative research to explore more about qualitative studies. I was interested in Interpretive Phenomenological Analysis (IPA), and therefore, I chose IPA as the research methodology for my initial PhD proposal. During my meeting with Prof. Karen, she explained the Grounded Theory (GT) methodology, which I had briefly learnt about during my Masters. At that time, I wondered who would use this methodology and invest time in developing a theory, as GT methods seemed too complex to me. Prof. Karen's knowledge and expertise in GT inspired me. She guided me to read seminal works on GT. With the encouragement of Prof. Karen, I decided that I would use GT methodology for my PhD study.

The current study topic of Indian immigrant children's asthma was drawn from my experience as a paediatric nurse and my desire to improve the health of these children.

Research Question and Objectives

The research question that guided the study was: “What are the beliefs, practices, and experiences of Indian immigrant children and their family carers around living with asthma in NZ?”

The central objective of this study was to explore the beliefs, practices, and experiences of asthma among Indian immigrant children and their family carers and develop a theoretical model to explain it.

The specific objectives of this study were to:

- explore Indian immigrant children’s thoughts, feelings, and experiences of living with asthma.
- uncover Indian immigrant children’s perceptions of barriers and facilitators to effective asthma management.
- examine family carers’ beliefs, practices, and experiences of asthma.
- discover and explore issues surrounding the provision of culturally competent care to Indian immigrant children with asthma and recommend how nursing can contribute to better care.
- construct a middle-range, substantive theory that is grounded in the experiences of children with asthma and their families.

Philosophical Position

My philosophical position in relation to the study topic is presented in the form of a journal article published in QRJ, which has an impact factor of 0.87 (2022). This article is made open access via ‘green’ route system. This means that Emerald publishers has removed the embargo period across all journals for the self-archiving of the Author Accepted Manuscript (AAM). The article is the AAM version deposited under the Creative Commons Attribution Non-commercial International Licence 4.0 (CC BY-NC 4.0).

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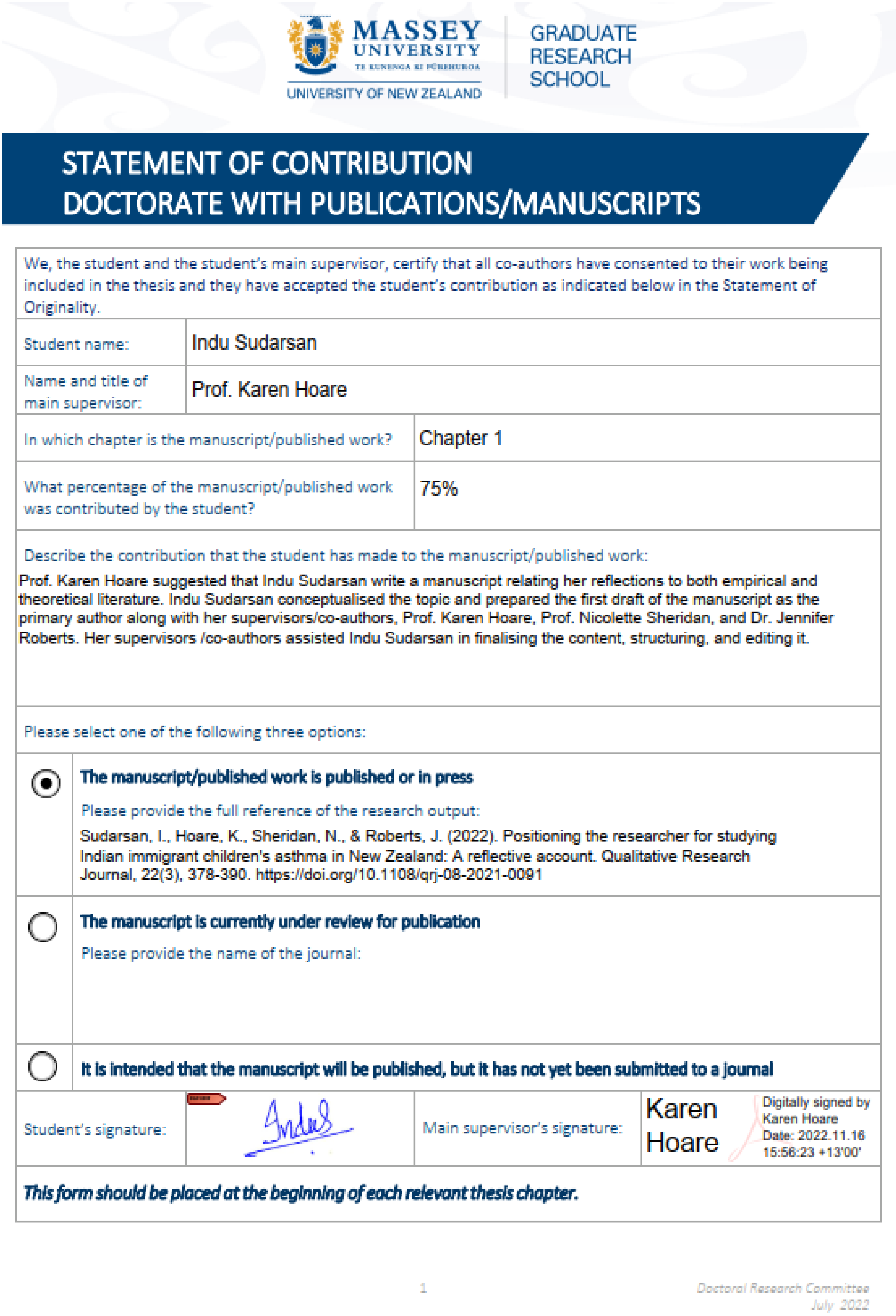

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Student name:	Indu Sudarsan
Name and title of main supervisor:	Prof. Karen Hoare
In which chapter is the manuscript/published work?	Chapter 1
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Describe the contribution that the student has made to the manuscript/published work:

Prof. Karen Hoare suggested that Indu Sudarsan write a manuscript relating her reflections to both empirical and theoretical literature. Indu Sudarsan conceptualised the topic and prepared the first draft of the manuscript as the primary author along with her supervisors/co-authors, Prof. Karen Hoare, Prof. Nicolette Sheridan, and Dr. Jennifer Roberts. Her supervisors /co-authors assisted Indu Sudarsan in finalising the content, structuring, and editing it.

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1

Doctoral Research Committee
July 2022

Article 1: Positioning the Researcher for Studying Indian Immigrant Children's Asthma in New Zealand: A Reflective Note

Abstract

Purpose: To explore the meanings of positionality and demonstrate how reflective memos can illustrate positionality in a CGT study.

Method: Acknowledging the positionality of the researcher through a reflective approach is an essential element of CGT studies. The first author (xx) used reflective memoing in her CGT study on Indian immigrant children's asthma to practise reflexivity and make her positionality explicit. Through memos, xx acknowledges her knowledge, beliefs, practices, experiences, and pre-existing assumptions about the research topic. This article is a compilation of the reflective memos that xx wrote during the initial phase of her research and draws on her motivations as they relate to the topic under study in the context of current literature.

Findings: The reflective accounts of a researcher's background and experience can act as a lens for understanding the research question and the choice of methodology.

Originality: This article provides practical guidance on how to outline positionality at the outset of a CGT study.

Implications: This article may be useful to novice qualitative researchers who are struggling to define and establish their own positionality. John Dewey's and David Schőn's works on reflective thinking serve as valuable tools to practise reflexivity. Philosophically underpinned reflections in the form of memos, employed from the outset and throughout the study, can enhance the study rigour by making research decisions transparent.

Keywords: positionality, reflexivity, grounded theory, constructivist, reflective, India, migrant, asthma, qualitative

Introduction

Positioning or positionality in research refers to how researchers identify themselves in relation to the study being undertaken and study participants (Pitard, 2017). It not only involves concepts such as age, gender, ethnicity, education, and social and political context but also philosophical views and assumptions accrued over a lifetime in the subconscious mind of the investigator. Thus, positioning in research involves an awareness of, and listening to our inner dialogues that enable our prior knowledge and experience to direct our present (Holmes, 2020; Pitard, 2017). This article is a reflective account of how the first author, an Indian immigrant and a NZ RN, positions herself within a doctoral study titled: *Indian immigrant children's and their family carers' beliefs, practices, and experiences of asthma in New Zealand.* This article is not structured to include every phase of the research process; rather, it aims to provide a snapshot of researcher positionality during the initial phase. Having a quantitative research background, the concept of positioning was relatively new to me (xx), and I was excited to put it down on paper as I started learning more about it. I also realised that the positionality of a researcher might change as the study progresses, which highlights the importance of documenting it from the outset (Holmes, 2020).

The passion for exploring Indian immigrants' health and well-being and my paediatric nursing background motivated me to choose my doctoral research topic. Nevertheless, I started to question myself: How will my prior knowledge, personal background, and experience influence the way I approach the study? How can I effectively make use of my knowledge and experience rather than treating it as bias or bracketing it? These questions influenced me to adopt a methodology that acknowledged my personal history and experience. At this stage of the research, I had already identified a relative ontological basis that gave way to a constructivist epistemology (Burr, 2015; Charmaz, 2014; Gergen, 2015).

As a result, I chose a CGT methodology that aligned with my world views, acknowledged my experience, and could address my research question (Charmaz, 2014).

Constructivist Grounded Theory: The Methodology of Choice

CGT involves active involvement of the researcher in the construction of the theory (an explanation of what is happening) from the data collected (Charmaz, 2014) unlike the original version of GT. In the original version, also known as classical GT, researchers adopt an objectivist and passive approach as they want to let data speak for itself (Glaser & Strauss, 1967). On the other hand, in CGT, the researcher actively engages with the participants whose existing knowledge and former experiences form the basis of how he or she attends to the research field (Charmaz, 2014). My decision to choose CGT was also influenced by my history and cultural background, which, I argue, contribute to a deeper understanding of data provided by the participants and institutions. Moreover, I believed that adopting an objective stance would restrict me from capturing the rich complexities of Indian immigrant children's and their family carers' asthma experiences (Charmaz, 2014).

Research Context

India is a major source of international immigrants (Azmat & Fujimoto, 2016; Khanna, 2020). NZ is an increasingly popular destination with Indian immigrants able to retain their values, beliefs, and practices, and establish cultural norms in the host country (Londhe, 2014; Nayar, 2011). Indian immigrants, by balancing parenting styles valued in India with parenting practices common in the host country, may develop a hybridising parental strategy (Arora et al., 2019; Londhe, 2014; Nayar, 2011). However, parenting may become challenging when a child develops a chronic condition, such as asthma, which is common among Indian immigrant children in NZ (Mehta, 2012; Scragg, 2016; Wong & Tsang, 2018). Indian immigrant parents may struggle to effectively manage their child's asthma as they navigate the differences in attitudes and practices. Cultural conflict may adversely affect the well-being of the child and the family (Arora et al., 2019; Nayar, 2011). While the role children play in the settlement of Indian immigrants is well documented, there has been no research to date specifically exploring the experiences of living with asthma by Indian immigrant children and their family carers in NZ (Nayar, 2011). The proposed study addresses this gap by exploring Indian immigrant children's experiences of asthma, alongside their family carers' views.

Positionality and Reflexivity in Constructivist Grounded Theory

CGT, the interpretivist version of GT, requires the researcher to be reflective throughout the research process to ensure the rigour of the study (Charmaz, 2014). Reflexivity refers to critical self-reflection of the researcher's inner self (Davis, 2020). Acknowledging the positionality of the researcher through a reflective approach has become an important aspect in the expanding field of qualitative research, and particularly in CGT (Davis, 2020; Pitard, 2017). Hesse-Biber (2006) encourages the researcher to ask the following questions to promote reflexivity:

> How does your own biography impact the research process; what shapes the questions you chose to study and your approach to studying them? How does the specific social, economic, and political context in which you reside impact the research process at all levels? (p. 129)

Researchers' personal, epistemological, and theoretical positions can influence how they develop the research question, design the study, analyse and interpret data, and present their study findings (Charmaz, 2014). Researchers and participants may come from the same or different social backgrounds, and their attributes and experiences may differ or be similar. As a result, CGT researchers must consider and document how their own social background, beliefs, values, opinions, and experiences impact what they observe and analyse (Hordge-Freeman, 2018). Unless researchers document their positionality, audiences may not fully comprehend the context in which a researcher conducted the study. Furthermore, communicating researchers' positionality enhances the study's credibility by increasing transparency in research decisions. However, there has been much debate about how to incorporate reflexivity into a specific study, and the writing approach used to demonstrate reflexivity is yet another source of intellectual tension (Davis, 2020; McGrath, 2021).

It is not uncommon for novice CGT researchers to face challenges in developing reflective tools, such as memos, journal entries, or field notes, because they may not know where to begin or what to include (Davis, 2020). Therefore, it is critical to publish unedited reflective accounts to guide novice CGT researchers towards effective reflexive writing practices. Nevertheless, publications often prefer authors to summarise the reflective processes involved in a study by highlighting excerpts from their reflective tools. There may be several factors contributing to this situation, including journal word restrictions and a perception that reflexive accounts are too subjective and are often regarded as personal documents written by the researcher primarily for their own references (McGrath, 2021).

CGT researchers demonstrate their positionality through a variety of reflective tools (Birks & Mills, 2015; Charmaz, 2014). For example, Davis (2020), in his CGT study on how South Asians (SAs) cope with life changes after a heart attack, used excerpts from his research journal to illustrate his reflexive journey throughout the study. Gemma Aburn, a Paediatric Palliative Care Nurse Specialist, used CGT to examine the experiences of staff working in children's blood and cancer centres in NZ, focusing particularly on maintaining resilience. She used reflective memos to establish her position at the start of the study and organised her reflective accounts around the five key themes identified in the preliminary literature review (Aburn et al., 2018). For novice CGT researchers, the best approach is to experiment with and develop a tailored approach to practise positioning based on their own natural interests, to find methods that work best for them. For instance, CGT researchers use musical memos, visual art, confessional tales, and field notes to illustrate their reflexivity. As the first strategy of reflection, CGT researchers must identify the characteristics of their multiple selves and recognise how it positions them in relation to the study (Birks & Mills, 2015; Subramani, 2019).

Exploring Insider-Outsider Status as a First Step

While positioning myself in relation to my doctoral research, I identified holding partial insider status. Wilkinson and Kitzinger (2013) define insider research as “where the investigator studies herself, those like her, her family or her community” (p. 252). I share the same ethnic background as that of the participants, know about the condition as an RN who has cared for Indian children with asthma, and have many close family members and friends with asthma. Although I play multiple roles such as a daughter, sister, wife, and friend, my identity as an Indian immigrant woman, an RN (previously in India and now in NZ), and a mother to three children (a schooler, a toddler, and an infant) takes dominance in relation to this research. Simultaneously, I am an outsider in the context that I do not have any children with asthma. Conscious explication of how these insider-outsider experiences influence research will improve a study’s knowledge statements by making it more thoughtful, meaningful, and reflective (Aburn et al., 2018). This explication is usually accomplished through positionality statements, which are critical to ensuring methodological rigour. One of the essential elements in devising a strong positionality statement is *reflective thinking* (Holmes, 2020).

Practising Reflective Thinking

It was John Dewey, a pragmatist philosopher and an educational theorist, who introduced the concept of reflective thinking through his seminal work *How We Think* (Dewey, 1933a). According to Dewey (1933a), thinking does not occur spontaneously and is often triggered by a situation that gives rise to a state of doubt, perplexity, or confusion. This type of reflective thinking leads the person to pursue possible solutions mostly based on their prior knowledge or experiences. He also posits that deliberate and critical reflection of one's experience shapes and reshapes their identity and determines how one acts in the world. While Dewey identified reflective thinking as an inevitable cognitive activity of our day-to-day life, it was David Schön who expanded the concept by applying it to various professional practices through his seminal work, *Reflective Practitioner* (Schön, 1983). He introduced the notion of reflective practice and advocated reflective thinking as an epistemology of practice (Schön, 1983). Within the context of research, Mortari (2015) claims that reflective thinking is an essential skill that researchers must have to be competent practitioners of rather than being mere technicians.

Memoing: A Powerful Tool to Practise Reflexivity and Demonstrate Positionality

Birks and Mills (2015) recommend memos, which are written records of the researcher's thought process, as one of the best means to practise reflexivity. Therefore, at the start of my research, I embarked on my reflective journey by doing reflective exercises in the form of memos to make my positionality explicit. This article is a compilation of the reflective memos I wrote during my research proposal stage using the following titles: *my childhood*, *migration to NZ*, *challenges as an immigrant*, *role of grandparents*, and *motivation to study Indian immigrant children's asthma*. It describes my motivations relating to my doctoral research topic and how I engaged with the theory underpinning the reflective process. This is followed by a discussion of how these philosophically underpinned reflections directed me towards the development of the research question.

My Childhood: I was born into a South Indian Hindu family. As my parents worked full-time at two distant places, my grandmother raised me until I was eight years old. In India, grandparents play the role of de facto child carers who find pleasure in nurturing their grandchildren physically and psychologically (Singh, 2014). Joint family is the most common system prevalent in India as many families live together with three or four generations. This system allows other members of the family, especially grandparents, to share the childrearing responsibility along with parents (Chadda & Deb, 2013). Although nuclear families are becoming a trend in modern India because of urbanisation and globalisation, parents usually maintain a close relationship with their extended family members, who help them with childrearing and domestic labour. Additionally, new parents seek guidance and support from the extended family in many matters. For example, parents usually consult elders to make decisions regarding children’s academic studies, career options, and marriage (Raina et al., 2020).

I remember the challenges that my parents encountered in bringing me and my brother up when I started living with them. They had to find arrangements to accommodate childcare and work commitments as they could not avail themselves of any extended family support. They did not have options other than employing maids, as there were no childcare centres in India at that time. Now, I can relate my parents’ hardships to my current experience, as I am living as an immigrant in a country where I do not have any extended family assistance. I struggled to maintain a work-life balance, especially in childcare. One of the key challenges faced by the Indian immigrant families is the disruption of assistance offered by extended families in childrearing and care distribution (Kõu et al., 2017). In addition to the lack of availability of informal social support systems, affordability and acceptability of formal childcare remain a key concern among many Indian immigrants (Kõu et al., 2017; Nayar, 2011).

Migration to New Zealand: I migrated to NZ in 2015 with a dream of pursuing a better career and a better quality of life. Being a nurse, the fastest option to secure a nursing job in NZ was to complete a short registration course. However, I realised that I did not have enough clinical experience to pursue the course, and the NCNZ would not consider my postgraduate nursing qualification from India. Further adding to my frustration, I was taken aback by the decision from NCNZ that I needed to do the *Bachelor of Nursing* course again if I wanted to continue my nursing career. In fact, at that point in time, I regretted not planning my career and felt guilty at blindly accepting the decision of getting married immediately after my studies.

According to Hindu culture, marriage age is determined based on astrology. Being from a conventional Hindu family, my parents wanted me to get married at a specific age based on the astrologer's findings. This is an example of the collectivistic nature of the Indian culture, where importance is given to the decisions made by elderly members rather than to personal choices (Raina et al., 2020). Moreover, the extended family exerts significant influence over most decisions made by a young married couple, who may also seek guidance from them in resolving family issues (Nayar, 2011). Hence, in my case, I got married soon after my postgraduate studies and moved to Abu Dhabi, where my husband was working, and where I gave birth to my first child.

As an educated, upper-middle-class Indian woman, I desired a robust intellectual life rather than remaining as a traditional Hindu housewife after having children. Existing evidence suggests that many Indian immigrants encounter this type of cultural discordance as they experience conflict between the immigrant culture of origin and the host culture in terms of cultural norms, behaviours, and social expectations (Nayar, 2011). Though modern trend permits Indian women to break the chain of patriarchy to an extent, it is a *socially constructed expectation* from women to take responsibility for childcare and domestic labour. Men are expected to be the breadwinners of the family, and women's employment is often treated as inferior to that of men (Azmat & Fujimoto, 2016; Raina et al., 2020). My limited clinical nursing experience meant that I could not obtain an RN job in Abu Dhabi. This motivated me to look for destinations where I could have a successful career and a better family life, and that ultimately attracted me to NZ.

Lee’s (1966) push and pull migration theory explains the basic drivers of migration. While a push factor is something that stands as the basic reason for a person to migrate, a pull factor is those elements that attract the person into the host country. These factors may be cultural, social, economic, or environmental. Push factors include unfavourable elements that prevail in the native country that may either adversely affect the person’s life or prevent further personal or familial or professional development. These may include war, drought, famine, and low education and job opportunities. The most common pull factors comprise reunion with families, safety, and improved living standards such as better education and job opportunities (Castelli, 2018).

Challenges as an Immigrant: My life as an immigrant has not been an easy journey. Migration research shows that acculturation is a complex process that involves a series of adaptational and psychological changes that the migrants may undergo as they settle into the new country (Akosah-Twumasi et al., 2020). My husband and I left our one-year-old daughter in India as we anticipated that we would not be able to look after her properly without any extended family support. We planned to bring her to NZ after my studies and left her with my in-laws to look after. Existing literature discusses the unique tension immigration can create on parenting (Akosah-Twumasi et al., 2020; Nayar, 2011).

Contrary to our plan, we were forced to bring my daughter to NZ after eight months as my husband’s parents became unwell. This created extra tension as I struggled to balance childcare, household chores, studies, and jobs. We were struggling financially because of immigration-related expenses, so we could not afford full-time childcare. Thus, my daughter was sent to a day-care centre on a casual basis. The occasions when my daughter got unwell were the most challenging times. We did not have options other than taking time off from study and work to take care of her. According to Nayar (2011), children's participation in the immigration process, as well as their age at the time of migration, may have a significant impact on the settlement and well-being of Indian immigrant families.

Although I expected an end to this struggle once I finished my studies, secured a good job and residency, it continued. The situation grew worse after I had my second daughter. The whole family routine became chaotic when any of the children became unwell, and this contributed to further emotional turmoil. A study conducted by Inman et al. (2007) assessed the influence of contextual factors on parenting experiences among Asian Indian parents in the United States of America (USA) highlights their struggles and regrets in parenting. While some fathers regretted sending their child to care centres as it is not the usual Indian custom, mothers were concerned about overworking as it compromised childcare. Consistent with many other studies, raising children without extended family support was highlighted as one of the major challenges by some of the participants. Akosah-Twumasi et al. (2020) suggest that the lack of an informal support system in the host country may cause anxiety, frustration, confusion, and feelings of loss among immigrant parents.

Different acculturation models explain the adaptation process between immigrants and their host countries. Berry's (1980) bi-dimensional model is a popular one which explains the adaptation process based on two dimensions, host culture acquisition and heritage culture maintenance, in the form of four strategies: assimilation (accepting host culture while rejecting heritage culture), integration (accepting and balancing both cultures), separation (retaining heritage culture and rejecting mainstream culture), and marginalisation (rejecting both). Integration is the most common strategy adopted by both first- and second-generation Indian immigrants and has been associated with better psychological adaptation (Joseph et al., 2020).

Role of Grandparents: It has been a common practice for Indian grandparents to go overseas and support their grandchildren. In my case, I was forced to bring my parents to NZ to assist with childcare. I had tried sending my daughter to childcare at the age of eight months, however, she did not cope despite repeated attempts. I had no other choice than to bring my parents from India, as I was a full-time student and my husband was working full-time. Their presence made a significant difference to our stressful routine. One of the key expectations from parents of Indian migrants is assisting with childcare thereby allowing migrant couples to sustain dual careers directly or indirectly (Kõu et al., 2017; Singh, 2014). Grandparents also play a key role in communicating cultural beliefs, values, and ideals to grandchildren. However, bringing parents into the country may not be as easy as one expects. In addition to the immigration eligibility criteria that must be met, bringing parents is expensive, and adaptation to the country may be challenging for some (Azmat & Fujimoto, 2016; Singh, 2014).

On the other hand, many Indian immigrant parents, including me, show reluctance to send their children to a care centre at a young age unless they do not have other options (Azmat & Fujimoto, 2016). The practice of sending young children to a care facility seems culturally unacceptable to many parents (Nandi et al., 2016). The primary mode of childcare in India is familial, with most responsibilities falling on mothers and grandparents (Nandi et al., 2020). In NZ and many other countries, I know of many Indian immigrant parents leaving either of their jobs to care for their children. This mostly happens if they do not have any extended family support or if the cost of childcare is unaffordable. Moreover, prejudgment exists about the quality of childcare as not being as good to that of family-provided care (Nandi et al., 2016). Therefore, most Indian immigrant parents bring their extended family members into the country to take care of their children. Some of them even send their children to their grandparents in India if they cannot avail of their support in the host country (Azmat & Fujimoto, 2016).

Motivation to Study Indian Immigrant Children's Asthma

Passion towards Indian Immigrant's Health and Well-being: I initially wanted to study the health and well-being of Indian immigrants. As I reviewed the literature, I could see the dearth of studies on Indian immigrant children's asthma in NZ despite the condition being the most common among them. Moreover, it ranked first as the cause of potentially avoidable hospitalisation (PAH) among this group (Mehta, 2012; Scragg, 2016; Wong & Tsang, 2018). Additionally, as a children's nurse, I had cared for many children with asthma in India.

Having Many Close Family Members with Asthma: My personal experience with asthma in my family, as well as its serious consequences, primarily motivated me to explore this topic. I had the impression of asthma as a very serious illness because I was brought up by my grandmother, who had severe asthma. I lived with her until I was eight years old and used to stay with her during my holidays until her death, which was when I was 20 years old. I have an image of my grandmother sitting on the bed or chair, leaning forward, struggling to breathe. She always had an inhaler and spacer by her side. I remember her being rushed to the hospital several times. She sadly died from asthma.

Although mild-moderate asthma can be well controlled with standard management regimens, it may remain refractory to treatment in those with severe disease. Poor health-related quality of life (HrQOL) can be one of the hallmarks of serious illness (McDonald et al., 2018). To manage the condition, 80% of the people in India with asthma use complementary and alternative medicine (CAM). While complementary medicine refers to various therapies that supplement mainstream medicine, alternative medicine includes other systems of medicine that serve as a substitute for it. Ayurveda is one of the most popular alternative systems of medicine in India (Sarvesh et al., 2018).

I had seen my grandmother taking Ayurveda medications for her asthma and advising others about its benefits. Ayurveda is one of India’s ancient systems of medicine that offers holistic treatment of several conditions. It primarily uses herbal preparations and recommends specific lifestyle modifications involving diet and exercise to treat various diseases (Patwardhan, 2014). Despite my mother’s concern about the potential interactions that Ayurveda can cause when used in combination with modern medicine, my grandmother followed both treatment modalities. She also took many natural remedies for her asthma. Her usual remedy for coughing was a mixture of dried ginger powder and powdered rock sugar. She gave me this mixture whenever I coughed, stating that it would soothe my throat and help to bring up phlegm. Additionally, she ingested organic honey and would drink water boiled with basil leaves. Unknowingly, her remedies are evidence-based, as ginger aids in bronchodilatation, basil leaves act as an expectorant, and honey has the properties of being both mucolytic and an expectorant (Sarvesh et al., 2018).

My grandmother always encouraged our family members to follow a precautionary approach due to their genetic predisposition for asthma. She often advised my mother to make sure that the home is free of dust. My mother never did any rigorous cleaning as she was worried about developing asthma. Her brother also has asthma and follows Ayurveda treatment along with Yoga to manage the condition. Growing evidence shows that many Indians substitute complementary therapies for scientific medicine as they are concerned about the side effects caused by the latter (Patwardhan, 2014).

On the other hand, my brother, who is a medical doctor, recommends Western medicine over any other therapies in the management of asthma. He uses preventer and reliever inhalers and does not recommend CAM as a primary treatment. He did not use inhalers during childhood, as nebulisation was the main treatment method. As a part of asthma management, my mother restricted my father from buying foods with cold bases such as yoghurt or banana for him, as she believed that it triggered his asthma. I was also not allowed to have any of these in front of him. He liked yoghurt very much and I had seen him quarrelling with my mother many times for restricting yoghurt. Many Indians follow similar dietary practices which are based on Ayurveda, in which some foods are categorised as either hot or cold. This classification, not related to physical temperature, is based on the thermal effects that these foods produce in the body and has health implications. Cold foods are believed to aggravate asthma by causing cough and increasing phlegm production (Sarvesh et al., 2018). I too follow these practices when any of my family members get a cough or cold.

One of the most interesting complementary therapies for asthma was a type of *fish treatment* offered in Hyderabad (Lorensia et al., 2018). Live murrels, with specially made herbal preparations, are administered orally to people of all ages with asthma. It occurs annually on a specific day fixed by the astrologer and is free of cost (The Hindu, 2016). The founders of fish medicine claim a complete cure for asthma if it is received for three consecutive years and a prescribed diet is followed for 45 days after each dose. The scientific rationale behind this practice may be associated with the role of omega-3-fatty-acids in controlling asthma symptoms. However, the efficacy of the treatment is not scientifically proven (Lorensia et al., 2018).

Having Nursed Many Cases of Asthma as a Paediatric Nurse in India: I had come across many children with asthma when I worked as a paediatric nurse in India. I have seen the struggles of children, their parents, and extended family members when they get asthma attacks. The main modes of treatment at the hospital were nebulisations, steam inhalations, and administration of oral and parenteral corticosteroids. I had never seen the use of inhalers for children while I practised in India. Doctors advised two-hourly salbutamol nebulisations to those with severe asthma rather than prescribing inhalers. Now, I question that the decreased use of inhalers may be because of the stigma existing towards inhalers in the Indian community (Lakhanpaul et al., 2019). Schőn (1983) points out that a reflective practitioner makes use of their past experiences to make better sense of the current situation and plans their further actions accordingly.

Discussion

This article explored the meanings of positionality and demonstrated how reflective memos were used to illustrate positionality in a CGT study on Indian immigrant children's asthma. According to Dewey (1933b),

> Reflection emancipates us from merely impulsive and merely routine activity, it enables us to direct our activities with foresight and to plan according to ends-in-view or purposes of which we are aware, to act in deliberate and intentional fashion, to know what we are about when we act (p. 17).

My epistemological stances directed me to adopt a CGT methodology that acknowledged the researcher's experience (Charmaz, 2014). Reflexivity enhances the epistemological integrity of the study as it allows the researcher to go back and forth in the research in a way that demonstrates how they view and interpret data, how they influence the research and are influenced (Carter et al., 2014).

I began this article by sharing my personal history, reflecting on my childhood. Exploring the researcher's personal history is critical to understanding their relationships with social systems and institutions (Subramani, 2019). This was followed by reflective accounts of my migration journey, challenges I encountered both as an *immigrant* and as an *immigrant parent*, the role of Indian grandparents in childrearing, and my personal and professional experience with asthma. Schőn (1983) further expanded Dewey's work by his theories of reflection-in-action, reflection-on-action, and reflection-for-action. While reflection-in-action involves the spontaneous thinking and reactions that occur during an activity, reflection-on-action refers to the purposeful thought process that occurs following an action. This article comes under the latter category, as I draw on my past experiences and use metacognitive action (Farrell, 2014). The third concept, reflection-for-action, is proactive in nature and includes judicial utilisation of knowledge gained from reflective thinking for future activities (Olteanu, 2017).

From my reflective accounts, many questions emerged in my mind when thinking about Indian immigrant children's asthma: How do Indian immigrant families cope if their children have asthma? What are their concerns? What are the children's feelings and thoughts about their asthma? How does it affect their physical and emotional well-being? How does it affect their studies, play, and social relationships? What psychological impact does the condition have on children, parents, siblings, and other family members? What type of management strategies do they adopt? Do they practise any CAM therapies for asthma? What type of support do they receive? How does it affect the families' work-life balance? How do they compare the health care system in NZ with that of India? What are the barriers and facilitators to effective asthma management? During my research proposal preparation, these questions directed me to undertake a scoping review of the relevant literature, which facilitated the development of my research question and further contributed to the formulation of the interview guide.

Moreover, the reflective memos enabled me to gain deeper insight into potential issues that participants may experience during the data collection (Aburn et al., 2018). These are examples of applications of reflection-for-action. I deeply considered my experiences and discussed these with my peers, colleagues, and relatives whose experiences resonated with many of mine. Common themes that emerged in these discussions were struggles faced by Indian immigrants in childrearing, challenges they encountered when their children became unwell, and stigma around asthma in the Indian community. According to Carter et al. (2014), reflection involves both individual and shared experiences. In addition to the great amount of introspection that is required, reflective thinking is fostered by probing and prompting by others, especially in the early stages of research.

Revealing personal experiences for the research is a vulnerable act as this requires the researcher to be as transparent as possible about their social background, philosophical and political assumptions, as well as emotions (Carter et al., 2014; Hoare et al., 2012b). However, this is a valuable act as it enhances the credibility of the study by allowing the audience to make sense of the researcher's knowledge claims and methodological decisions (Savvides et al., 2014). Furthermore, Subramani (2019) suggests that reflective accounts of a researcher's background and experience can also act as a lens for understanding the research question.

Implications

This article may be useful to novice qualitative researchers who are struggling to define and establish their own positionality. It demonstrates how John Dewey's and David Schon's works on reflective thinking and practice can be applied to practise reflexivity. Although this article is limited to reflective memos that I have written at the initial phase of the research, similar philosophically underpinned reflective memos can be employed throughout the study to make a better sense of the participants' feelings, emotions, and experiences. Moreover, reflective memos will help the researcher to capture an audit trail of their lived experience as a qualitative researcher and will allow them to realise the change in their positionality as the study progresses. These reflective memos can enhance the rigour of the study as it makes the research decisions transparent (Birks & Mills, 2015).

Conclusion

The importance of addressing the positionality of the researcher and its influence on the study has long been recognised in qualitative social science research. Positionality is informed by reflexivity, that requires researchers to be sensitive to their views, social, political, and cultural contexts and to be able to identify how these may have a direct or indirect influence on the entire research process. Employing reflexivity at every phase of the research enhances the rigour of the study and enriches knowledge production.

Postscript to the Manuscript

Working on this manuscript enabled me to realise the pivotal role that reflective thinking and memo writing play in CGT. This initial reflective memo writing exercise enhanced my theoretical sensitivity and taught me how to remain open-minded throughout the entire research process. Moreover, it contributed to the formulation of my research question and objectives.

Significance of the Study

NZ is a multicultural country, with people from diverse immigrant backgrounds (Kanengoni et al., 2018; Stats NZ–Tatauranga Aotearoa., 2019). The Indian population is one of the fastest-growing groups, accounting for about 4.7% of the current population. They are the second-largest Asian ethnic group after the Chinese. Within the Asian ethnic group, the number of people identifying as Indian increased by up to 43.01% between 2013 and 2018, compared to a 34.99% increase in Chinese people. One in every twenty New Zealanders is of Indian ancestry (Eaqub, 2020; Statistics New Zealand, 2014; Stats NZ–Tatauranga Aotearoa, 2020).

Table 1

Comparison of Chinese and Indian Populations: 2001, 2006, 2013, and 2018 NZ Censuses

Ethnic group	**2001 Census**	**2006 Census**	**2013 Census**	**2018 Census**	**Percentage Change: 2001–2006**	**Percentage Change: 2006–2013**	**Percentage Change: 2013–2018**
Chinese	**105,057**	147,567	171,411	**231,387**	40.5	16.2	34.99
Indian	**62,187**	104,583	155,178	**221,916**	68.2	48.4	43.01

Note: The data from 2001–2013 are adapted from *2013 Census QuickStats about Culture and Identity*, 2014, by Statistics New Zealand (https://www.stats.govt.nz/assets/Uploads/Retirement-of-archive-website-project-files/Reports/2013-Census-QuickStats-about-culture-and-identity/quickstats-culture-identity.pdf). Copyright 2014 by Statistics New Zealand. The data from 2013–2018 are adapted from *New Zealand's Population Reflects Growing Diversity | Stats NZ*, 2019, by Stats NZ–Tatauranga Aotearoa (https://www.stats.govt.nz/news/new-zealands-population-reflects-growing diversity). Copyright 2019 by Statistics New Zealand.

The National Ethnic Population Projections estimates the Chinese population (0.20 million in 2013) to rise to 0.31–0.37 million in 2025 and to 0.38–0.50 million in 2038. The population forecast for the Indian population remains close to that of the Chinese, with growth expected from 0.18 million in 2013 to between 0.28 and 0.35 million in 2025 and between 0.35 and 0.47 million in 2038 (Stats NZ–Tatauranga Aotearoa, 2017). The Indian immigrant population is young, with the majority under the age of five and between the ages of 20 and 40. Despite being present in every region of NZ, the Indian population in the country is primarily concentrated in three regions: Auckland (65%), Wellington (9%), and Waikato (7%). The Indian language, Hindi, is the fifth most common language spoken in NZ (Eaqub, 2020).

It is important to note that Indian communities are diverse at multiple levels and assigning a single ethnic identity to Indians can be misleading (Mehrotra et al., 2014; Sudarsan et al., 2022b, 2022d). The identity of an *Indian* is the sum of several subsets of identities, which are determined by region, caste, class, religion, language, and culture. Additionally, Indian identity has been influenced by centuries of conquests, ramifications, immigration, evolution, and globalisation. The existence of multiple group identities implies that in-group loyalties and divisions also exist, even within an ostensibly unified group. This complex nature of Indian society makes them distinct from other immigrant communities (Ray & Singh, 2015).

While Indian immigrants are significantly heterogeneous in terms of religions, diets, languages, and other various aspects, they share cultural similarities, particularly in their attitude towards various health-related beliefs and practices (Mehrotra et al., 2014). Immigration can create significant stress on Indian immigrant families and may adversely affect their health and well-being unless effectively managed (Hussain, 2018; Nayar, 2011). It can be challenging for parents to balance the processes of enculturation (the process of maintaining the norms of their own culture) and acculturation (the process of adapting to the host country’s culture) as they struggle to meet their child's needs (Hussain, 2018; Kim et al., 2022).

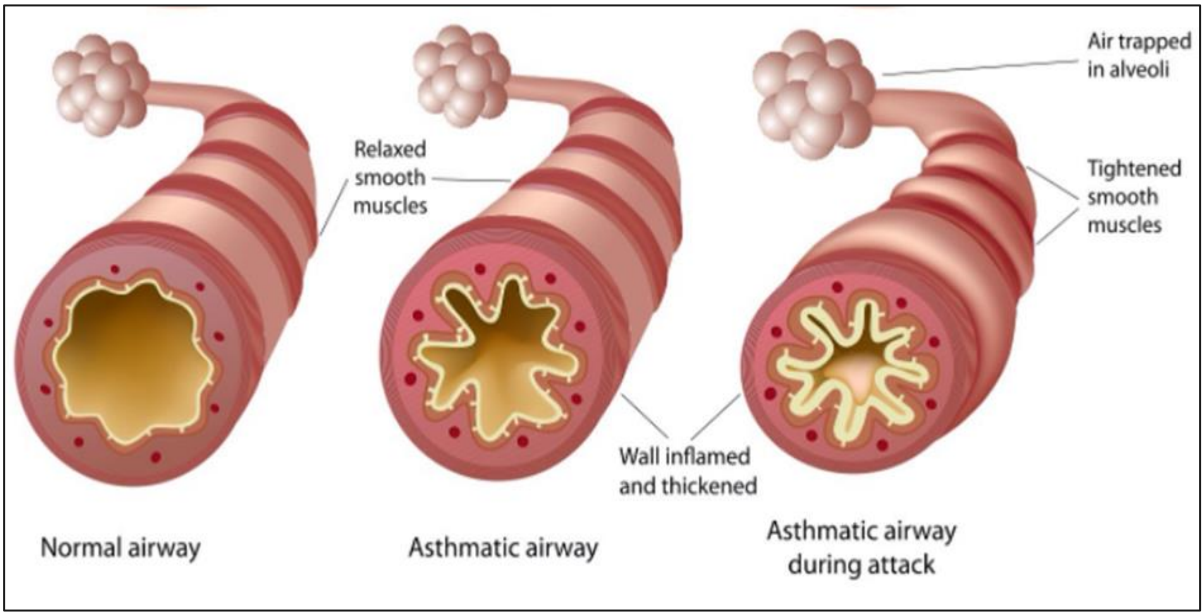
Although Indians generally follow the Western biomedical model of health, they hold specific traditional, spiritual, and cultural beliefs about health and illness (Mehrotra et al., 2014). This may pose several challenges, as Indian immigrants may become more questioning of Westernised health care when they have children with chronic conditions such as asthma. While some families adapt well to Western medicine, others may experience difficulties (Mehrotra et al., 2014; Yong, 2018).

Childhood Asthma: An Overview of the Biomedical Model

The term *asthma* is derived from a Greek word that means *panting* (Netuveli et al., 2007). The disease is characterised by reversible paroxysmal airway constriction, chronic airway inflammation, and obstruction that is caused by persistent airway hypersensitivity to a variety of nonspecific stimuli (Quirt et al., 2018). A combination of bronchospasm, mucosal oedema, and increased mucus production can cause significant airway obstruction resulting in impaired gas exchange (see Figure 1).

Figure 1

Airway Obstruction in Asthma



Note: Reprinted from *Asthma*, 2022, by Asthma and Respiratory Foundation NZ (https://www.asthmafoundation.org.nz/your-health/living-with-asthma). Copyright 2022 by Asthma and Respiratory Foundation NZ.

Because children's airways are smaller in diameter, they are more likely to have severe airway obstruction. This is one reason why asthma-related morbidity and mortality are more common in children than in adults. Some children may outgrow asthma by the time they reach adolescence. In other cases, asthma may gradually develop into an LTC in adulthood (Arenofsky, 2004; Trivedi et al., 2019).

Even though asthma has multiple risk factors, its exact aetiology is still unknown. Asthma is believed to be caused by a complex interaction of genetic, epigenetic, environmental, and lifestyle factors (Rehalia et al., 2020). Genetic predisposition (family history of asthma or atopy), prenatal (maternal smoking and antenatal complications), and perinatal factors (preterm birth and low birth weight) have been implicated as risk factors. Asthma can be broadly divided into two types based on common risk factors: atopic and non-atopic asthma. Atopic (intrinsic) asthma develops as a result of exposure to allergens. Allergenic triggers include indoor allergens such as moulds, house dust mites, pets, rodents, and cockroaches, as well as outdoor allergens such as pollens. In non-atopic (extrinsic) asthma, the triggers are not allergic in origin. Nonallergenic triggers include active and passive smoking, viral infections, emotional outbursts, occupational exposures, and weather changes. In children, viral infections are the most common asthma triggers. Moreover, social factors such as poverty and housing conditions may be associated with an individual's increased risk of developing asthma. Asthma is often accompanied by eczema (atopic dermatitis) and seasonal allergies (allergic rhinitis). These three conditions are known as the *atopic triad* (Abebe et al., 2021; Gautier & Charpin, 2017; Rehalia et al., 2020).

The symptoms of asthma can include recurrent episodes of wheezing, chest tightness, dry cough, and dyspnoea, and can be mild, moderate, or severe (Fletcher et al., 2022). Asthma can manifest clinically in two ways: acute and chronic. Acute asthma symptoms may develop gradually or abruptly and can be life-threatening. During acute exacerbations, the child may appear cyanosed, restless, confused, anxious, and lethargic. Symptoms of asthma that occur outside of an acute episode are referred to as chronic asthma. These symptoms may appear intermittently or may be present almost all the time. It is likely that chronic symptoms will change with time and in intensity, as well as the extent to which they affect expiratory airflow. (Reddel et al., 2021).

There has been tremendous progress in diagnosing and treating asthma over the past few decades (Jat & Gupta, 2022). The diagnosis is first made by establishing a distinctive pattern of signs and symptoms. However, diagnosing asthma in children remains challenging, particularly in younger children. Children who are unable to effectively communicate their symptoms make assessment more difficult. The family carers may often serve as proxy interpreters and communicators of the child's experience, which may not always reflect the child's actual experience. Moreover, there is no gold standard diagnostic test for asthma (Drake et al., 2019). Standard steps for diagnosing asthma include obtaining a full medical history, performing a focused physical examination, checking for variable expiratory airflow limitation, and monitoring clinical and spirometry responses to treatment with inhaled bronchodilators and/or inhaled corticosteroids (ICSs). The initial diagnosis is probability-based, and it should always be reviewed if the child does not respond to therapy or displays unusual symptoms or signs. Usually, the symptomatic response to treatment helps confirm the diagnosis of asthma. However, limited response to an ICS or a bronchodilator treatment does not rule out asthma (Jat & Gupta, 2022; McNamara et al., 2020; Quirt et al., 2018).

Asthma management necessitates collaboration between the child, their parents, close family caregivers, and their healthcare team (Asher et al., 2017; Reddel et al., 2021). The aims of asthma management include achieving good symptom control, relieving acute symptoms, as well as minimising the risk of asthma attacks and associated deaths, persistent airflow limitation, and treatment-related side effects. Initial management plans are made based on modifiable risk factors, the frequency and severity of symptoms, and lung function tests; whereas, long-term plans are developed based on a series of routine assessments, treatment adjustments, and response evaluations (Asher et al., 2017; Reddel et al., 2021).

Asthma cannot be cured, but it can be controlled with pharmacologic and non-pharmacologic treatments, both of which are critical in improving the outcome. Non-pharmacologic treatment entails reducing triggers and controlling environmental factors. Exercise is advised because exercise-induced asthma can be controlled by an appropriate treatment plan. Pharmacologic treatment usually includes controller and reliever medications given as aerosols via inhalation using various devices (Asher et al., 2017). Asthma management is discussed in detail in chapter two.

Childhood Asthma: Stats and Facts

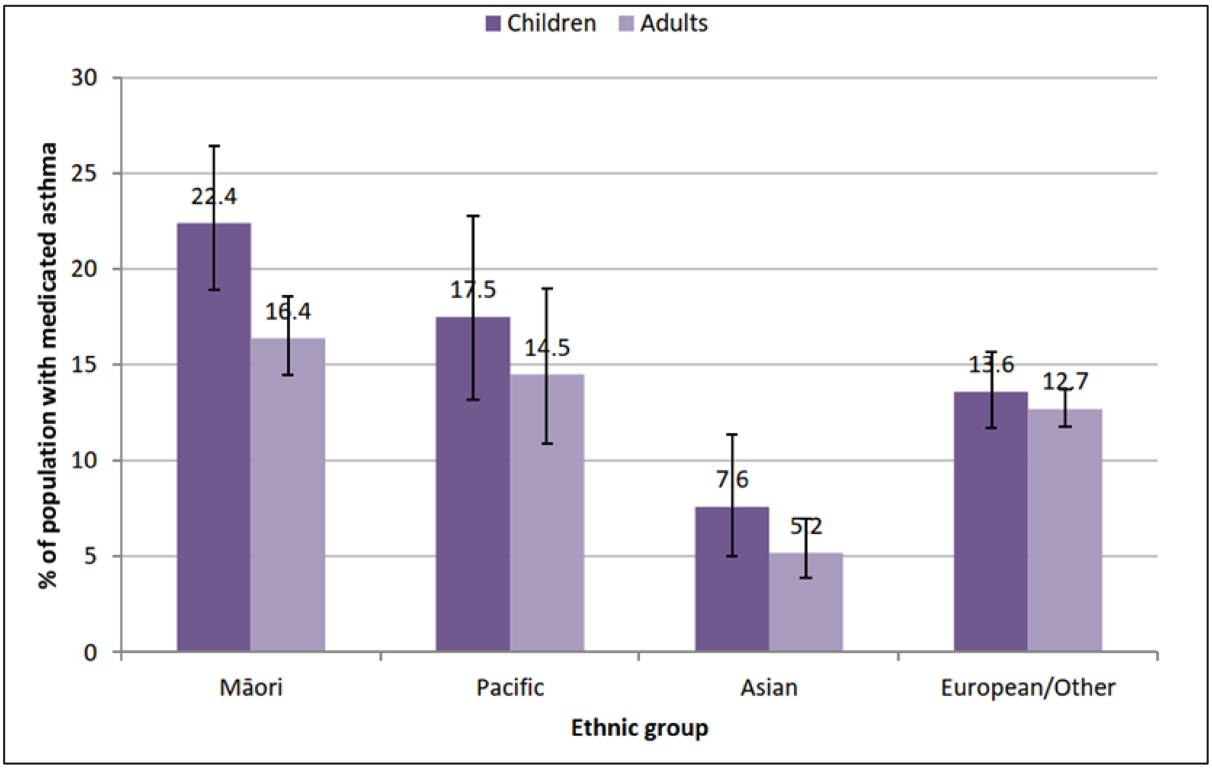
Asthma is the most common non-communicable disease among children worldwide and can be life-threatening (Asher et al., 2021; Rehalia et al., 2021; Schlichting et al., 2021). It affects about 339 million people globally, and approximately 1000 people die from this condition daily. Although the mortality rate is high in the middle- and lower-income countries, asthma remains a major global healthcare burden in all countries, irrespective of the level of development. The rising prevalence of childhood asthma in many countries is a major public health issue (Global Asthma Network [GAN], 2018; Global Initiative for Asthma Network [GINA], 2021; Ramdzan et al., 2019; Schlichting et al., 2021; World Health Organisation [WHO], 2022).

NZ has one of the highest prevalence rates of childhood asthma in the world (Schlichting et al., 2021). It is one of the most common chronic diseases among children of all ethnicities (Barnard & Zhang, 2021; Scragg, 2016; Wong & Tsang, 2018). The latest NZ Health Survey 2020/2021 provides current estimates for medicated asthma based on self-report; one in eight children aged 2–14 years (13.5%) reports taking asthma medication (Ministry of Health [MOH], 2022; MOH, 2021). In 2019, the report on the *Global Burden of Disease* showed that rates of asthma-related deaths among children in the 10–14-year age group in NZ were nearly four times higher than those globally, at 3.06% compared with

0.70%. Furthermore, the proportion of Disability Adjusted Life Years (DALY) caused by asthma for children aged 5–9 years in NZ is 3.6 times higher than the global figure (Schlichting et al., 2021; Vos et al., 2020). The prevalence and hospitalisation rates of asthma are higher among Māori and Pacific children compared to other minority ethnic groups (see Figures 2, 3, and 4). This may be due to the problems associated with access to culturally appropriate asthma-related care and education (Asher et al., 2017; MOH, 2021).

Figure 2

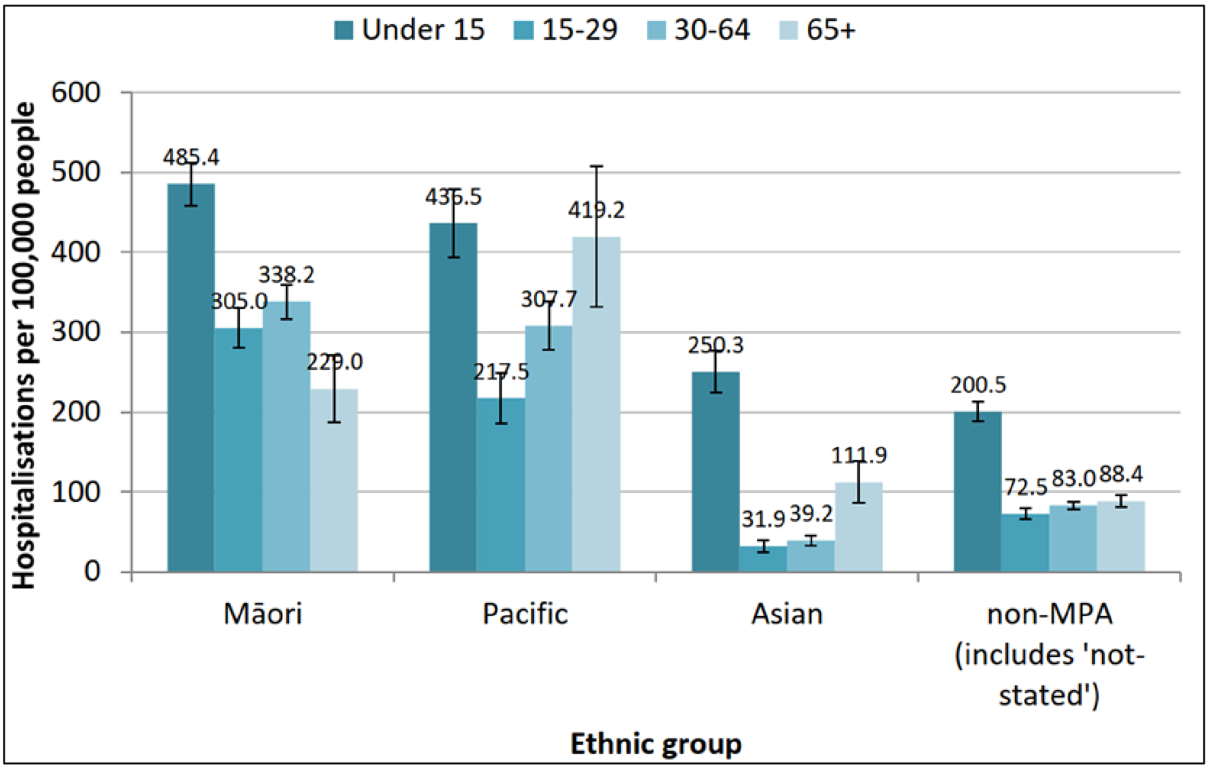
Medicated Asthma Prevalence by Ethnic Group 2019/20, Children and Adults



Note: Reprinted from *The Impact of Respiratory Disease in NZ: 2020 Update*, by L. T. Barnard, and J. Zhang, 2021, by Asthma and Respiratory Foundation NZ (https://www.asthmafoundation.org.nz/assets/documents/Respiratory-Impact-report-final-2021Aug11.pdf). Copyright 2022 Asthma and Respiratory Foundation NZ.

Figure 3

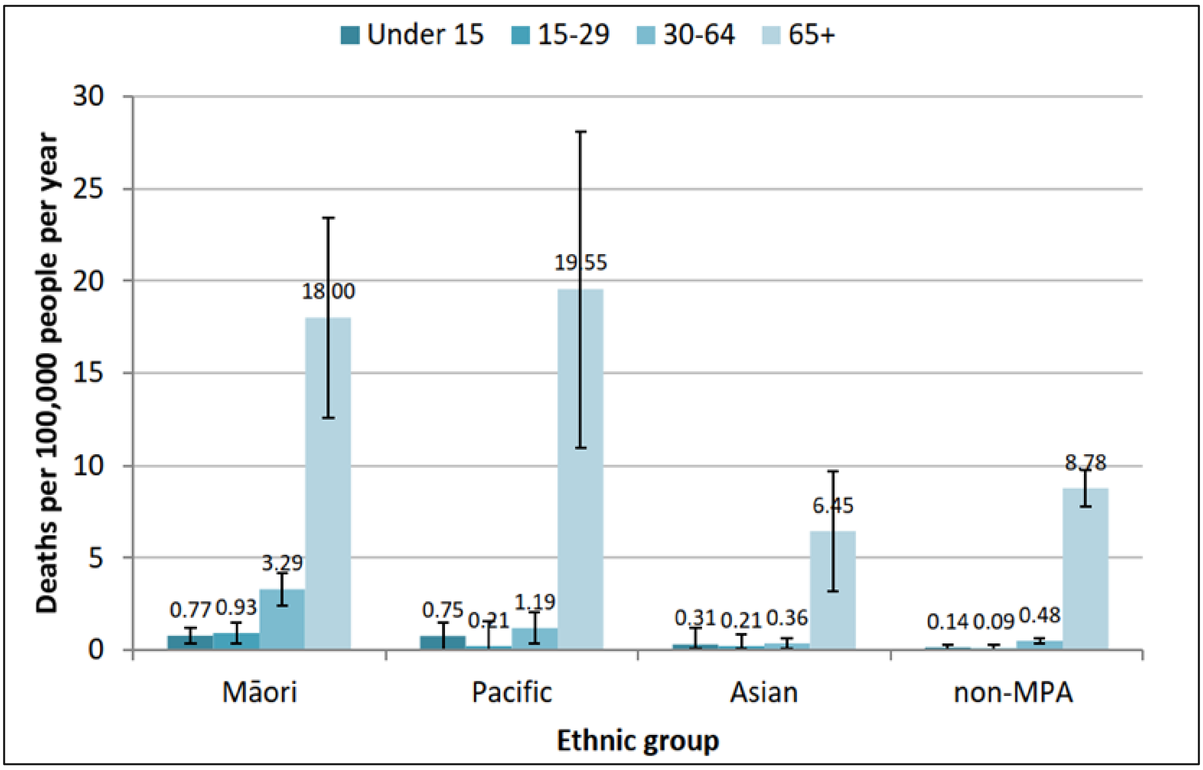
Asthma Hospitalisations per 100,000 People by Ethnic Group and Age Group, 2019



Note: Reprinted from *The Impact of Respiratory Disease in NZ: 2020 Update*, by L. T. Barnard, and J. Zhang, 2021, by Asthma and Respiratory Foundation NZ (https://www.asthmafoundation.org.nz/assets/documents/Respiratory-Impact-report-final-2021Aug11.pdf). Copyright 2022 Asthma and Respiratory Foundation NZ.

Figure 4

Asthma Deaths per 100,000 People per Year, by Ethnic Group and Age Group, 2012–2017



Note: Reprinted from *The Impact of Respiratory Disease in NZ: 2020 Update*, by L. T. Barnard, and J. Zhang, 2021, by Asthma and Respiratory Foundation NZ (https://www.asthmafoundation.org.nz/assets/documents/Respiratory-Impact-report-final-2021Aug11.pdf). Copyright 2022 Asthma and Respiratory Foundation NZ.

Asthma care and associated hospitalisations in children have significant economic and psychosocial consequences. The cost of asthma to the NZ economy is substantial and is estimated to be around $1.018 billion (Barnard & Zhang, 2021). There are significant psychosocial consequences for children and their families, including missed school and workdays, and adverse outcomes on academic achievement, sports performance, and emotional well-being. Furthermore, it can lead to premature disability and death. Therefore, a child’s asthma may adversely affect the entire family dynamics, which may become even more burdensome when an immigrant child presents with the condition. They may not be able to get the support from their extended family members, friends, and community that they usually receive from their home country (Lakhanpaul et al., 2017; Nunes et al., 2017; Rydström & Englund, 2015).

Asthma among Indian Immigrant Children in New Zealand

The prevalence, frequency, exacerbation, treatment response, and hospitalisation rates of asthma vary across ethnic groups (Barnard & Zhang, 2021; Wong & Tsang, 2018). Childhood asthma raises serious concerns among Indian immigrant children in NZ. The current context of asthma among Indian immigrant children in NZ and overseas is further explained in the published journal articles presented in this chapter and chapters two, three, and five (Mehta, 2012; Scragg, 2016; Sudarsan et al., 2022a, 2022b, 2022d).

National Research on Childhood Asthma

The majority of childhood asthma research in NZ has been focused on the general population. There is a recent trend of giving more attention to the Māori and Pacific populations in the context that the morbidity, mortality, and hospitalisation rates in these groups are exceptionally high (Jones et al., 2013). However, there is an absolute paucity of asthma research among the immigrant population, despite their rapid growth. Studies conducted in the United Kingdom (UK), the USA, and Canada have demonstrated the effectiveness of targeted health promotion in improving the health of Asian communities (Wong, 2015; Zhou & Bennett, 2017). However, one of the current weaknesses of the *New Zealand Health Research Strategy 2017–2027* is the limited investment in Asian health research despite this group being the fastest-growing ethnic group in the country (Ministry of Business, Innovation, and Employment [MBIE], 2017).

In addition, despite the call for giving voices to children and young people (CYP), the existing asthma research mostly focuses on the perspectives of healthcare professionals (HCPs) and family carers, with only a few studies seeking to explore the child’s perspective (Jones et al., 2013; Lakhanpaul et al., 2019). Children have historically had few opportunities to participate and share their opinions, emotions, and perceptions. Prout and Hallett (2003) claim that “[h]earing children’s voice is critical to creating institutions (whether statutory, voluntary, private, or in the informal sector of family and community) that are responsive and flexible in their work for children” (p. 2). Therefore, it is necessary to examine children’s conceptualisations, experiences, and understandings of asthma in order to advance practice in their best interests.

However, despite all interventions to manage childhood asthma, significant health disparities persist (Asher et al., 2017). To combat this issue, the health sector is accountable to ensure equitable distribution of health resources based on the existing health inequalities. The MOH (2019) has given a broader working definition of equity in terms of health outcomes: “In Aotearoa NZ, people have differences in health that are not only avoidable but unfair and unjust. Equity recognises different people with different levels of advantage may require different approaches and resources to get equitable outcomes” (p. 7). The Treaty of Waitangi (TOW), the founding document of NZ, serves as a framework to reduce health inequalities in NZ (MOH, 2002; MOH, 2019).

The Treaty of Waitangi

The TOW, also known as *Te Tiriti o Waitangi* in *te Reo Māori* (the Māori language), has a significant impact on NZ's political system (NCNZ, 2020; The Treaty of Waitangi, 1840; Wepa, 2015). In 1840, representatives of the British crown and Māori chiefs signed the TOW which legitimised British settlement and guaranteed the protection of Māori interests. The principles of the TOW, as articulated by the courts and Waitangi Tribunal, provide the framework for HCPs to carry out their daily work obligations. Fundamental principles of the NCNZ are based on the latest Waitangi Tribunal Claim, *Wai 2575: The health services and outcomes inquiry* (NCNZ, 2020; Waitangi Tribunal, 2019). The enhanced set of principles is included in Table 2.

Table 2

The Enhanced Set of Principles of the Treaty of Waitangi

Sl No	Principle	Explanation
1	Self-determination/ *Tino Rangatiratanga*	A principle that affirms Māori sovereignty and sets out the principles of Māori self-determination and *mana motuhake.*
2.	Partnership/*Pātuitanga*	This principle calls for the Nursing Council and Māori to build a strong and long-lasting relationship.
3.	Equity/*Mana Taurite*	According to the principle of equity, the Nursing Council is accountable for ensuring equitable health outcomes for Māori through its activities.
4.	Active Protection/ *Whakamarumarutia*	The principle of active protection requires the council to have a comprehensive understanding of both Māori health outcomes and strategies for achieving Māori health equity through culturally safe practices and nursing standards.
5.	Options/*Kōwhiringa*	This principle reflects the council's responsibility to ensure the provision of culturally appropriate services while acknowledging and supporting the implementation of Te Ao Māori models of care.

Note: Adapted from *Te Tiriti o Waitangi*, by Nursing Council of New Zealand, 2020 (https://www.nursingcouncil.org.nz/Public/Treaty_of_Waitangi/NCNZ/About-section/Te_Tiriti_o_Waitangi.aspx?hkey=36e3b0b6-da14-4186-bf0a-720446b56c52). Copyright 2020 by The Nursing Council of New Zealand.

The Treaty of Waitangi provides a foundation for biculturalism and cultural safety in NZ (Nayar, 2013). In Aotearoa, *Te Tiriti o Waitangi* demands equity in outcomes for Indigenous Māori. Māori retained *tino rangatiratanga* (sovereignty) over their *taonga* (treasures) and health is considered a *taonga* (Came & Tudor, 2016; NCNZ, 2020). Immigrants to Aotearoa have a right to expect fairness in policies, structures, and practices, such as those concerning health, and it may be easier to achieve due to the TOW and decisions by the Waitangi Tribunal regarding fairness for Māori. These decisions may serve as a guide in creating more equitable healthcare systems in Aotearoa. The principles and ideologies of the TOW can be applied in healthcare contexts as a basis for addressing health inequities, beginning with a bicultural lens as a strategy to promote and support both biculturalism and multiculturalism (Came & Tudor, 2016; MOH, 2019; Nayar, 2013; Waitangi Tribunal, 2019). This is similar to the way in which a road map can be used to help a driver find their destination. The roadmap provides a clear path to a desired outcome and guides people to their destination. In the same way, the TOW can be used as a road map to create more equitable healthcare systems. By understanding and following the principles outlined in the TOW, HCPs can create healthcare systems that are respectful of cultural diversity and provide equitable access to quality care (Came et al., 2018; MOH, 2018; Nayar, 2013). As a nurse researcher, I respected, acknowledged, and followed the main principles of the TOW during the entire study process.

Also, there is an expectation that HCPs in NZ will provide culturally safe care (NCNZ, 2011). Cultural safety extends to everyone or any group of people who might differ from the HCPs because of differences such as gender, age, ethnicity, sexual orientation, socioeconomic status, religious beliefs, migrant/refugee status, disability, or other factors. HCPs should value these differences and work in partnership with diverse populations to effectively address their health priorities (Came et al., 2018; MOH, 2018). The key component of cultural safety is the transfer of power to the individual who is receiving care from the HCP who is providing it. It is important to note that the safety component of cultural safety is determined by the recipient of healthcare services (NCNZ, 2011; Ramsden, 1997; Westenra, 2019). Culturally unsafe care is defined by NCNZ (2011) as any situation in which a patient or their family feels their cultural identity is devalued, demeaned, or disempowered in some way. Within the registered nurse scope of practice, I am required to meet competencies related to cultural safety (NCNZ, 2022).

What does this Study Add?

Bridges the Research Gap on Indian Immigrant Children's Asthma: The increased morbidity and hospitalisation due to asthma among Indian immigrant children in NZ have been reported for more than a decade (Mehta, 2012; Plunket, 2015; Scragg, 2016; Yong, 2018). The latest survey results highlighting the high PAH among Indian immigrant children due to asthma were mentioned by Mehta (2012) in his report on the *Health needs assessment of Asian people living in the Auckland region*. However, even after several years, the same findings are again highlighted in the reports published in 2018 on Indian immigrant children's health (Wong, 2018; Yong, 2018). It is evident from these data that the problems associated with high PAH rates among Indian immigrant children with asthma have received insufficient attention. Moreover, in NZ, information on childhood asthma among Indian immigrants is highly fragmented with a paucity of research documenting changes in the health of this group. There is a need for more research and initiatives to be undertaken in order to ensure that these children receive adequate health care and support. As Indian immigrants are on the rise and childhood asthma continues to be one of the leading causes of mortality and morbidity in the country, it is critical to bridge the research gap in this area (GAN, 2018; Stats NZ–Tatauranga Aotearoa, 2019). Furthermore, similar trends of increased morbidity and healthcare use among Indian immigrant children with asthma are found in overseas studies. International research points out the complex multifactorial issues involved in childhood asthma management among Indian immigrant families and the need for further exploratory research (Lakhanpaul et al., 2014; Lakhanpaul et al., 2017).

Contributes to the Limited Disaggregated Health Research Among Asian Immigrants: The Asian, or SA community is extremely diverse in terms of health status, beliefs and practices, housing, geographical distribution, migration history, English language proficiency, and socioeconomic status (Wong, 2015). According to Parackal et al. (2021), using the term *Asian* or *South Asian* as an umbrella term in population health surveys such as the NZ health surveys is misleading. This broad-brush approach to ethnicity classification fails to adequately address Asian health issues and does not provide a comprehensive picture of their health status. In the latest NZ ethnicity-specific surveys, the prevalence of asthma among SA children aged 0–14 years was reported to be 11%, compared to 20%, 12%, and 11%, respectively, for Māori, Pacific, and European/other ethnic groups. An increase in admission rates for asthma among SA children, from 1% in 2006–07 to 6% in 2011–2013, remains largely unexplored (Scragg, 2016). The use of revised ethnicity codes and disaggregated health statistics is essential to the development of both research and health promotion initiatives to address Asian health issues in NZ in an efficient way (Parackal et al., 2021).

Gives Voice to Children: The current study gives voice to a diverse, relevant, but often marginalised population. The primary emphasis of this study was to explore the experiences of Indian immigrant children with asthma from their perspective, examine the context in which their experiences were situated, and the processes they were engaged in. Since children may often have little influence over the decision to migrate, they can often be unwittingly forced migrants. It is common for them to experience a complex mix of emotions as they adapt to their new surroundings (Deng et al., 2022). Exploring Indian immigrant children’s experiences is important as it may provide parents, siblings, other family members, friends, schools, health care providers, and the community at large a plan for a better understanding of and insight into various aspects of an asthma diagnosis. This study gives voices to these children by recognising them as active social agents and as primary informants of their own lives. The current research is also in line with the United Nation Convention on the Rights of the Child’s (UNCRC) goals and the new sociology of childhood. These theoretical frameworks are further explained in the published article presented in chapter four. The caregivers' views of their children's asthma are also important to consider, considering the collectivistic nature of Indian society (Nayar, 2011; Raina et al., 2020).

Theoretical Framework: Social Constructionism

The study is based on the theoretical framework of social constructionism. Berger and Luckman (1966) introduced the concept of social constructionism through their seminal work, *The Social Construction of Reality*. The approach of CGT aligns with the notion of social constructionism, which works on the principle that reality is socially constructed and applies to specific social contexts. The study assumes that the health beliefs and practices about asthma among Indian immigrant families are socially constructed (Berger & Luckmann, 1991; Burr, 2015; Gergen, 2015). Social constructionism is explained further in the following chapters.

Researching during the COVID-19 Pandemic

The major phases of this study, ranging from data collection and analysis through the dissemination of the study findings, took place during the COVID-19 pandemic. I devised and implemented various strategies to accommodate for the possibility of potential restrictions and disruptions caused by the pandemic. COVID-19 undoubtedly had an impact on the study, as discussed in greater detail in chapters three and four.

Synopsis of the Thesis

This thesis is structured and presented in a *thesis with publications* format, where four journal articles are presented and integrated. Chapters one, two, three, and five, each contain a journal article which is published in peer-reviewed journals. These chapters also include additional content that provides context for the manuscript as well as further details that could not be included in the published article.

This chapter serves as a general introduction to the entire thesis. The rest of the thesis is divided into six chapters.

Chapter two will enable the reader to develop an understanding of the context related to the area under investigation and identify the potential gaps in the existing literature. Moreover, chapter two discusses the disputed role of the literature review in GT as well as how I reviewed the literature for the current study. It includes a journal article published in the *Journal of Advanced Nursing* (JAN) titled, “Beliefs, practices, and experiences of South Asian immigrant children and their family carers towards asthma: An integrative literature review.” The integrative literature review presents a critical analysis of the literature on SA immigrant children’s asthma and concludes by recommending a participant-driven research approach to understand the complexities of their asthma experience.

Chapter three is the methodology chapter, which presents a discussion of the relevant research paradigms, my philosophical positioning, different versions of GT, and the rationale for choosing the CGT methodology. This chapter includes a published journal article, which discusses how CGT researchers can effectively promote children's voices through effective knowledge co-construction.

Chapter four explains the methods employed, including the CGT procedures used for sampling, data collection, and analysis, and further explains the rationale for choosing specific methods. This chapter also discusses the measures taken to meet the ethical requirements of this research.

The research findings are described in chapter five. The final GT constructed is presented in the form of a journal article titled “Navigating asthma—the immigrant child in a tug-of-war: A constructivist grounded theory.” This chapter also highlights several barriers and facilitators to effective asthma management among Indian immigrant children.

Chapter six provides a discussion of the study findings in relation to the existing literature. This chapter explicates how the constructed theory can be linked to the relevant extant literature and theories.

Finally, the concluding chapter presents a summary of the research and an analytic explanation of how the constructed theory makes an original contribution to new knowledge. This chapter also discusses the quality considerations and implications for nursing practice, policy, future research, and education.

Summary

Through this chapter, I have demonstrated my ability to be reflective in order to establish the context from which I approached this study. As I explored and reported on my professional and personal experiences as well as childhood asthma literature, my theoretical sensitivity was enhanced, and I became more open-minded. The next chapter provides a background to the study by reviewing relevant literature on the study topic.

Chapter 2–Setting the Scene

> The literature review gives you an opportunity to set the stage for what you do in subsequent sections or chapters *(Charmaz, 2014, p. 308)*

Chapter two sets the scene by presenting the contextual literature that informed the study. It builds on the first chapter, in which the findings from the preliminary literature review are summarised to ascertain the current state of knowledge regarding the study topic. Considering the controversy surrounding the literature review in GT, this chapter begins by discussing the role and timing of the literature review in GT and explains how these tensions were addressed in this study. This is followed by an illustration of relevant literature about India and NZ to assist readers in interpreting the study's conduct and findings. The next section provides a brief overview of the management of childhood asthma. Finally, the chapter concludes with an integrative review published in the JAN that explores SA immigrants’ and their family carers' beliefs, practices, and experiences of childhood long-term conditions (LTCs).

The Contested Literature Review in Grounded Theory

A literature review is a fundamental step in establishing knowledge gaps, refining research questions, proposing theoretical frameworks, and selecting the most appropriate research designs (Polit & Beck, 2021). Nevertheless, one of the most debatable issues in GT is when and how to use the extant literature. In GT, there are two different schools of thought concerning the timing of a literature review: conducting a preliminary literature review as usual or delaying it until after data collection (Birks & Mills, 2015; Charmaz, 2014; Corbin & Strauss, 2015; Deering & Williams, 2020; Glaser & Strauss, 1967; Ramalho et al., 2015).

The authors of Classic GT/Glaserian GT, Glaser and Strauss (1967), suggest that the literature review be postponed until after the data has been collected and categories have been established. Delaying the literature review is considered a key component to avoiding imposing preconceived ideas on the development of the emergent theory. Later, Glaser advised researchers to read literature outside their areas of study to avoid being constrained by extant concepts during data analysis (Glaser, 1978, 1992). However, critics argue that most researchers come into the study with previous experience in their study area and a working knowledge of pertinent literature. Thus, the researcher may subconsciously or consciously look for those concepts, relationships, or variables identified in the literature in the collected data (Chenitz & Swanson, 1986).

Additionally, literature reviews performed late in the research process may result in the loss of valuable information, as well as the likelihood of reinventing the wheel, reproducing previous errors, and producing trivial products that reflect the researchers' lack of knowledge of the literature (Charmaz et al., 2018). Charmaz (2006) further goes on to argue that Glaser's position on literature reviews is ambiguous. While Glaser advocates abstaining from a literature review to keep the GT researcher uncontaminated by extant ideas, he advises them to become familiar with as many theoretical codes as possible in order to more accurately capture the subtleties of the relationships in their data. Charmaz (2014) questions this by asking, "How do we know these codes if they have not become part of our repertoire? And if they have, would we not know something of the major works from which they are derived?" (p. 165).

Strauss, who later collaborated with Corbin to develop the Straussian GT (explained in chapter three), challenged the practice of avoiding the preliminary literature review by arguing that open-mindedness is distinct from having an empty mind (Corbin & Strauss, 2015). According to Corbin and Strauss (2008), knowledge of relevant literature may assist GT researchers in several ways: it enhances theoretical sensitivity, indicates areas for conceptual development, facilitates comparisons with emerging data, and stimulates analytical questions. Theoretical sensitivity is a multidimensional concept that refers to the level of insight the researcher has about the study area, how they relate to participants' perspectives, their ability to distinguish between relevant and irrelevant data, and their skill to reconstruct meaning out of the data collected from the participants (Glaser, 1978; Strauss & Corbin, 1990; Timonen et al., 2018). Strauss' and Corbin's stance also encourages GT researchers to maintain a critical attitude towards developing concepts, particularly when they employ the constant comparison method and its inherent abductive logic. In this context, Charmaz (2014) points out that "sensitising concepts may guide but do not command inquiry, much less commandeer it "(p. 30).

According to Charmazian GT, a literature review should be tailored to the purpose of the research (Charmaz, 2014). She is against disregarding a preliminary literature review. A GT researcher may conduct a literature review whenever necessary as long as they maintain a critical and reflexive stance. In other words, researchers should "use the literature review without letting it stifle your creativity or strangle your theory" (Charmaz, 2014, p. 308). Charmaz concurs with Thornberg's (2012) concept of informed GT as a means of remaining grounded in the data. Informed grounded theorists utilise existing literature with sensitivity and creativity instead of seeing it as an obstacle.

Thornberg (2012) proposes several principles for conducting literature reviews in GT, including theoretical pluralism (openness to a wide range of theoretical perspectives by avoiding a pet code approach); theoretical agnosticism (critically evaluating various extant theories and considering them as fallible, disputable, provisional, and modifiable); theoretical playfulness (creatively employing concepts, theories, and models); and theoretical sampling of literature.

The current study followed Charmaz's (2014) and Thornberg's (2012) approaches to reviewing the literature. Charmaz (2014) argues that engaging literature in CGT goes beyond integrating it into one section of a paper or a single chapter of a thesis. Instead, CGT researchers incorporate pertinent literature throughout their thesis. Although this thesis is organised into sequential chapters, the literature review for this GT research was nonlinear and iterative. In accordance with Charmazian GT, the relevant literature that guided and informed the theorising of this GT study is intertwined throughout the thesis. The literature reviews conducted during the study served as sensitising tools, allowing me to better understand and explore the asthma experience of Indian immigrant children (Charmaz, 2014). Ramalho et al. (2015) recommend three stages for conducting a literature review in GT: 1) before commencing the study, 2) during data collection and analysis, and 3) after the theory development.

As a PhD student, I was required to conduct a preliminary literature review to identify knowledge gaps and comply with relevant ethical and course requirements. Birks and Mills (2015) recommend that the initial literature review for a GT study should be limited to the information necessary to justify the study. Charmaz (2014) also cautions novice GT researchers against conducting extensive literature reviews prior to data collection, as they may be more influenced by established theories. At the beginning of my study, being a novice GT researcher, I chose to carry out a scoping review on my research topic instead of an extensive integrative review. As a part of my scoping review, I conducted a systematic search for the literature related to asthma among SA immigrants. This allowed me to gain an overview of the literature on the subject, giving me a good indication of what was already known, and more importantly, what questions had yet to be answered. As emphasised by Charmaz (2014), key elements from the initial literature review are often incorporated into the introduction of an article or thesis. In chapter one, I discussed the gaps in the extant literature and how this study could help fill those gaps. In most theses, chapter two is reserved for reviewing relevant literature. Charmaz (2014) suggests that the researcher should use the required section of the literature review in an article or thesis to set the stage for the study.

Thornberg (2012) agrees with Charmaz, claiming that literature can be used as a source of data, inspiration, creative associations, ideas, and critical reflections throughout a GT study. During the data collection and analysis, I returned to the literature as required to delve deeper into the topics I encountered. This second stage of the literature review provided me with initial, but tentative, ideas to guide further investigation. To guide the literature review process, I used Thornberg's (2012) principles of informed GT and treated the literature as data. In line with the principles of GT, a final literature review was conducted after the completion of the data analysis, which enhanced my theoretical sensitivity and enabled me to develop theoretical codes (Birks & Mills, 2015; Ramalho et al., 2015).

The topics discussed under the following sections—*India and New Zealand–A Brief Comparison,* and *Childhood Asthma–An Overview of the Biomedical Model*—include the literature reviewed before and during the data collection phase of the study. The integrative literature review, presented later in this chapter, incorporates the literature conducted during the data collection and analysis, and after the development of the theory. For the integrative review, I broadened my search criteria to include literature related to various LTCs among SA immigrants. By expanding my search criteria, I gained valuable insights into the complex challenges encountered by SA immigrants with various LTCs, making my review more comprehensive and enhancing my ability to synthesise my results. Thus, the integrative review during data analysis assisted me in advancing my theoretical sensitivity and contributed significantly to the theoretical integration phase as described in chapter four. Moreover, chapter six discusses other relevant literature reviewed in the final phase and demonstrates the importance of conducting a thorough review of relevant theories and literature in order to enhance the explanatory power of the constructed theory.

India and New Zealand–A Brief Comparison

Stats and Facts

India is a vast nation with many geographical, social, and cultural variations across its different regions, and it occupies a significant portion of South Asia (Singh et al., 2016). With a land area of 3,287,263 km2, India is the seventh largest country in the world, roughly one-third the size of the USA. India is the largest democracy in the world and ranks second in terms of population after China, with approximately 1.37 billion people (about one sixth of the world's population). New Delhi is India's capital city and the second most populous city in the world after Tokyo. India is divided into 28 states and eight union territories. Each state is further divided into several districts (Central Intelligence Agency, 2020; Central Intelligence Agency, 2021).

The Indian Constitution is among the largest in the world, and it strongly adheres to secularism and equality (Stroope, 2012). Hinduism and Buddhism, the third and fourth most widely practised religions in the world respectively, are believed to have originated in India. It is estimated that 79.8% of the Indian population belongs to the Hindu religion, 14.2% to Islam, 2.3% to the Christian faith, 1.7% to the Sikh faith, and 2% come under the unspecified/ other categories (Central Intelligence Agency, 2020). India was previously a British colony. Europeans started arriving in India in the late 1400s and began establishing trading companies. By 1757, most of the country was under British control. Protests against British rule started in 1856. India, a British colony till then, gained full independence officially on August 15th, 1947 (Asif, 2020).

As the oldest civilisation in the world, India has a constitutional republican government that is tasked with managing a vastly diverse population made up of thousands of ethnic groups and hundreds of languages (Ray & Singh, 2015). India has 22 recognised languages, with Hindi and English serving as the country's two official languages.

The English language has been elevated to the status of a lingua franca in India–an almost universal second language that is widely used as a teaching medium in schools, as a medium of communication by various government and non-government organisations, and as a means by which individuals from different ethnic groups communicate when they do not know each other's primary language (Iyer & Ramachandran, 2019; Ray & Singh, 2015).

Conversely, NZ is a small island country located in the southwest Pacific Ocean, about 2000 kilometres off the south-east coast of Australia. NZ is known in te Reo Māori as *Aotearoa*, or *the land of the long white cloud* (Congressional Research Service, 2021). There are two main islands, the North Island (*Te-Ika-a-Maui*) and the South Island (*Te Wai Pounamu*), separated by the Cook Strait, as well as several smaller islands, collectively covering a total land area of 270,467 km^2. In terms of land area, the country is slightly larger than the UK (242,900 km2), or about the same size as the state of Colorado in the USA. Wellington is the country's capital, and Auckland is its largest city. New Zealanders are often referred to as *Kiwis*, after their national bird and the nation's exclusive export fruit. English and Māori (the native language of NZ's Māori people) are the most widely spoken languages in the nation (Britannica, 2022; Congressional Research Service, 2021). Most people practise Christianity as their religion of choice; however, over two million New Zealanders have no religious affiliations. NZ shares democratic ideals similar to India. About 70.2 percent of the five million residents have European ancestry, primarily British. Māori people account for about 16.5% of the population. People from Asia make up 15.1% of the population, and Pacific Islanders constitute 8.1% (Stats NZ–Tatauranga Aotearoa, 2019).

NZ has historical ties with India as a former colonial settlement society of the British (Britannica, 2022). The Polynesian Māori people began to settle in the country around the 10th century. Captain James Cook circumnavigated the islands on three separate voyages in 1769, 1773, and 1777 and mapped the country (Orange, 2015). The British established their first organised colonial settlement in 1840. The Indigenous Māori people were defeated by the British in a series of wars between 1843 and 1872. NZ became a British Dominion in 1907. In 1947, the country achieved complete legal independence from British rule under the *Statute of Westminster Adoption Act* (Chin et al., 2018; Congressional Research Service, 2021).

Collectivistic versus Individualistic Culture

There are considerable differences between the cultures of India and NZ. Collectivism is highly valued in Indian culture, and it promotes familial interdependence throughout a person's lifetime. Indian society prioritises the needs of the family over those of the individual (Chadda & Sinha, 2013). Even though modernisation has instilled individualistic characteristics in Indians, the collectivist mentality dominates and is motivated by a desire to promote communal values. The joint family system, followed by most Indian families, involves an elderly male or female member of the family, such as a grandparent, who is responsible for most of the decisions, even if their children have grown up and have established their own families. Joint families are also common, as adult children have a reciprocal obligation to care for their ageing parents. However, with modernisation, there are a lot of different types of families in India. Depending on social and economic factors, they can be one-parent families, nuclear families, or extended families (Bhasin, 2016).

In general, Indian families are patriarchal, where the father earns an income, and the mother takes care of and nurtures the children (Sondhi & Jain, 2020; Sudarsan et al., 2022c). Children are taught the value of responsibility, duty, relationships, and obligation in their roles within the family. Indian parents frequently discourage child autonomy, including adolescent autonomy, because it is not viewed positively, and they may interpret their children's independence as a loss of parental control. Religion has a significant influence on parenting practices since it serves as a vehicle for transmitting cultural values. It is common for parents to support and finance their children's education until they are financially independent (DeSouza, 2010; Sondhi & Jain, 2020; Sudarsan et al., 2022a, 2022c).

Due to the history of the caste system in India, the practice of intra-caste and intra-religious marriage has been encouraged. These are called *arranged marriages*. Most inter-caste marriages are not arranged. Marriages of this type are referred to as *love marriages* and are now becoming increasingly common. In general, dating is considered a prelude to marriage, and premarital sexual relations are generally considered inappropriate. After marriage, women usually move in with their husband’s families, and they no longer consider themselves members of their own families (Chakravorty et al., 2021; DeSouza, 2010; Sondhi & Jain, 2020).

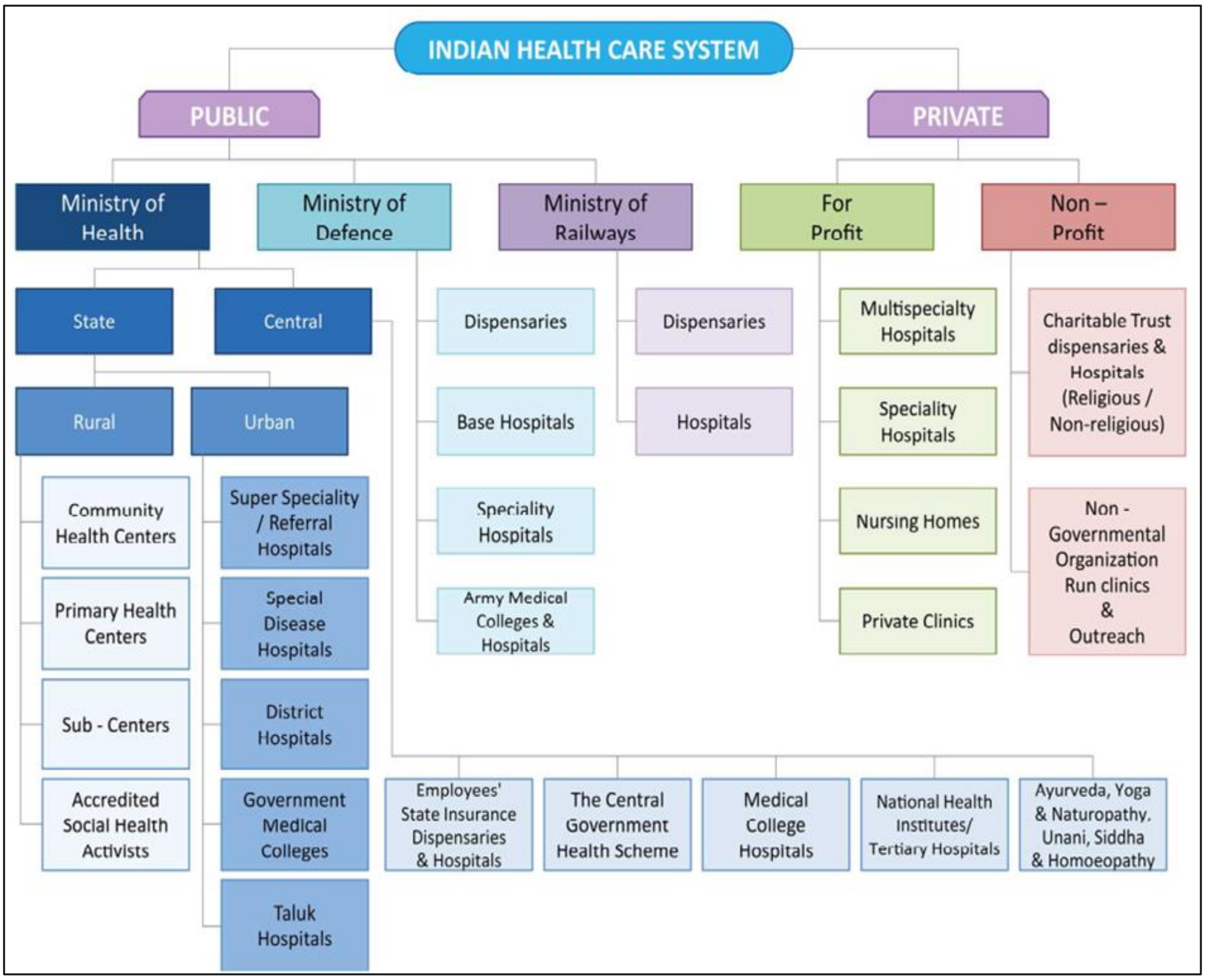
Contrary to Indian culture, NZ is strongly influenced by Western culture, as evidenced by the large number of people of European descent living in the country. NZ is generally considered to be an individualistic society where individuals value autonomy and place special emphasis on fulfilling their own needs and desires. NZ families are more likely to be nuclear. In terms of parental involvement in raising children, Indian and NZ cultures differ significantly. In NZ culture, it is expected that children will be independent and develop their own interests by the time they reach adolescence (Podsiadlowski & Fox, 2011). On the other hand, Māori and Pacific families are usually collectivistic. In Māori culture, loyalty and a sense of belonging to the tribe are of paramount importance. They are highly family oriented. In traditional Māori society, families are large or extended and organised into subtribes *(hapū)* and tribes *(iwi)*. As with Māori cultures, Pacific cultures also emphasise the importance of the extended family, with a sense of obligation, respect, and support for elders (Enari & Haua, 2021; Meissel & Rubie-Davies, 2015).

Healthcare Delivery Systems

It is essential to have a fundamental understanding of the healthcare delivery systems of India and NZ in order to make sense of the participants' experiences and expectations about healthcare. The healthcare system in India consists of three sectors: the public sector, the private sector, and the informal system of providers (see Figure 5) (Morampudi et al., 2017).

Figure 5

Structure of the Indian Healthcare System



Note: Reprinted from "The Challenges and Recommendations for Gestational Diabetes Mellitus Care in India: A Review," by S. Morampudi, G. Balasubramanian, A. Gowda, B. Zomorodi, and A. S. Patil, 2017, *Frontiers in Endocrinology*, *8*, p. 56 (https://doi.org/10.3389/fendo.2017.00056f). Copyright 2017 by Morampudi, Balasubramanian, Gowda, Zomorodi and Patil.

The public sector mainly consists of primary healthcare facilities located in rural areas and secondary and tertiary care facilities in major cities. In contrast, the private sector provides most of the healthcare services in the country through secondary, tertiary, and quaternary institutions, with a particular emphasis on major cities (Morampudi et al., 2017; Wani et al., 2013).

The healthcare infrastructure in India is therefore inequitably distributed, particularly in rural areas. While the public sector provides subsidised or free services to the public, healthcare services offered by the private sector are more expensive. Although several insurance packages are available to assist with healthcare costs, the majority of Indians do not have health insurance, and out-of-pocket costs constitute a significant portion of their medical expenses. Although the private sector has made significant advances, it has contributed to growing healthcare inequity in the country (Morampudi et al., 2017; Wani et al., 2013).

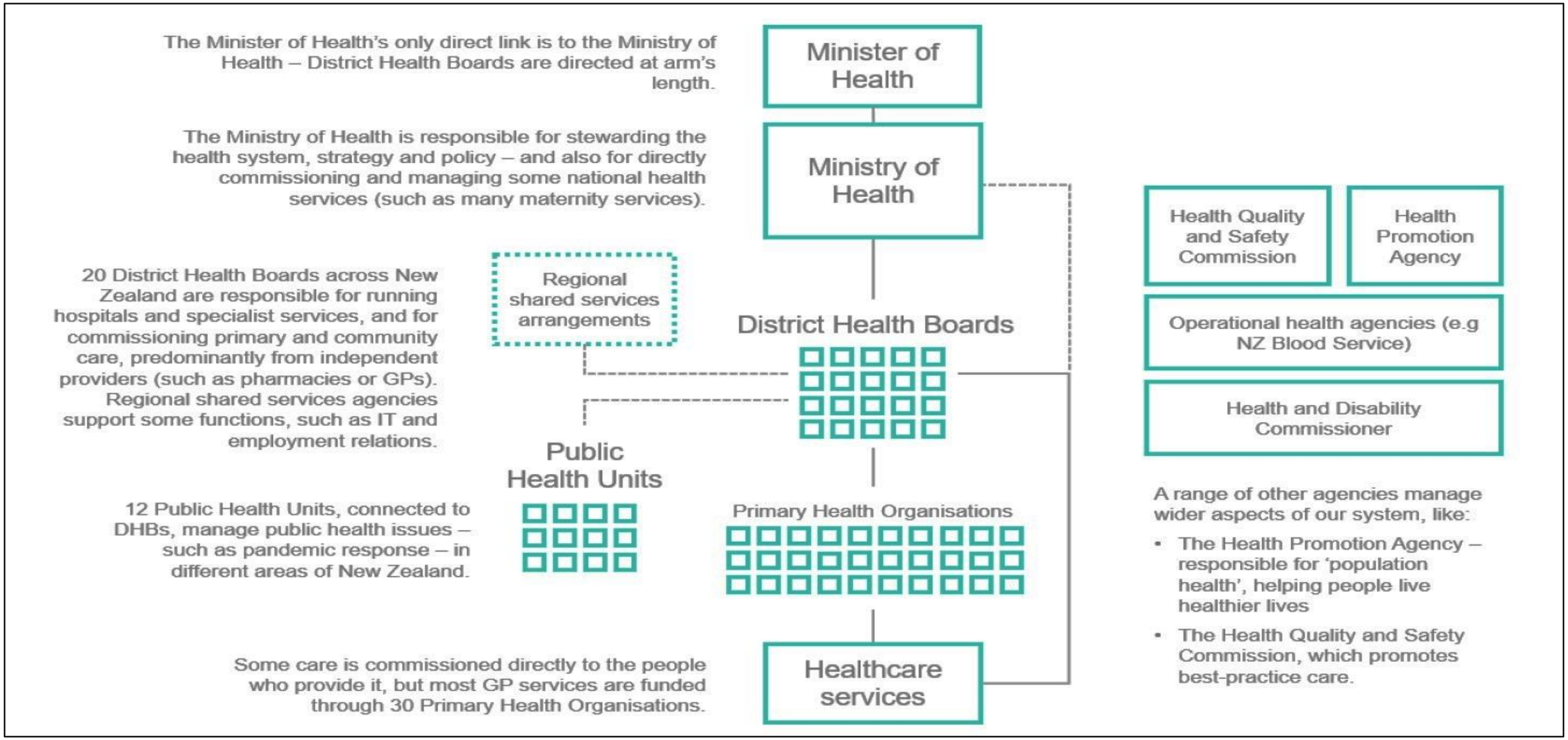
The health system in India is primarily organised at the central, state, and local levels. It is the responsibility of the central government to plan, guide, assist, evaluate, and collaborate with the state health ministries to ensure the equitable distribution of health services. National health programmes are designed by the central government and implemented by the states (Park, 2021). *The Ministry of Health and Family Welfare* is responsible for implementing a variety of programmes aimed at improving health and family welfare, preventing, and controlling communicable diseases, and promoting Indigenous and traditional health systems (Sheela & Seilan, 2010).

In rural areas, there is a three-tiered system for providing healthcare (Park, 2021; Sheela & Seilan, 2010). Health sub-centres serve as the foundation for primary healthcare in rural areas. Sub-centres provide primary medical care, vaccinations, and referral services. Each sub-centre, usually staffed by one to two HCPs, is responsible for providing essential services to a population of 5,000. Primary health centres (PHCs) are the next tier of care, providing both curative and preventive care. Each PHC provides care to approximately 30,000 individuals and has a maximum bed capacity of five. The staffing usually consists of one or two doctors, 14 paramedics, and other support personnel, including nurses. A PHC generally serves as a referral centre for a group of six subcentres. Secondary healthcare is provided by rural hospitals and community health centres (CHCs). Each CHC is responsible for four PHCs that provide specialised medical services to approximately 100,000 people (Park, 2021; Sheela & Seilan, 2010).

The NZ health system, on the other hand, is comprised of numerous organisations, each with its own set of roles and relationships. On July 1st, 2022, NZ launched a new national healthcare system. It is important to note that the present study was conducted before the current healthcare system was implemented. Therefore, the discussion on NZ healthcare system throughout my thesis is based on the old healthcare system (see Figure 6), although I briefly discuss the new healthcare system in this chapter (see Figure 7).

Figure 6

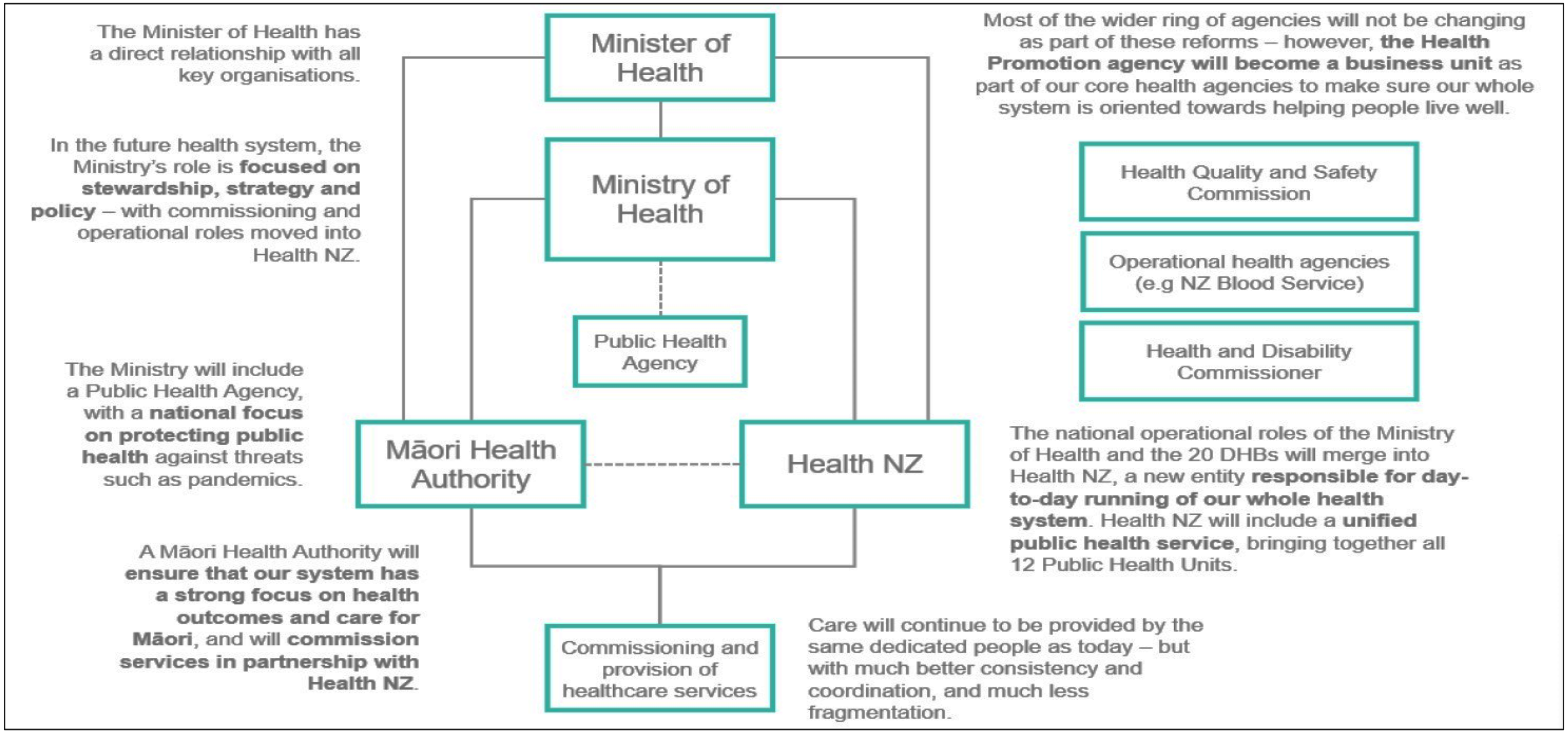
Structure of the Old New Zealand Health and Disability System



Note: Reprinted from *Our Health and Disability System: Building a Stronger Health and Disability System that Delivers for All New Zealanders*, by Department of the Prime Minister and the Cabinet, 2021, p. 5 (https://dpmc.govt.nz/sites/default/files/2021-04/heallth-reform-white-paper-summary-apr21.pdf). Copyright 2022 by Department of the Prime Minister and Cabinet.

Figure 7

Structure of the Current New Zealand Health and Disability System



The Minister of Health has a direct relationship with all key organisations.

In the future health system, the Ministry's role is **focused on stewardship, strategy and policy** – with commissioning and operational roles moved into Health NZ.

The Ministry will include a Public Health Agency, with a **national focus on protecting public health** against threats such as pandemics.

A Māori Health Authority will **ensure that our system has a strong focus on health outcomes and care for Māori**, and will **commission services in partnership with Health NZ**.

Most of the wider ring of agencies will not be changing as part of these reforms – however, **the Health Promotion agency will become a business unit** as part of our core health agencies to make sure our whole system is oriented towards helping people live well.

The national operational roles of the Ministry of Health and the 20 DHBs will merge into Health NZ, a new entity **responsible for day-to-day running of our whole health system**. Health NZ will include a **unified public health service**, bringing together all 12 Public Health Units.

Care will continue to be provided by the same dedicated people as today – but with much better consistency and coordination, and much less fragmentation.

Note: Reprinted from *Our Health and Disability System: Building a Stronger Health and Disability System that Delivers for All New Zealanders*, by Department of the Prime Minister and the Cabinet, 2021, p. 6 (https://dpmc.govt.nz/sites/default/files/2021-04/heallth-reform-white-paper-summary-apr21.pdf). Copyright 2022 by Department of the Prime Minister and Cabinet.

The new healthcare system, *Te Whatu Ora (Health New Zealand*), was established to ensure efficient and consistent delivery of healthcare throughout NZ. Te Whatu Ora's main objective is to build healthier and more empowered communities through integrated, equitable, and sustainable healthcare delivery (Future of Health, 2022). Previously, District Health Boards (DHBs) were responsible for the planning, management, and funding of healthcare services (hospitals and primary care/general practices) within their geographically defined districts. In the last two decades, despite efforts to better integrate primary and secondary services, the decentralised approach of DHBs has not sufficiently reduced the fragmentation of services and the complexity of the health system. The 20 DHBs have been merged into Te Whatu Ora, a single entitiy responsible for the day-to-day operations of the entire healthcare system (Future of Health, 2022).

The NZ healthcare system also consists of both public and private service providers. With this two-tier system, those with private insurance have the privilege of easier access to doctors, diagnostic tests, surgeries, and follow-up care than those who only have public coverage (Chin et al., 2018). Publicly funded healthcare services are available to citizens and permanent residents throughout NZ. These services include outpatient and inpatient care, preventive care, primary care, mental health services, paediatric dental care, prescription drugs, homecare assistance, long-term residential care for the elderly, support services for the disabled, as well as services through non-governmental health care providers, such as Māori and Pacific providers. The Accident Compensation Corporation (ACC) insures NZ residents and visitors against personal injury, including treatment expenses, and pays up to 80% of an individual's pre-accident earnings (Chin et al., 2018; Sheridan et al., 2011).

Public hospital accident and emergency departments serve as the first point of contact for patients and continue to be responsible for providing primary healthcare. However, general practices are evolving, and nurses' roles are increasingly expanding (Little, 2022).

For example, there are more nursing clinics now, and nurses are taking on more case management tasks that are within their scope of practice. It has become increasingly common for nurse practitioners (NPs), nurse prescribers, practice nurses, and nurses in accident and emergency departments to serve as the first point of contact in healthcare. As clinical care remains the cornerstone of primary healthcare, doctors work in teams with other healthcare providers to give patients access to a wide range of health services without having to be referred to somewhere else. A large number of primary healthcare teams today include clinical pharmacists, healthcare assistants, behavioural consultants, health coaches, social workers, navigators, and physiotherapists, among other professionals (General Practice NZ, n.d.).

Moreover, changes in the healthcare industry over the past decade have resulted in a shift away from traditional episodic, healthcare practitioner-based consultations to different modes of delivery, so that first-contact care is no longer always provided in person (General Practice NZ, n.d.). Primary healthcare services are increasingly taking advantage of technology in order to deliver more convenient and effective care to patients, whether it is through email consultations, providing advice and information through patient portals, or providing consultations via videoconferencing platforms (Little, 2022).

General Practitioners (GPs) are independent practitioners who, in the main, charge for their services. These fees are partly subsidised by the government if the patient is registered with a primary health organisation. Children aged 14 years and under who are eligible for publicly funded health services and who are enrolled in general practice will not be charged a fee for a standard visit with a physician or nurse. GPs may refer patients to specialists or hospitals for advanced treatment, which may incur a charge if the referral is to a private specialist service. Public hospitals provide most secondary health care services at no cost to

NZ citizens and residents. Further subsidies are available for low-income patients (Gillies et al., 2013).

Complementary and Alternative Medicine

The Indian Medical Degrees Act of 1916 defines *Western medicine* as allopathic medicine, obstetrics, and surgery, but it excludes Ayurvedic, Homeopathic, and Unani systems (Payyappallimana, 2021). The practice of Western medicine in India began in the 16th century under Portuguese influence. The coexistence of multiple health systems, otherwise known as *medical pluralism*, is widespread in Indian societies. The WHO's *Traditional Medicine Strategy 2014–2023* recognises the importance of CAM as an essential part of national health systems in order to ensure universal access to healthcare services and ensure their safety, quality, and effectiveness (Negi & Azeez, 2021).

Traditional healthcare practitioners were primarily responsible for providing society's healthcare needs before the country gained independence from Britain. However, the situation changed during British colonial rule. Christian missionaries began operating hospitals based on Western medicine (Sheela & Seilan, 2010). Although traditional medicine has been practised in India for centuries, with the advent of modern healthcare, traditional medicine has been criticised by Western health practitioners as lacking in scientific rigour. However, it remains popular in India alongside modern medicine (Sen & Chakraborty, 2015).

The traditional Indian healthcare system can be broadly classified into two categories: classical and folk streams. Ayurveda, Siddha, and Unani are examples of classical systems, which are distinguished from folk stream medicine by their emphasis on scientific underpinnings, formally recognised status, and institutionalised educational and training systems (Sen & Chakraborty, 2015). Classical systems are well-codified and documented. In contrast to the folk stream, practitioners of these medical systems are legally recognised, licensed, and registered (Shankar, 1997; Upadhya et al., 2014). Folk stream medicine is an uncodified form of medicine that is sustained through oral tradition. Folk stream medicine is unique to India's various ethnic communities and includes a collection of regionally specific health traditions that are based on empirical observations of so-called eco-systems. Although they lack legal standing, they are held in high regard within their communities. Folk healers include herbal healers, bone setters, vishavaidyas (venom doctors), monks, and birth attendants. Certain professions such as potters, welders, goldsmiths, blacksmiths, and barbers are also included (Mishra et al., 2018; Shankar, 1997).

The carriers of folk tradition comprise both tribal and non-tribal groups (Negi & Singh, 2018). Generally, tribal people have a very close relationship with the environment. Many of them hold a belief in supernatural powers and physical forces regarding health and illness. The evil eye, ill spirits, spirits of ancestors, and natural causes are among the many factors considered to contribute to poor health conditions. In tribal communities, folk healers who are members of their community are generally more accepted than doctors trained in Western biomedicine (Negi & Singh, 2018). Folk healers serve as an immediate point of contact for rural communities and play a vital role in primary healthcare. Patients who have been successfully treated recommend the folk healer to others. Furthermore, one-quarter of the tribal population lacks access to modern health care. As a result, many of them rely primarily on traditional healing practices. In India, not only tribal people but also the majority of the population rely on folk healing as their primary treatment method. There is a widespread inequity between rural and urban populations with regard to the availability, accessibility, and affordability of modern healthcare. As a result, this population ultimately turns to traditional medicine or folk medicine (Negi & Azeez, 2021).

The use of CAM is becoming increasingly popular in NZ, even though Western medicine remains the dominant method of healthcare (Gall et al., 2018). There are approximately 69 CAM modalities available in NZ. The regulation of CAM in accordance with the standards applicable to conventional medicine is challenging due to the variety of therapies included in the CAM context (Liu et al., 2021). Osteopathy and Chiropractice are the only two CAM therapies regulated by the Health Care Practitioners Act 2003 (Liu et al., 2021).

Rongo Māori, a traditional Māori healing method, is one of the most popular CAMs among Māori population (Liu et al., 2021; Williams, 2021). It encompasses herbal remedies, physical therapies such as massages and manipulations, and spiritual healing. The aim of Rongoā is to restore balance, harmony, and order at all levels of the spiritual, physical, emotional, cultural, social, and cultural dimensions of life. In this traditional healing system, practitioners are referred to as *tohunga*. Rongo Māori comprises a vast array of healing methods; all are based on a Māori worldview and their concept of well-being. Therapies include *ritenga* and *karakia* (healing incantations and rituals), *rongoā* (physical remedies derived from leaves, fruits, bark, trees, and moss), *mirimiri* (similar to physiotherapy or massage), *wai* (use of water as a healing agent), and surgical procedures (Mark et al., 2022; Williams, 2021). Healers do not practise uniformly, and there is considerable diversity in the application of particular modalities. The reason for this could be due to the uniqueness of traditional Māori healing practices in different regions of the country, which are founded on the knowledge of iwi, hapū, and whānau (extended family), as well as cultural traditions. There are currently 30 providers in the country who are funded by the Ministry to provide rongoā services. The subsidised services include karakia (pastoral support), whitiwhiti kōrero (cultural support), and mirimiri (wellbeing) (Liu et al., 2021).

Growing awareness of the benefits of holistic health, which combines mind, body, spirit, and lifestyle in order to achieve total well-being, as well as the increasing demand for culturally sensitive healthcare, are the primary reasons for people choosing CAM. Some other reasons for using CAM therapies include unsuccessful conventional treatment, past positive experiences with CAM, and to complement existing therapy. GPs and NPs can also refer patients to certain CAM therapies that are funded by government or ACC programmes (Liu et al., 2021; New Zealand Nurses Organisation, 2011).

Indian Immigration to New Zealand

Historically, the Indian diaspora in NZ dates back to the nineteenth century, and Indian immigrants have since become an integral part of NZ society (Leckie, 2021; Roche & Venkateswar, 2019). According to DeSouza (2006), the first Indian to land in NZ was in 1810, when he jumped a ship to marry a Māori woman. However, it is believed that India's relationship with NZ began in the late 1800s when Indian soldiers and sailors transported supplies to Australia's penal colonies via British East India Company ships. The roots of the permanent Indian population can be traced back to two Sikh brothers who arrived in NZ around 1890. In the late 1800s, *Abraham Singh & Co*. became the first Indian business to open in Whanganui. However, Indian settlers have taken up a wide variety of occupations and businesses since then, from fruit shops to scrub cutting to dairy farming and professional work (Leckie, 2021; Roche & Venkateswar, 2019).

Indians migrated to NZ without any difficulty since they were considered British subjects until the introduction of the *Immigration Restriction Act* of 1899 (Nayar & Clair, 2020). As British subjects, they were exempt from poll tax and permitted to settle in NZ. The Immigration Restriction Act restricted Indian immigration; only family members of Indians who already resided in NZ were permitted entry. The *Immigration Act 1987* allowed Indian migrants to enter NZ once again (Leckie, 2021; Nayar & Clair, 2020).

There is a large ethnic diversity among Indians in NZ. This diversity depends on the region of India from which they originate, as well as differences in language, religion, and socioeconomic status (Statistics NZ–Tatauranga Aotearoa, 2019). Even after immigration, Indian families may retain a strong sense of obligation to their extended family members who remain in India. It is not uncommon for extended family members to gradually join them in NZ. Similarly, immigrant families may assist their parents or siblings financially and consult with their elders about significant issues affecting them (Mehrotra et al., 2014; Sudarsan et al., 2022a, 2022b, 2022c).

While this structure can still be found in many parts of India, it is important to consider whether these traditional norms apply to Indian households living abroad, particularly in the West. In Indian immigrant families, Western values may have had a significant impact on traditional values concerning marriage, family, and partner selection. Indian immigrants may encounter health beliefs and systems that are markedly different from those prevalent in their home country (Leckie, 2021; Nayar, 2011).

Management of Childhood Asthma

Asthma medications generally fall into three categories: *relievers, preventers /controllers,* and *add-on therapies* for children with severe asthma. Preventers are usually taken daily and help manage chronic symptoms and prevent acute asthma attacks, while relievers are taken when needed, usually for fast relief (during an acute asthma attack) (Papi et al., 2020; Quirt et al., 2018). Inhalers are the cornerstone of asthma management since they deliver medication directly to the lungs. Asthma medications are also administered orally, via nebulisation, or by intravenous injection. Medication adherence and correct inhaler techniques are key factors in attaining optimal asthma control (Thomas & Pugalenthi, 2022).

There are mainly three types of inhalers: a) reliever inhalers; b) preventer inhalers; and c) combination inhalers (Reddel et al., 2021). Reliever inhalers contain a short-acting inhaled β2-agonist (SABA) that causes bronchodilation, which provides instant relief from breathlessness and is taken when in need, usually during an asthma flare-up. Although relievers provide temporary relief, they do not address the underlying cause of asthma. Relievers have a short-term effect, lasting about two to four hours. Long-acting β2-agonists

(LABA) also have a rapid onset of action and can be used as a reliever medicine, in addition to their use as a controller medicine. SABA (e.g., salbutamol or terbutaline) has a duration of action of 3–5 hours at standard recommended doses, compared to approximately 12 hours for LABA (e.g., salmeterol or formoterol). SABA can also be used before exercise as a measure to prevent exercise-induced bronchoconstriction (Papi et al., 2020; Quirt et al., 2018; Thomas & Pugalenthi, 2022).

Appropriate preventative treatment is critical for asthma management (Schlichting et al., 2021). Medicines that act as preventers work slowly, and it may take up to three months of regular daily use for the child to experience their full effects. Preventer inhalers in the NZ market are usually brown and orange in colour. Most of the preventer medications are steroids and are administered through inhalers and spacers. Clinical studies have shown that the use of ICS can alleviate symptoms, improve pulmonary function, reduce the degree of bronchial hyperreactivity, and decrease the risk of exacerbation, asthma-related hospitalisations, and death, thereby enhancing the quality of life for those with asthma (Maijers et al., 2020; van Aalderen & Sprikkelman, 2011; Ye et al., 2017).

A large body of research shows that ICS are effective and safe for long-term use if used appropriately. A low-to-medium dose of ICS treatment outweighs any potential risks that may be associated with it. Even though children are less likely than adults to develop localised adverse effects, such as oral candidiasis, dysphonia, and hoarseness of voice, they may experience significant discomfort if such symptoms develop. Long-term use of high-dose ICS may be associated with systemic side effects such as stunted growth in children, easy bruising, skin thinning, osteoporosis, glaucoma, and cataracts (Ye et al., 2017).

The devices used to administer inhaled medications to children with asthma include pressurised-metered dose inhalers (pMDIs), dry powder inhalers (DPIs), soft mist inhalers (SMIs), and nebulisers (see Figure 8) (Thomas & Pugalenthi, 2022). pMDIs are the most popular devices for administering inhaled medications. A major limitation of pMDI is the requirement to coordinate actuation and inhalation, which can be challenging for children. The use of spacers and BA-pMDIs assists in resolving this issue. International guidelines on the management of asthma strongly recommend the use of spacers along with the pMDIs. Spacers act as a reservoir for the aerosol plume created when the device is actuated, allowing the patient to inhale the aerosol, effectively obviating the need for good hand-breath coordination. Additionally, spacers minimise the likelihood of oropharyngeal impaction of drug particles, the cold-freon[1] effect, and the possibility of localised side effects caused by ICS (Thomas & Pugalenthi, 2022; Ye et al., 2017).

BA-pMDIs, on the other hand, are equipped with an airflow-sensing mechanism that delivers a single dose at inspiratory flow rates of 25–35 litres per minute. Another type of inhaler, SMI, uses mechanical energy to aerosolise liquid medication and generate a low-velocity mist at a rate of 10 mm/s over 1.1–1.5 seconds, thereby reducing the child's need to coordinate hand-breath movements and reducing the need for the use of spacers (Thomas & Pugalenthi, 2022).

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[1] An inadvertent reaction to the chilling sensation felt at the back of the throat after the actuation of an MDI (Rogliani et al., 2017).

Figure 8

Types of Inhalation Devices for Asthma

<table>
<tr><th colspan="3">Pressurised Metered Dose Inhaler (pMDI) with Spacer</th><th colspan="2">Breath actuated-pressurised Metered Dose inhaler (BA-pMDI)</th></tr>
<tr><td colspan="3"></td><td colspan="2"></td></tr>
<tr><th colspan="5">Dry Powder Inhalers (DPI)</th></tr>
<tr><td>Turbuhaler</td><td>Accuhaler</td><td>Handihaler</td><td>Ellipta inhaler</td><td>Breezhaler</td></tr>
<tr><td> </td><td> </td><td> </td><td> </td><td> </td></tr>
<tr><th colspan="2">Soft Mist Inhaler (SMI)</th><th colspan="3">Nebuliser</th></tr>
<tr><td colspan="2"></td><td colspan="3"></td></tr>
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Note: Reprinted from *Inhaler Devices*, 2018, by Health Navigator New Zealand (https://www.healthnavigator.org.nz/medicines/i/inhaler-devices/).

The use of nebulised medications for long-term asthma control in children is no longer recommended (Reddel et al., 2021). Nebulisers are less effective in administering constant and accurate dosages of medication than pMDIs. As nebulisation usually delivers a higher dose of the drug, there is an increased risk of side effects. Due to this, it results in the wastage of drugs and is, therefore, more expensive than other forms of inhalation therapy (Chandel et al., 2019). However, nebulised medications may be occasionally used to manage acute asthma exacerbations or life-threatening asthma in clinical settings. A variety of medications, including bronchodilators (salbutamol, terbutaline, and ipratropium) and steroids (e.g., budesonide), are typically administered by nebulisation (Reddel et al., 2021; Thomas & Pugalenthi, 2022).

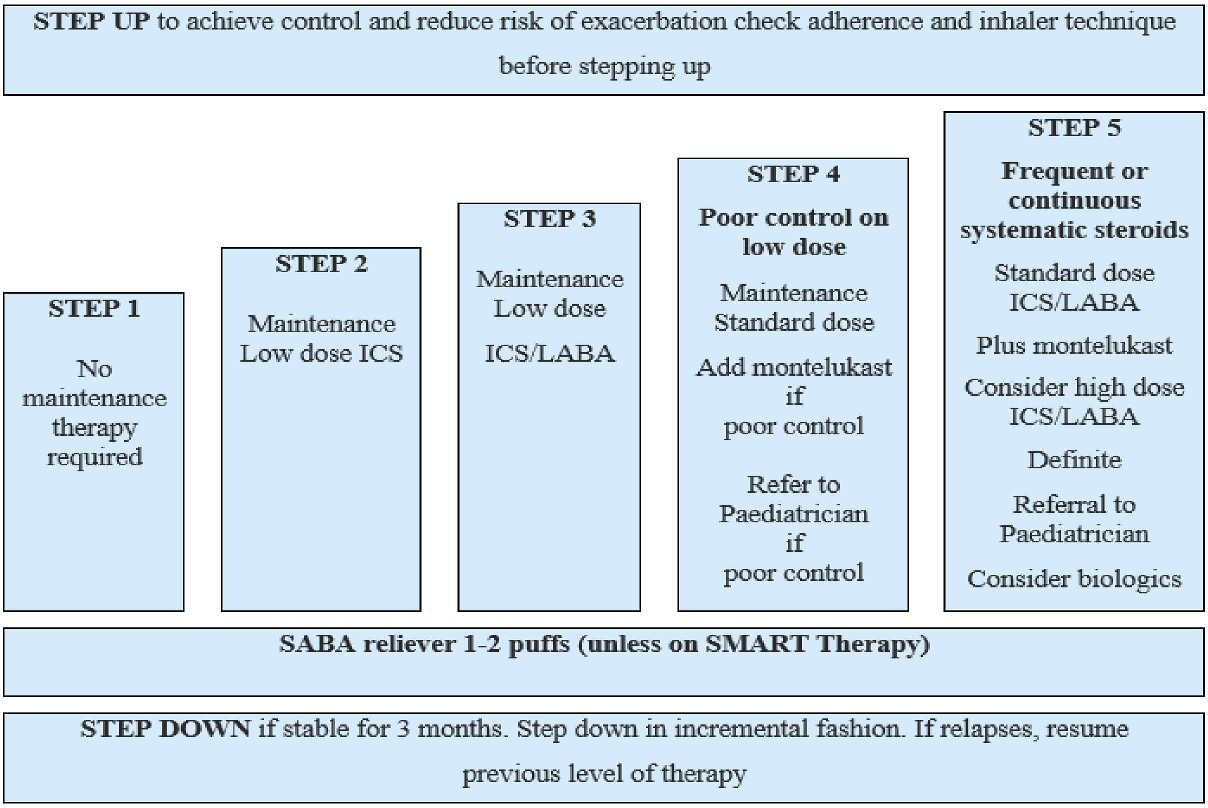
The asthma management guidelines in NZ are divided into three broad categories based on age groups: children below five years of age; children between five and eleven years of age; and adolescents and adults (Beasley et al., 2020; McNamara et al., 2020). The following sections provide an overview of asthma management, with a focus on the latter two categories.

The *stepwise* treatment protocol depicted in Figures 9 and 10 provides guidance on pharmacological management for children aged five to eleven, and adolescents and adults, respectively. HCPs are responsible for initiating treatment at the appropriate step, based on the severity of symptoms. Stepwise treatment is based on the principle that treatment will be stepped up to achieve control and reduce the risk of exacerbations and will be stepped down if the condition remains stable after a prolonged period of control. Thus, the goal of stepwise treatment is to achieve optimal symptom control, manage exacerbation risk, and minimise side effects. The treatment is reviewed regularly to ensure the optimal health of the child (Beasley et al., 2018; Beasley et al., 2020; McNamara et al., 2020).

Figure 9 illustrates the stepwise treatment protocol for managing asthma in children aged five to eleven years. SABA inhalers or relievers are usually prescribed for these children at the time of their diagnosis. NZ's child asthma guidelines clearly state the appropriate timing for the addition of ICS to a child's treatment plan (McNamara et al., 2020). ICS therapy is initiated if children present with symptoms more than twice a week, have used their reliever more than twice a week, experience frequent night wakings, or have had a flare-up requiring oral steroids in the previous year. Additionally, if a child's asthma is more likely to flare-up during a specific season or time of year, ICS therapy may be prescribed during this period. For children, a daily dose that achieves 80–90 percent of maximum efficacy is considered low (McNamara et al., 2020).

Figure 9

Stepwise Treatment Protocol for Managing Asthma in Children Aged Five to Eleven Years



STEP UP to achieve control and reduce risk of exacerbation check adherence and inhaler technique before stepping up

STEP 1
No maintenance therapy required

STEP 2
Maintenance Low dose ICS

STEP 3
Maintenance Low dose
ICS/LABA

STEP 4
Poor control on low dose
Maintenance Standard dose
Add montelukast if poor control
Refer to Paediatrician if poor control

STEP 5
Frequent or continuous systematic steroids
Standard dose ICS/LABA
Plus montelukast
Consider high dose ICS/LABA
Definite
Referral to Paediatrician
Consider biologics

SABA reliever 1-2 puffs (unless on SMART Therapy)

STEP DOWN if stable for 3 months. Step down in incremental fashion. If relapses, resume previous level of therapy

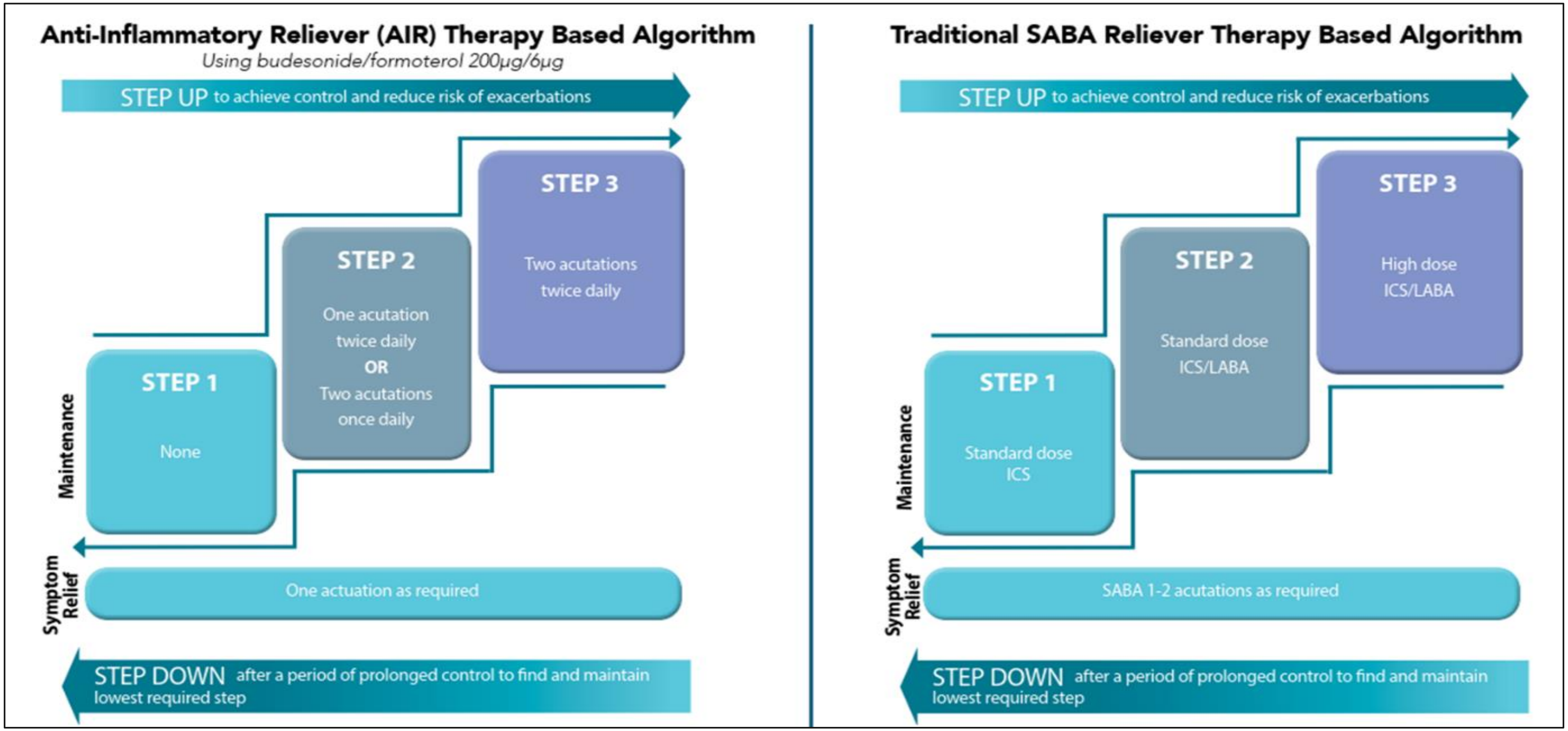
Note: Reprinted from *New Zealand Child Asthma Guidelines: A Quick Reference Guide*, by D. McNamara, I. Asher, C. Davies, T. Demetriou, T. Fleming, M. Harwood, L. Hetaraka, T. Ingham, J. Kristiansen, J. Reid, D. Rickard, D. Ryan, and J. Turner, 2020, Asthma and Respiratory Foundation NZ (https://www.asthmafoundation.org.nz/assets/documents/ARF-NZ-Child-asthma-guidelines-update-30.6.20.pdf). Copyright 2022 Asthma and Respiratory Foundation NZ.

Sometimes, a combination of ICS and LABA may be used both as a reliever and a maintenance treatment for asthma management. This is referred to as *single maintenance and reliever therapy* (SMART). However, current NZ child asthma guidelines do not recommend SMART as first-line therapy in children under 11 years of age, but it may be considered on specialist advice in children who are poorly controlled on Steps 3–5. In school-aged children with poorly controlled asthma who are receiving combined ICS/LABA therapy, Montelukast is being tested as an add-on treatment. A short course of oral corticosteroids is often used in the treatment of acute asthma exacerbations (McNamara et al., 2020).

The latest published NZ asthma guidelines for adolescents and adults include a new stepwise treatment pathway that represents one of the most significant changes in asthma treatment (see Figure 10). SABA-only therapy is no longer recommended for long-term asthma management in adolescents and adults. Although SABAs are effective in reducing acute asthma symptoms, they are ineffective in controlling underlying inflammation. Asthma treatment with ICS/fast-onset β2-agonists improves treatment effectiveness regardless of asthma severity level, while also decreasing potential risks associated with SABA due to patients' tendency to overuse it (Beasley et al., 2020).

Figure 10

Stepwise Treatment Protocol for Managing Asthma in Adolescents and Adults



Note: Reprinted from "Asthma and Respiratory Foundation NZ Adolescent and Adult Asthma Guidelines: A Quick Reference Guide," by R. Beasley, L. Beckert, J. Fingleton, R. J. Hancox, M. Harwood, M. Hurst, S. Jones, S. Jones, C. Kearns, D. McNamara, B. Poot and J. Reid, 2020, *The New Zealand Medical Journal*, *133*(1517), p. 82. Copyright 2020 by NZMA

Budesonide/formoterol is now the standard of care for adolescents and adults experiencing asthma symptoms (Papi et al., 2020). It can be used in two ways. Initially, it can be used for immediate symptom relief alone without maintenance treatment (Step 1). Additionally, this combination can be used both for symptom relief and maintenance by adding additional doses, and relief can be achieved with a single inhaler (Steps 2 and 3). This change has led to the emergence of a new term, *anti-inflammatory reliever* (AIR) therapy, to describe the use of budesonide/formoterol as a reliever medication, with or without maintenance budesonide/formoterol therapy. It is recommended that all adolescents and adults with asthma be prescribed an ICS, but those who are not taking budesonide/formoterol should receive either an ICS or a combination of an ICS/LABA as an alternative to a SABA, both of which require two inhalers (Beasley et al., 2020).

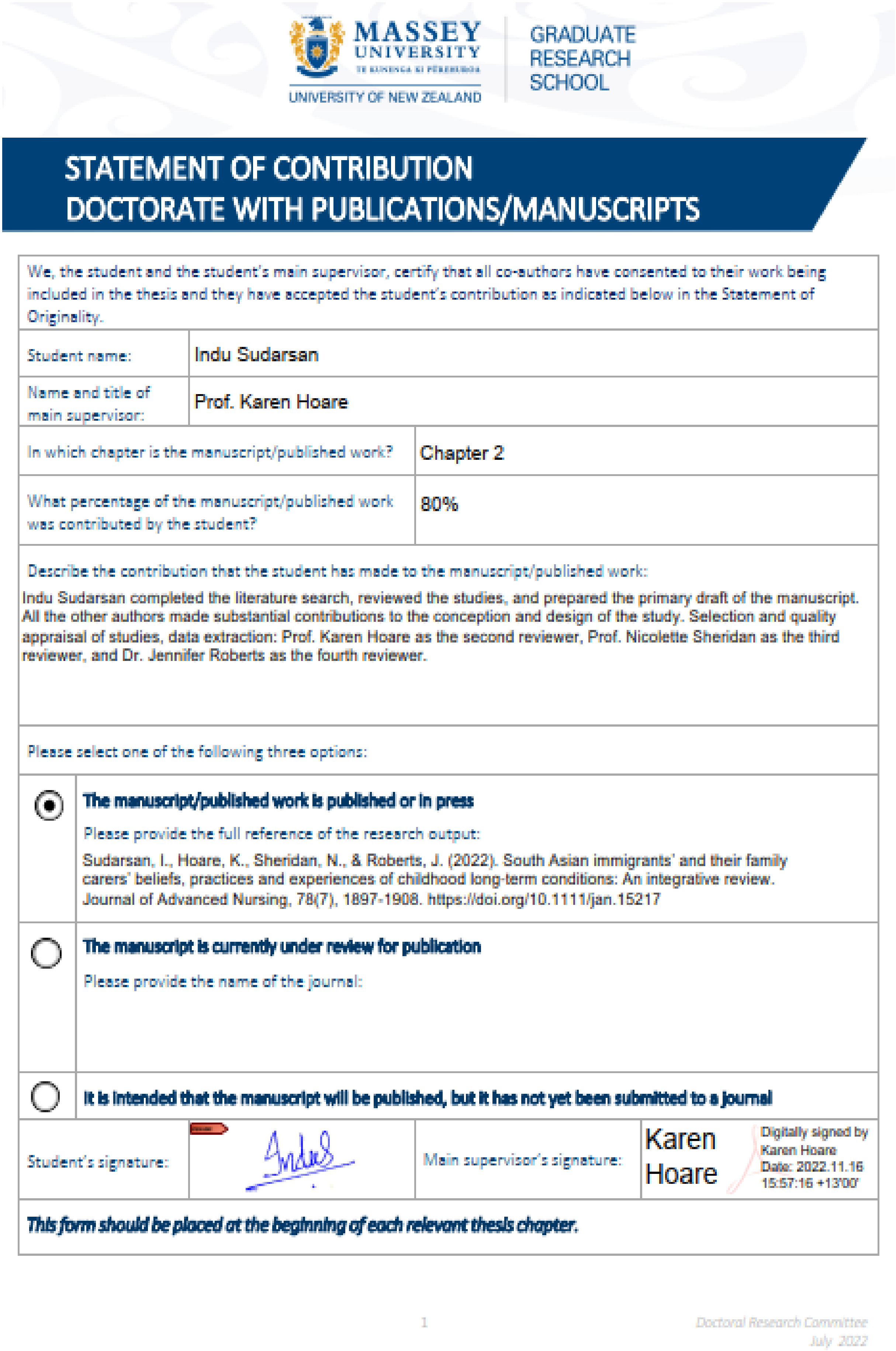
In general, add-on asthma medications are not routinely recommended, but they may be appropriate for certain types of patients, such as those with mild symptoms who cannot tolerate an ICS and those with severe, uncontrolled asthma. Add-on medications include Montelukast, Sodium Cromoglicate (Intal Forte), and Nedocromil (Tilade) for mild asthma, and Tiotropium, oral corticosteroids, and a high dose of ICS for severe asthma. Children with poorly controlled asthma may require repeated courses of oral steroids, which may result in steroid-related side effects such as weight gain, diabetes, psychological side effects, hypertension, and an increased risk of infection (Jat & Gupta, 2022).

Often, the terms *asthma management* and *asthma control* are used synonymously. The management of asthma is typically focused on symptom control, maintaining normal activity levels, and minimising asthma flare-ups, lung damage, and medication side effects. Asthma control is determined by the frequency of asthma flare-ups, the degree to which symptoms interfere with activity and sleep, and the frequency of the need for reliever medications (GINA, 2021). Good asthma control is defined by the absence of symptoms or the presence of very mild symptoms, no emergency department (ED) visits, the absence of flare-ups, no limitations on activities, no sleep disturbances caused by asthma, minimal reliever medication usage (less than twice a week), and fewer side effects from asthma medications. The term poor asthma control refers to persistent symptoms that occur regularly throughout a typical week and adversely affect the patient's quality of life. Poor asthma control necessitates a review of treatment adherence, preventer therapy, and inhaler technique (GINA, 2021).

In NZ, there are a variety of tools available to assess and monitor asthma control. One method is the use of validated questionnaires, such as the Asthma Control Test (ACT), the Child-ACT, and the Asthma Control Questionnaire (GINA, 2021; Mahmoud et al., 2021). According to NZ child asthma guidelines, all children with asthma should have an asthma action plan. Asthma action plans provide a personalised set of instructions for children with asthma (or their caregivers) and are regularly reviewed and updated by their HCPs in consultation with the child and family members. It is recommended to keep a *child asthma symptom diary* to monitor the pattern of symptoms and the response to treatment, which can be beneficial when reviewing the action plan. A smartphone application called *My Asthma app* provides children with asthma and their family caregivers with information about asthma, including signs and symptoms, treatment and prevention strategies, the use of ACT, and where to find helpful contacts and resources. This smartphone application is capable of developing an asthma action plan specifically for each user (Beasley et al., 2020; McNamara et al., 2020).

Integrative Literature Review

The integrative literature review—conducted during, and after the data collection and analysis—is presented in the form of a journal article published in JAN. This journal has an impact factor of 3.187 (2020). As the preliminary search elicited limited studies on asthma, the review was expanded to include all LTCs.



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STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the student and the student's main supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the student's contribution as indicated below in the Statement of Originality.

Student name:	Indu Sudarsan
Name and title of main supervisor:	Prof. Karen Hoare
In which chapter is the manuscript/published work?	Chapter 2
What percentage of the manuscript/published work was contributed by the student?	80%

Describe the contribution that the student has made to the manuscript/published work:

Indu Sudarsan completed the literature search, reviewed the studies, and prepared the primary draft of the manuscript. All the other authors made substantial contributions to the conception and design of the study. Selection and quality appraisal of studies, data extraction: Prof. Karen Hoare as the second reviewer, Prof. Nicolette Sheridan as the third reviewer, and Dr. Jennifer Roberts as the fourth reviewer.

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Sudarsan, I., Hoare, K., Sheridan, N., & Roberts, J. (2022). South Asian immigrants' and their family carers' beliefs, practices and experiences of childhood long-term conditions: An integrative review. Journal of Advanced Nursing, 78(7), 1897-1908. https://doi.org/10.1111/jan.15217

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Student's signature:		Main supervisor's signature:	Karen Hoare Digitally signed by Karen Hoare Date: 2022.11.16 15:57:16 +13'00'

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Article 2: South Asian Immigrants' and their Family Carers' Beliefs, Practices, and Experiences of Childhood Long-Term Conditions: An Integrative Review

Abstract

Aim: The aim was to examine SA immigrants' beliefs, practices, and experiences of childhood LTCs.

Design: This was an integrative review.

Data Sources: MEDLINE, PsycINFO, PubMed, Scopus, and Web of Science were searched for primary peer-reviewed articles published in English between January 2011 and April 2021.

Review Methods: Articles were screened based on PRISMA guidelines. The quality of the studies was evaluated using the Critical Appraisal Skills Programme Checklist for qualitative studies, and the Joanna Brigg's Institute Critical Appraisal Checklist for quantitative studies.

Results: Fourteen studies were included in the review. SA immigrant children and their family carers experienced cultural clashes as they attempted to incorporate their cultural beliefs about long-term conditions into a more Westernised biomedical approach. Families were overburdened by caregiving and struggled to find additional support for their children. The main findings were categorised into three themes: (1) cultural beliefs; (2) religious, spiritual, and CAM practices; and (3) care and support of the child.

Conclusion: Healthcare providers should use a combination of culturally safe management strategies and a nuanced approach to educational initiatives on the biomedical aspects of various long-term conditions to effectively engage SA immigrant families with health services.

Impact: The growth of SAs worldwide, along with the increased burden of LTCs among SA immigrant children, has implications for health service delivery. However, no reviews to date have explored SA immigrants' experience of childhood long-term conditions. Incorporating SA immigrants' beliefs and practices into the plan of care promotes collaborative decision-

making that can lead to better treatment adherence, improved health outcomes, and higher patient and family satisfaction. The findings encourage clinicians, researchers, and policymakers to develop culturally safe child/family-centred interventions to address the specific needs of SA immigrant children with long-term conditions.

Introduction

SA countries continue to be the main sources of international migration (Batra et al., 2019). Geographically, South Asia comprises countries such as Pakistan, India, Nepal, Bhutan, Bangladesh, and Sri Lanka (Mann, 2014). However, countries differ in their definition of the SA group. For instance, in NZ, the term SA also includes people of SA descent who are from Malaysia, Fiji, and other countries (Didham, 2010). In the UK, the SA group refers mainly to the population from the Indian sub-continent (Liu et al., 2016). Despite geographic, religious, and linguistic differences, SAs share many unique cultural norms and social values that may influence their healthcare beliefs and practices (Ramaswamy et al., 2019). The growth of SAs worldwide, along with the increased burden of LTCs among children, has implications for health service delivery (Liu et al., 2016). In addition to the difficulties encountered by any parent of a child with a LTC, the context of being an immigrant makes some experiences, especially daunting (Englund & Rydström, 2012).

Background

SA immigrant children are particularly vulnerable in terms of morbidity and mortality from LTCs (Lakhanpaul et al., 2020; Zechella & Raval, 2016). For example, SA children in the UK are more likely to present with uncontrolled asthma symptoms and become hospitalised with acute asthma exacerbations compared with their White British counterparts (Lakhanpaul et al., 2020). These hospitalisations are often identified as potentially preventable. Similar ethnic disparities in asthma outcomes have also been noted in the USA, NZ, and Canada (Benchimol et al., 2015; Lakhanpaul et al., 2020; Mehrotra et al., 2014; Mehta, 2012).

Health disparities among SA immigrants may be the result of beliefs and practices that contrast with that of HCP’s advice, who are obliged to follow evidence-based guidelines where available (Lakhanpaul et al., 2019). The philosophy of child- and family-centred care (CFCC), which has been widely practised in paediatrics for decades, is central to reducing health disparities (Ford et al., 2018; Gerlach & Varcoe, 2020; Watt et al., 2011). CFCC involves HCPs listening to and respecting families' and children’s perspectives, ensuring that their priorities, knowledge, and beliefs are appropriately integrated into all aspects of care planning and delivery, as well as providing accessible and timely information that supports their participation in decision-making at a level suitable for their maturity and understanding (Gerlach & Varcoe, 2020). However, a growing body of literature indicates an inconsistency in the implementation of CFCC in practice, particularly among immigrants. This could be due to several factors, including a lack of culturally congruent care, insufficient organisational support, budget constraints, and cuts to human resources and services. The challenge for healthcare services is to maintain a balance between the child's best interests, respect for the family and community as a unit, and professional expertise to provide optimal care for the child (Watt et al., 2011).

With the large-scale migration of SAs worldwide, more HCPs will encounter this group of people. No reviews to date have explored SA immigrants' experience of childhood LTCs. However, a few reviews that examined the experiences of childhood LTC among SAs included studies on SAs in both minority and majority settings. Although there is some degree of generalisability of these findings to SA immigrants, it may not be an accurate representation of their illness experience in their host country. SAs may experience ongoing social and cultural transitions because of migration, which may impact their health behaviour and utilisation of healthcare (Ahmed et al., 2018). Therefore, exploring SAs' cultural needs and incorporating them in the host country’s model of care becomes crucial to the optimal management of childhood LTCs. To the best of our knowledge, the current review is the first of its kind to explore SA children's and their family carers' experience of LTC in their host country.

Simultaneously, listening to the voices of SA immigrant children with LTCs is as important as that of their family carers to effective management (Lakhanpaul et al., 2019). However, studies on childhood LTCs among SA immigrants predominantly focus on the voices of family caregivers and HCPs. Only a few studies seek to give voice to SA immigrant children. This is despite Article 12 of the UNCRC, which articulates the significance of giving voice to children in all matters affecting them (Lakhanpaul et al., 2019). The current review addresses this gap by examining studies with first- and second-generation SA immigrant children and young people, as well as studies involving first-generation SA family caregivers.

Conceptual Framework

The tenets of social constructionism served as the conceptual framework to conduct this review. First introduced by Berger and Luckmann, social constructionism is based on the principle that the meanings of social reality are not discovered but constructed by people as they interact in a given context. This concept is widely used to explain the concept of illness (Berger & Luckmann, 1991; Burr, 2003; Conrad & Barker, 2010). Burr (2003) considers illness as a socially constructed phenomenon rather than a fixed physiological entity. Perceptions of illness vary with the values, beliefs, and norms of the group of people being studied. Social constructs related to illness differ not only with groups of people but also with place and time. For example, people's constructs about an illness may vary as they move settings such as when they migrate (Berger & Luckmann, 1991; Burr, 2015). There may also be a change in these constructs as they experience illness over time. For instance, following diagnosis, people may regularly seek and process new information about the condition, which may result in a change in attitude towards the illness and resultant behaviour (Burr, 2015; Gergen, 2015; Gupta, 2010). The current integrative review posits that SA immigrant children with LTCs and their family caregivers construct their own interpretations of reality and shared meanings about various LTCs. These constructs exist in a specific social, cultural, and historical context and may change over time (Burr, 2015; Gergen, 2015).

The Review

Aim: The aim was to synthesise primary research on SA immigrant children's and their family carers' beliefs, practices, and experiences of childhood LTCs.

Design: The modified integrative review framework developed by Whittemore and Knafl (2005) guided this literature review. The main feature that distinguishes an integrative review from other types of literature reviews is its scope; the flexibility in including diverse methodologies (both quantitative and qualitative), empirical and theoretical literature. High quality integrative reviews can guide the development of evidence-based policy and practice initiatives and make recommendations for future research (Knafl & Whittemore, 2017).

Integrative reviews play a key role in transcultural nursing as they allow exploration of complex inherent concepts related to the health-related beliefs and practices of people from diverse backgrounds (Whittemore & Knafl, 2005). However, the key challenge in conducting an integrative review is ensuring rigour as it combines a large volume of data from primary research that employs various methodologies. To address this issue, Whittemore and Knafl (2005) and Knafl and Whittemore (2017) developed systematic methodological strategies specifically for each stage of the review process, thus making it popular as a standard framework for undertaking integrative reviews.

Search Methods: Five electronic databases were searched: CINAHL, MEDLINE, PsycINFO, PubMed, Scopus, and Web of Science. The following keywords and phrases were used: asthma, wheeze, respiratory, eczema, cancer, diabetes, autism, developmental, congenital, illness, sickness, health, chronic, long term, South Asia, India, Pakistan, Bangladesh, Punjab, Gujarat, child, paediatric, adolescent, teenage, young adult, migrant, immigrant, care giver, carer, caregiver, parent, and family. Modifications were made to the search strategy to fit each database. Boolean operators such as ‘AND’ and ‘OR’ combined the keywords. In some databases, truncations such as asterisks (*) were used with the root forms of the keywords to retrieve all the related variant terms and quotation marks (“”) to indicate phrases (see Appendix M). The database search was limited to the years 2011–2021 due to two reasons; firstly, to review the most up-to- date studies, and secondly, due to the last decade seeing the largest migration of SAs (International Organisation for Migration, 2019). The online database search was supplemented by ancestry searching, citation searching, and manual searching of selected journals. Table 3 lists the inclusion and exclusion criteria applied to the literature search.

Table 3

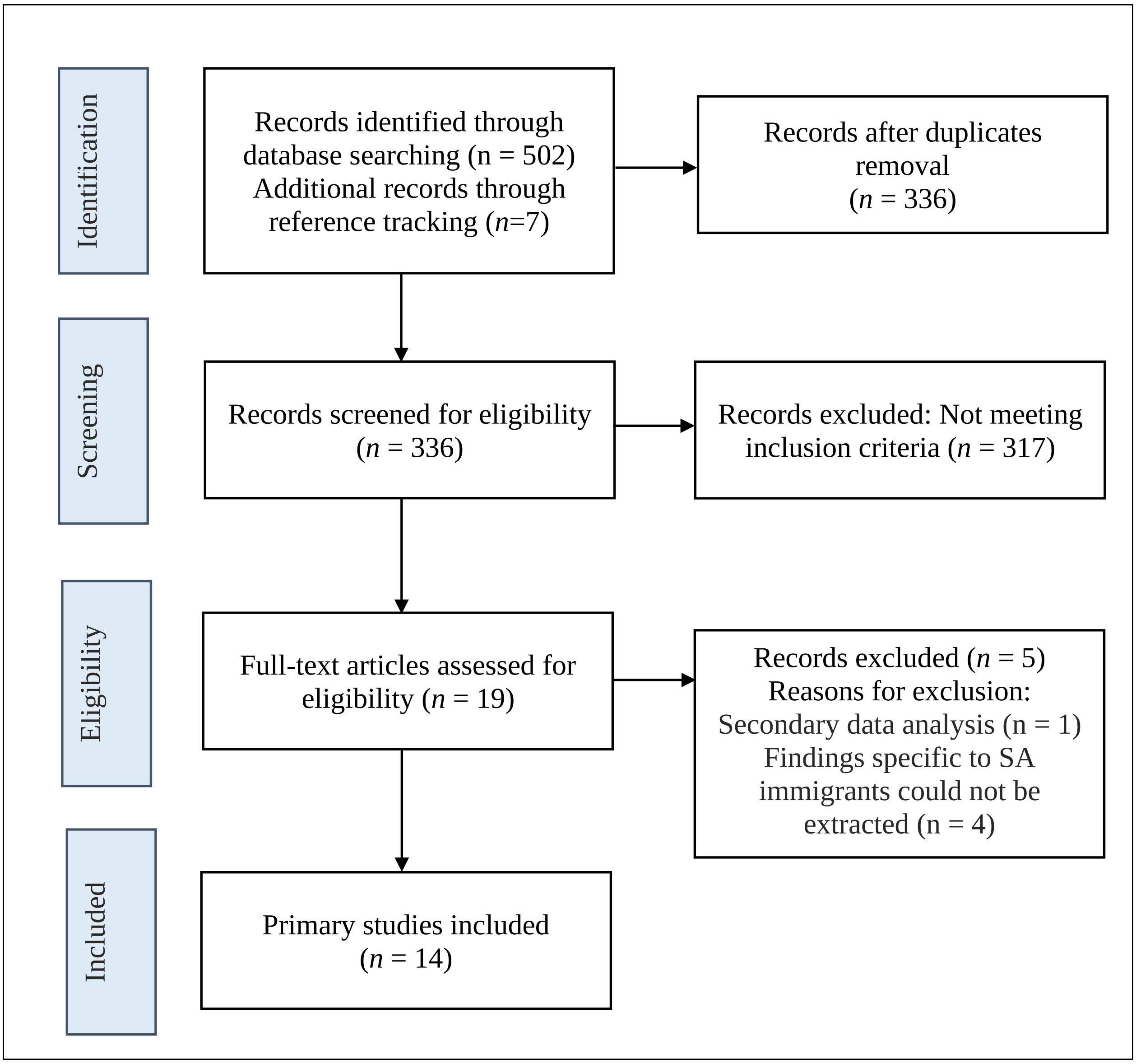
Article Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
1) Participants: SA immigrant children (0-18 years) and young people (10-24 years) (WHO, 2014) with LTC and/their family carers. 2) Includes one of the following: attitudes, beliefs, practices, experiences, or perceptions of children and/ family caregivers. 3) Primary, peer-reviewed studies in English and published between January 2011 and April 2021.	1) Intervention studies. 2) Grey literature (policy, proceedings, etc.).

Search Outcome: Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines were used for the article selection and screening procedure (Moher et al., 2009) (see Figure 11). The first two authors, Indu Sudarsan (IS) and Karen Hoare (KH), independently examined the titles and abstracts from the initial search. Those articles that met the eligibility criteria were chosen for full-text review (see Appendix N). IS and KH separately reviewed the full-text articles and then jointly if there was any doubt or disagreement.

Figure 11

PRISMA Flow Diagram of the Literature Search Process



Note: Adapted from "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement," by D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, and Prisma Group, 2009, *Annals of Internal Medicine*, *151*(4), p. 267 (https://doi.org/10.7326/0003-4819-151-4-200908180-00135). Copyright 2022 by Ovid Technologies.

Quality Appraisal: The quality of the studies was evaluated using the Critical Appraisal Skills Programme Checklist (2018) for qualitative studies (see Appendix P) and the Joanna Brigg's Institute (2020) Critical Appraisal Checklist for quantitative studies (see Appendix O). No studies were excluded following the quality appraisal.

Data Abstraction and Synthesis: A data display table was used to present the data extracted from each study, which included information on the author, year of publication, country, study objectives, sample characteristics, chronic condition, study design, research methods, and key findings. Data analysis involved identifying the constructs of beliefs, practices, and experiences from each study. A constant comparison approach was employed to facilitate the identification of patterns, variations, themes, and relationships when analysing the data. The main findings were categorised into three themes: (1) cultural beliefs; (2) religious, spiritual, and CAM practices; and (3) care and support of the child.

Results

Characteristics of the Studies: Table 4 shows the characteristics of the 14 studies included in the final review. Most studies were qualitative (n = 13) and used a wide range of methodologies such as IPA, GT, case report, descriptive design, constructivist interpretative paradigm, and ethnography. The only quantitative study included in the review used an online survey. Most studies were conducted in the UK (n = 8) with the rest conducted in the United States (n = 4), Canada (n=1) and Ireland (n = 1). The LTCs included: asthma (n = 3), autism (n = 3), cancer (n = 1), beta-thalassemia major (n = 1), and developmental disabilities/intellectual disabilities (n = 6). The age of participants ranged from 2 to 23 years. The majority of studies had parents or grandparents as informants (n = 11). One study included a comparison group of 17 White British parents. Two studies included children as the sole participants, one study was a case report on children, and another study included a child-parent dyad as the focus of observation for an ethnographic study. The sample size ranged from 3 to 66, with a total of 266 participants.

Table 4

Characteristics of Studies Included in the Review

Sl No	Author(s), Year (Country)	Title/Journal	Aim (excerpt from the article)	Methodology/ method	Sample	Types of chronic conditions
1	Croot et al., 2012 (UK)	Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child. *Disability and Rehabilitation*	To explore the coping strategies of Pakistani parents living in the UK and caring for children with severe learning disabilities. To examine factors that influenced participants' choice or ability to use the different strategies.	Qualitative design In-depth interviews	Purposive sampling n = 12 (11 parents and one grandparent) (Children's age: Four–16 years)	Developmental delay, Cerebral palsy, Autism, and other syndromes
2	Daudji et al., 2011 (Canada)	Perceptions of disability among SA immigrant mothers of children with disabilities in Canada: Implications for rehabilitation service	To describe perceptions of disability among SA immigrant mothers of children with disabilities in a large multicultural urban centre in Ontario, Canada,	Qualitative descriptive design In-depth face-face semi-structured interviews	Purposive sampling n = 7 mothers (Children's age: Two–14 years)	Spina Bifida and Congenital spinal cord injury

		delivery *Disability and Rehabilitation*	and to explore how these perceptions influence rehabilitation services.			
3	Heer et al., 2012 (UK)	The cultural context of caregiving: Qualitative accounts from SA parents who care for a child with intellectual disabilities in the UK. *Advances in Mental Health and Intellectual Disabilities*	To contribute to the development of culturally appropriate support and interventions in children's intellectual disability services.	IPA Focused group interviews	n = 9 parents (5 mothers & 4 fathers) (Child's age: Seven–19 years)	Intellectual disabilities
4	Heer et al., 2015 (UK)	The experiences of British SA carers caring for a child with developmental disabilities in the UK. *Tizard Learning Disability Review*	To explore how British SA parents, make sense of caregiving in the context of two different cultures	IPA In-depth interviews	Purposive sampling n = 7 parents (5 mothers and 2 fathers) (Children's age: Seven–14 years)	Intellectual disabilities and Developmental disabilities

5	Habib et al., 2017 (Ireland)	Pakistani mothers' experiences of parenting a child with autism spectrum disorder in Ireland. *Educational & Child Psychology*	To explore the parental experiences of Pakistani mothers living in Ireland who have a child with ASD	Constructivist interpretative paradigm Semi-structured in-depth interviews (5 face to face, 2 Skype)	Purposive sampling Seven mothers (Children's age: Four–17 years)	Autism
6	Kelly & Kelly, 2012 (UK)	Childhood cancer-parenting work for British Bangladeshi families during treatment: An ethnographic study *International Journal of Nursing Studies*	To detail the day-to-day management experiences (including the social and cultural aspects) of cancer treatment for British Bangladeshi children and their parents.	Ethnography Participant observation in the home, community, and clinical settings (22 months) Focused interviews (6 families)	Purposive sampling n = 15 Parent-child dyads (eight mothers and seven fathers) (Children's age: Two and a half–12 years)	Cancer
7	Lakhanpaul et al., 2017	A qualitative study to identify parents' perceptions of and barriers	To explore perceptions and experiences of asthma and asthma management in	Qualitative methodology	Purposive sampling n = 66 (SA carers–	Asthma

	(UK)	to asthma management in children from SA and White British families *BMC Pulmonary Medicine*	British SA and White British families, to identify barriers to optimal management and to inform culturally appropriate interventions to improve management.	Semi-structured interviews	29 mothers, 15 fathers, five secondary carers and White British parents–17) (Children’s age: Four–12 years)	
8	Lakhanpaul et al., 2019 (UK)	Qualitative study to identify ethnicity specific perceptions of and barriers to asthma management in SA and white British children with asthma *BMJ Open*	To explore the perceptions and experiences of asthma in British SA and White British children using semi-structured interviews.	Qualitative methodology Semi-structured interviews	Purposive sampling n = 47 (33 SA and 14 White British children) (Children’s age: Five–12 years)	Asthma
9	Mehrotra et al., 2014 (USA)	Cultural factors impacting asthma management in Asian Indian children *Indian Journal of*	To outline the cultural factors and health beliefs in the Asian Indian population which impact the care and outcome of these patients.	Case report	Purposive sampling n = 3 (Children at a pulmonary clinic)	Asthma

		Allergy Asthma Immunology				
10	Mufti et al., 2015 (UK)	Pakistani children's experiences of growing up with beta-Thalassemia Major. *Qualitative Health Research*	To provide a rich account of children's experiences of living with beta-Thalassemia Major, its management, and the meanings ascribed to these experiences.	IPA Stage 1: Focused group interviews and role plays. Stage 2: Semi-structured individual interviews	Purposive sampling n = 12 SA children (Children's age: Eight–12 years)	Beta-Thalassemia Major
11	Ravindran & Myers, 2012 (USA)	Beliefs and practices regarding autism in Indian families now settled abroad: An internet survey. *Focus on Autism and Other Developmental Disabilities*	To examine beliefs and practices about autism in Indian immigrant families having a child with autism.	Qualitative descriptive design Online questionnaire/Semi-structured telephone interviews	Purposive sampling n = 24 parents (21 mothers and three fathers) (Children's age: Three–15 years)	Autism
12	Theara & Abbott,	Understanding the experiences of SA parents	To investigate the experiences of SA parents	GT	Purposive sampling n = 9 parents, (five	Autism

	2015 (UK)	who have a child with autism *Educational & Child Psychology*	living in the UK who have a child with autism.	In-depth interviews	mothers, two sets of mothers and fathers) (Children's age: Not specified)	
13	John et al., 2016 (USA)	Indian immigrant parents of children with developmental disabilities: stressors and support systems *Early Child Development and Care*	To identify key stressors and social support systems (including spousal support) among Indian immigrant families in the USA raising a child with a developmental disability. To assess the extent of parental stress and perceived quality of social support. To examine the link between parental stress and perceived quality of support	Quantitative study Online survey	n = 33 (25 mothers and eight fathers) (Child's age: Four–21 years)	Autism, Cerebral palsy, Down syndrome, and other developmental disabilities
14	Zechella &	Parenting children with	To examine unique	Qualitative	n = 15 Asian Indian	Developmental

Raval, 2016 (USA)	intellectual and developmental disabilities in Asian Indian families in the United States *Journal of Child and Family Studies*	challenges experienced by Asian Indian parents of children with intellectual and developmental disabilities in the USA, focusing on the cultural explanations of disability, sources of stress and support, immigration experience, and perceptions of the child's future.	Open-ended interviews	parents (8 mothers, 7 fathers) (Child's age: Six–23 years)	disabilities

Key Findings: When interpreting the findings, it is important to remember that SA ethnic groups are diverse, and that the health beliefs, practices, and experiences discussed may not apply to all SA immigrants.

Theme 1–Cultural Beliefs: Several beliefs existed about the causes, symptoms, and management of childhood LTCs (Croot et al., 2012; Daudji et al., 2011; Habib et al., 2017; Heer et al., 2012; Lakhanpaul et al., 2017; Theara & Abbott, 2015; Zechella & Raval, 2016). Family carers' beliefs significantly influenced their child's attitudes towards their illness and its management. Despite the chronic nature of their child’s condition, some family carers believed that it might one day be cured. A significant amount of time and money was spent on experimenting with different remedies, and there were often feelings of disappointment when a child did not respond as expected (Croot et al., 2012; Daudji et al., 2011; Habib et al., 2017; Lakhanpaul et al., 2017; Theara & Abbott, 2015; Zechella & Raval, 2016). In the case of childhood asthma, family carers sometimes limited the use of inhalers unless there were symptoms because they considered asthma to be an acute condition (Lakhanpaul et al., 2017).

Extended families and SA community groups had a powerful impact on carers and their child's approach towards the LTC (Croot et al., 2012; Daudji et al., 2011; Habib et al., 2017; Heer et al., 2012; Heer et al., 2015; Kelly & Kelly, 2013; Lakhanpaul et al., 2017; Lakhanpaul et al., 2019; Mehrotra et al., 2014; Mufti et al., 2015; Ravindran & Myers, 2013; Theara & Abbott, 2015; Zechella & Raval, 2016). SA society held rigid traditional views about some of the LTCs as being bad or serious or deadly or life-threatening or contagious (Croot et al., 2012; Kelly & Kelly, 2013; Lakhanpaul et al., 2017; Mehrotra et al., 2014). As a result, children and their family members received negative views from SA society. They feared stigma, especially if the LTC was visible or if the treatment was evident. For example, parents felt stigmatised if their child's behaviour was disruptive in a public setting because such behaviours were viewed as culturally inappropriate and unacceptable by the local community (Croot et al., 2012). Whilst children with beta-thalassemia major preferred to hide their infusion pumps from public view, children with asthma found using an inhaler in public to be embarrassing (Lakhanpaul et al., 2017; Lakhanpaul et al., 2019; Mufti et al., 2015). SA immigrant families preferred not to disclose the condition because of stigma. They frequently kept their children at home to reduce social interaction and delayed or minimised seeking help (Croot et al., 2012; Daudji et al., 2011; Habib et al., 2017; Heer et al., 2012; Heer et al., 2015; Kelly & Kelly, 2013; Lakhanpaul et al., 2017; Mehrotra et al., 2014; Mufti et al., 2015; Ravindran & Myers, 2013; Theara & Abbott, 2015; Zechella & Raval, 2016).

Regardless of the type of LTC, SA family carers provided several religious explanations for the cause of their child's condition. Many believed that the LTC was the consequence of God’s will and associated it with karma (a concept that one's past actions influence their destiny) (Croot et al., 2012; Lakhanpaul et al., 2017; Mufti et al., 2015; Ravindran & Myers, 2013). Others associated the LTC with a curse from ancestors or a punishment from God, or a test from God (Croot et al., 2012; Zechella & Raval, 2016). Conversely, some parents believed that children with developmental disabilities were a gift from God; they viewed parenting as an opportunity for personal development or discovery of a greater purpose in life (Croot et al., 2012; Zechella & Raval, 2016). Many parents, even with a clear understanding of the medical cause of their child's condition, explored the spiritual meaning of their experiences and identified it as an important coping resource (Croot et al., 2012; Daudji et al., 2011; Habib et al., 2017; Heer et al., 2012; Heer et al., 2015; Lakhanpaul et al., 2017; Lakhanpaul et al., 2019; Mehrotra et al., 2014; Mufti et al., 2015; Ravindran & Myers, 2013; Theara & Abbott, 2015; Zechella & Raval, 2016).

The review provided insights into beliefs specific to certain conditions. SA family carers related the cause of their child's developmental disorders to non-biomedical factors such as vaccine injury, poor medical care during pregnancy, and ineffective parenting (Croot et al., 2012; Heer et al., 2012; Kelly & Kelly, 2013; Ravindran & Myers, 2013). Going out during an eclipse whilst pregnant has been linked to causing developmental disorders by some Indian families because of the belief that it would result in the accumulation of negative energy (Zechella & Raval, 2016). Smoking during pregnancy was cited as the cause of asthma in one study (Lakhanpaul et al., 2017). Mothers were blamed for their child's illnesses based on such beliefs. SA parents believed that asthma is triggered because of a hot-cold imbalance. According to the hot-cold theory, illness occurs when the body’s equilibrium is disrupted by being excessively hot or cold (Roodaki et al., 2018). SA immigrants expected asthma flare-ups if their children had physically cold foods or foods with a cold base (banana, yoghurt, grapes, etc.), had a cold shower or were improperly dressed. Many of them held a misconception around activities as a trigger for asthma exacerbation, which resulted in the imposition of restrictions on a child's activities (Lakhanpaul et al., 2017; Lakhanpaul et al., 2019; Mehrotra et al., 2014).

Theme 2–Religious, Spiritual, and CAM Practices: SA family carers engaged in various religious and spiritual practices to help them cope with their child’s LTC. Offering prayers, visiting holy places, checking horoscopes, making oaths, wearing special stones, and amulets, fasting, and consulting spiritual healers were some examples (Croot et al., 2012; Daudji et al., 2011; Habib et al., 2017; Heer et al., 2012; Heer et al., 2015; Kelly & Kelly, 2013; Lakhanpaul et al., 2017; Lakhanpaul et al., 2019; Mehrotra et al., 2014; Mufti et al., 2015; Ravindran & Myers, 2013; Theara & Abbott, 2015; Zechella & Raval, 2016).

SA family carers used CAM for their children, believing that it had fewer side effects but was as effective as Western medicine (Daudji et al., 2011; Habib et al., 2017; Heer et al., 2015; Lakhanpaul et al., 2017; Lakhanpaul et al., 2019; Mehrotra et al., 2014; Mufti et al., 2015; Ravindran & Myers, 2013; Theara & Abbott, 2015; Zechella & Raval, 2016). Ravindran and Myers (2013) found that many Indian immigrant parents of children with autism adopted a combination of modern treatments and traditional Indian treatment methods (e.g., used Homoeopathy, Ayurveda, Yoga, music therapies, etc.) to ensure the best possible care. Although CAM was used as an adjunct treatment in most childhood LTCs, these practices were especially popular in the case of childhood asthma as parents were concerned about medication side effects, predominantly steroid addiction (Mehrotra et al., 2014). Parents were frequently pressured by their extended older family members to use traditional medicine or other natural treatments for a cure (Heer et al., 2015; Mehrotra et al., 2014).

Theme 3–Care and Support of the Child: Although mothers were typically the primary caregivers in most SA immigrant families, they received enormous support from their spouses in childcare (Croot et al., 2012; Daudji et al., 2011). Mothers stayed at home or worked part-time to care for their children. Caring for their children with LTC was reported as physically and emotionally exhausting. They made personal sacrifices with respect to paid employment or self-care, prioritising the well-being of the child and the family. Mothers balanced multiple roles ranging from being a full-time caregiver to that of an advocate for their child (Croot et al., 2012; Daudji et al., 2011; Heer et al., 2015; Kelly & Kelly, 2013; Lakhanpaul et al., 2017; Lakhanpaul et al., 2019; Zechella & Raval, 2016). They encountered challenges with HCPs and school staff to ensure optimal care for their children (Croot et al., 2012; Habib et al., 2017; Kelly & Kelly, 2013; Lakhanpaul et al., 2017; Ravindran & Myers, 2013; Zechella & Raval, 2016).

Schools were one of the main sources of support, and school services were widely acknowledged as important to the child’s well-being (Croot et al., 2012; Habib et al., 2017; Lakhanpaul et al., 2019; Mufti et al., 2015; Ravindran & Myers, 2013). For children with developmental disorders, some parents found school valuable because it provided them with time away from their children and others found their children learnt new skills (Croot et al., 2012). In contrast, participants also expressed their dissatisfaction with the school system for a variety of reasons, including peer bullying, discrimination from school staff, lack of resources including adequately trained staff, administrative bureaucracy, and poor services

(Croot et al., 2012; Habib et al., 2017; Mufti et al., 2015; Ravindran & Myers, 2013; Zechella & Raval, 2016).

The findings from the review on informal support systems were mixed. Children described their parents as an enormous source of support throughout their illness journey (Lakhanpaul et al., 2019; Mufti et al., 2015). They also reported negative consequences related to parental care that led to overindulgence and overprotection, which reinforced children's perception of being different (Mufti et al., 2015).

Lack of extended family support in the host country was a major concern (Croot et al., 2012; Habib et al., 2017; Ravindran & Myers, 2013; Zechella & Raval, 2016). Some of the studies of participants with asthma and cancer found that carers relied substantially on family and relatives for support. However, studies reporting on children with developmental disabilities revealed that they received little assistance from their extended family network (Croot et al., 2012). Parents with children who had physical and mental disabilities experienced loneliness. They struggled even if they had their extended families in the host country because they did not accept these children due to stigma or challenges related to providing care (Croot et al., 2012). According to a study conducted by John et al. (2016) among Indian immigrant parents of children with developmental disabilities, a negative link was identified between the parents' reported quality of social support and their stress levels. In this study, the most important source of support for the participants was their spouse, followed by support groups and friends, with HCPs at the bottom of the list.

Family caregivers and children expressed diverse feelings about the healthcare services they received. HCPs were appreciated for the informational and emotional support provided which helped them cope with their challenges. Simultaneously, negative experiences with HCPs included a range of areas: lack of proper care during pregnancy resulting in child's illness, delay in getting a diagnosis, not being listened to, showing culture blaming and a discriminatory attitude, poor service quality, etc (Croot et al., 2012; Heer et al., 2015; Kelly &

Kelly, 2013; Lakhanpaul et al., 2017; Lakhanpaul et al., 2019). In the study by Lakhanpaul et al. (2019), some children expressed their concern about feeling ‘left out’ during doctors' consultations, which they highlighted as more family carer-centred discussions. Additionally, one of the significant barriers to building meaningful relationships with HCPs was limited English proficiency which also restricted the family carers from seeking timely care (Croot et al., 2012; Heer et al., 2015; Lakhanpaul et al., 2017; Mehrotra et al., 2014).

Many studies found that health service uptake was low among Indian immigrant parents with certain LTCs, such as developmental and intellectual disabilities (Croot et al., 2012; Heer et al., 2012). Even if they used services, they accessed generic welfare services such as day care, rather than specialist options and long-term respite services. According to the studies, one possible explanation is that most SA children grew up in two-parent families, and children from such households were less likely to use formal services. Poor knowledge about the healthcare system, such as availability and accessibility of services, was yet another key barrier to health service utilisation. Barriers in accessing health services included challenges with appointment accessibility, long waiting times, after-hours access, language barriers, lack of trust in the host healthcare system, etc. (Croot et al., 2012; Heer et al., 2015; Lakhanpaul et al., 2017; Mehrotra et al., 2014).

Discussion

The findings of the review suggest that SA immigrant children's and their family carers' interpretations of LTCs are predominantly based on their sociocultural influences and often contrast with the biomedical models (Heer et al., 2015; Lakhanpaul et al., 2017; Ravindran & Myers, 2013; Theara & Abbott, 2015). For example, the biomedical model shapes people’s perceptions of autism by portraying disability as a deficit and children with disabilities as those who need to be fixed (Bagatell, 2010). Social models, on the other hand, argue that disability is a socially constructed concept, with the sociocultural context having a substantial impact on how children, their families, and the wider society view and manage disability (Theara & Abbott, 2015).

The findings, consistent with the social models, reveal a complex interaction of various sociocultural factors such as cultural beliefs, religious, spiritual, and CAM practices and migration, influencing SA immigrants' experiences of childhood LTCs (Heer et al., 2012; Heer et al., 2015; Lakhanpaul et al., 2017; Mehrotra et al., 2014; Ravindran & Myers, 2013; Theara & Abbott, 2015). This is commensurate with Ahmed et al.'s (2018) systematic review of randomised controlled trials on SA's asthma self-management behaviour. The researchers found out that interventions delivered to SAs in their host country were less effective than those provided to South Asia's Indigenous population. The findings, therefore, emphasise the need to explore the impact of sociocultural factors, which are dynamic and constantly shaped by place and time. CFCC enables HCPs to examine, build on, and incorporate these sociocultural factors into management plans for better compliance. However, in line with other studies, our findings show a significant disparity between what CFCC should be and what occurs in practice (Gerlach & Varcoe, 2020; Watt et al., 2011).

The findings reflect the attitude of SA immigrants. who may choose to keep their traditional beliefs, practices, and experiences to themselves without disclosing it to HCPs. For example, Mehrotra et al. (2014) highlighted the use of CAM as the first-line treatment strategy for childhood asthma by many Indian parents without the awareness of their physician. Some of the factors identified that restricted these parents from disclosing their beliefs and practices included lack of confidence in the host health-care system, fear of being blamed for their beliefs, and fear of discrimination. These findings are consistent with previous research on health disparities among minority groups. For example, similar attitudes were shown by Hispanic parents who hesitated to share their folk-related practices on common childhood illnesses with HCPs (Acorda et al., 2020). On the other hand, SA immigrants may also assume that HCPs share the same tacit understanding as their own.

The findings, therefore, reiterate the call for HCPs to be proactive by asking culturally relevant questions to elicit the SA immigrant children's and family carers' cultural needs and expectations (Englund & Rydström, 2012).

This review has highlighted the interconnectedness of culture and health and the importance of HCPs to work in a culturally safe manner (Curtis et al., 2019). Curtis et al. (2019) describe, “cultural safety is about acknowledging the barriers to clinical effectiveness arising from the inherent power imbalance between provider and patient” (p. 13). Culturally safe HCPs empower SA immigrant families to be involved in their own care and facilitate the development of a mutually agreed realistic care plan (Lakhanpaul et al., 2014). For instance, an awareness of the close-knit family and community structure of SA families will allow HCPs to consider the involvement of extended family members and community experts as a part of the decision-making process. Simultaneously, HCPs should be aware that the extended family and community can be a source of both support (informational, instrumental and emotional support) and stress (contradictory views about treatment options and stigmatising attitude) for the SA family carers and children. Therefore, the exploration of complex family dynamics becomes crucial when working with these families (Daudji et al., 2011; Heer et al., 2015; Theara & Abbott, 2015).

Additionally, HCPs must realise that cultural safety cannot be attained through the application of generalised cultural assumptions (Curtis et al., 2019; Englund & Rydström, 2012; Heer et al., 2015). Although traditional values, beliefs, and cultural norms play a key role in shaping the health behaviours of SA immigrant children and their families, each family differs in their degree of acceptance of these traditional norms. Factors such as education, socio-economic status, religion, degree of acculturation, length of stay in the host country, and English proficiency have a significant impact on an SA immigrants’ health beliefs and practices. HCPs should work on the principle that each member of an ethnic group has their own distinct culture (Heer et al., 2015). These findings are consistent with the results from

Ahmed et al.'s (2018) systematic review, which identified a lack of cultural awareness and a failure to recognise the ethnoreligious heterogeneity in the SA community as the primary reasons for the failure of targeted interventions aimed at improving asthma outcomes. Therefore, the challenge for clinicians, researchers, and policymakers is to develop culturally safe child- and family-centred interventions to address the specific needs of SA immigrant children.

Limitations

The review included studies published only in English. Therefore, not all studies on this topic may have been retrieved. A major portion of the studies focused on one group of LTC– developmental disorders. Hence, the findings are more probably a reflection of the beliefs, practices, and experiences of SA immigrant families who have children with developmental disorders. Moreover, the findings might be a more accurate reflection of family carers' perspectives than that of the children's because most studies listened to the voices of family carers. Given the exploratory nature of this review, differences in beliefs, practices, and experiences between different LTCs, sub-ethnic SA groups and host countries have not been adequately explored. The review also did not distinguish between the experiences of newly migrated and already established SA immigrants. This is significant because an immigrant family's length of stay in a country may influence their healthcare choices. All these limitations should be considered when interpreting the findings of the review and when designing future studies.

Implications for Healthcare Practice and Research

The review demonstrates the significant influence of the sociocultural context in reinforcing the meanings ascribed to childhood LTCs management among SA immigrants. Hence, HCPs should consider the collectivist cultural nature of SA immigrants when planning interventions for this ethnically diverse population. This could be accomplished by integrating cultural assessments into treatment care pathways. The findings have implications for healthcare delivery in general since they emphasise the importance of cultural safety.

Longitudinal studies on how SA family caregivers gain the expertise to manage their child’s illness might help determine the best strategies to support these families. The methods for researching experiences of a SA immigrant child with an LTC are dominated by face-to-face interviews. A broader population can be reached by offering alternative data collection options such as internet-based research methods, alongside the traditional ones. This approach will allow eliciting the views of those who choose to remain anonymous. The current review showed a dominance of family carer-oriented studies despite the increasing emphasis on giving voice to children in all the matters affecting them. Therefore, more child-centred research using child-friendly data collection techniques must be undertaken to obtain a unique and detailed understanding of the experiences of these children. Additionally, future studies should include a wide range of LTCs as well as SA immigrant children from non-English speaking countries. Furthermore, future studies should focus on analysing the health beliefs and practices of individuals in each SA country rather than the entire SA population.

Conclusion

The review provides insights into the disparities in expectations around the management of childhood LTCs that exist between SA immigrant families and HCPs, resulting in misunderstanding and strain in their relationships. HCPs should use a combination of culturally safe management strategies and a nuanced approach to educational initiatives on the biomedical aspects of various LTCs to effectively engage SA immigrant families with health services. The review also uncovers the burden of care for SA family caregivers in the host country and emphasises the necessity of additional support measures. The clinicians, researchers and policymakers can use the findings to better understand and support the needs of SA immigrant families who have children with LTCs.

Postscript to the Manuscript

This integrative literature review identified several key concepts, including SA immigrants' beliefs, practices, and experiences with various LTCs, acculturation issues, the significance of culturally safe care, and the notion of a social constructionist approach to illness. In chapter six, I will discuss and explore further the findings of this review.

The purpose of the integrative review in the context of this study was to advance theoretical sensitivity in the field of LTCs. However, the majority of papers in the integrative review focused on the caregiving experience of parents of children with developmental disabilities. It could be argued that such conditions are mental and behavioural disorders (ICD-10) and as such would provide limited insights into the challenges of managing LTCs in childhood. In spite of this, I found these papers to further enhance my theoretical sensitivity (explained in chapter four) as they primarily discussed the process of cultural clash among SA immigrants caring for children with developmental disabilities when they attempted to integrate their traditional SA cultural values into Western care approaches. These papers ultimately led to a better understanding of the complexities and nuances of SA culture when it comes to caregiving.

Summary

Chapter two, together with the first, outlines the sociocultural, historical, and theoretical context of the study. This chapter has included literature reviews at three distinct phases of the study: the preliminary phase, the data collection and analysis phase, and the theoretical integration phase. The integrated literature review revealed a dearth of studies conducted on Indian immigrant children's asthma, justifying the current study. The next chapter provides an overview of the research methodology used to conduct this study.

Chapter 3–Methodology

> Someone asked me very recently why I have 8 million views on TED– ‘your work resonates, what are you doing?’ What I think my contribution is, what I do well, is I name experiences that are very universal that no one really talks about. That is the researcher in me; that is really part of being a grounded theory researcher–putting names to concepts and experiences that people have. That is the researcher part.
>
> —*Brene Brown*

This chapter presents an overview of the research methodology. The chapter begins with a discussion of factors that influenced my decision to choose a qualitative research approach, followed by an explanation of my rationale for selecting GT. What follows is an explication of my ontological and epistemological stances under the title *research paradigm*, which explains the theoretical framework of social constructionism. The philosophical underpinnings of GT are described, including symbolic interactionism (SI) and pragmatism. The versions of GT will be explored in the subsequent section, and the chapter concludes with my justification for selecting the CGT methodology. The links between paradigms and methodologies are explored. The next section explains how CGT can be one of the appropriate methodological choices to explicitly promote the voice of the child. This discussion is presented in the form of a published journal article in *Research in Nursing and Health* (RINAH). The article also offers a critical analysis of child-sensitive research methods, such as drawing and photography, and explains how they were employed in the current study.

The methodology of a study is its mechanics or logistics (Norwood, 2010). According to Holloway and Wheeler (2010), “research methodology refers to the ideas and principles on which researchers base their procedures and strategies” (p. 35). It deals with the discussion of the methods by which a researcher conducts a specific piece of research and the robust rationales that underpin the way they carry out it (Austin & Sutton, 2014; Grix, 2010).

The judicious choice of research methodology depends upon various factors: the nature of the research question, the philosophical stance of the researcher, the researcher expertise (knowledge, skills, training, and capabilities), and the resources available for the project. Moreover, the methodology guides the researcher in determining the most suitable data collection tools required to attain the study objectives (Holloway & Wheeler, 2010; Rehman & Alharthi, 2016). Given that the central aim of the present study was to develop a theoretical model that explains the beliefs, practices, and experiences of asthma for Indian immigrant children and their family carers, I adopted a CGT approach (Charmaz, 2014). In the following sections, I explain the various steps undertaken to conduct the study and the rationale behind each of them.

A Qualitative Research Approach

Various factors supported my choice of a qualitative approach. A qualitative mode of inquiry seemed to be the best way to answer the research question, as the main aim was to explore a relatively under-researched topic (Richards & Morse, 2012). Qualitative inquiry facilitates intense interaction with human subjects, which enables the researcher to explore the real life of human beings in their natural settings, their perceptions, and the meanings they give to their experiences (Corbin & Strauss, 2015; Denzin & Lincoln, 2008; Richards & Morse, 2012). Gaining insights directly from children and their family carers was fundamental to obtaining a better understanding of Indian immigrant children's asthma.

A qualitative approach facilitates the construction of a theoretical model (Corbin & Strauss, 2015; Richards & Morse, 2012). Unlike quantitative studies, where the testing of hypotheses and theories dominates, qualitative studies give priority to the information collected from the participants. Thus, qualitative inquiry allows the researcher to make sense of complex natural situations, obtain new insights, generate themes, and formulate theories (Corbin & Strauss, 2015; Holloway & Wheeler, 2010).

Moreover, qualitative research focuses on human beings within their sociocultural context, not only on clinical symptoms, thereby moving away from the biomedical model (Creswell & Creswell, 2017). Richards and Morse (2012) further support this by pointing out that qualitative approaches are highly suitable to make sense of “multi-context data” and “varying and shifting phenomena” (p. 28), where there exists the need for reducing and managing the collected data without destroying context and complexity. In summary, qualitative inquiry promotes *thick description* (Holloway & Wheeler, 2010). Denzin (1989) defines a thick description as “deep, dense, detailed accounts of problematic experiences… it presents detail, context, emotion, and the webs of social relationship that joins person to one another” (p. 83). The informed literature highlights the influence of multiple complex sociocultural elements on the experiences of Indian immigrant children with asthma, necessitating an in-depth inquiry into these contextual factors (Lakhanpaul, 2014).

Additionally, the interpretive nature of qualitative research enabled me to acknowledge my prior knowledge and experiences rather than considering them as biases (Sudarsan et al., 2022a, 2022b, 2022c). I believed that I could not separate myself from what I knew or from my personal and professional experiences on the topic. Strauss and Corbin (1998) argue that researchers cannot set aside their personal and professional experiences on the topic under investigation. They recommend that this pre-existing knowledge and experience be used to enhance sensitivity to the meanings in the collected data rather than forcing preconceived explanations.

Furthermore, the present study required a design that was flexible enough to respond to the changing research situation as it involved intense interaction with vulnerable human subjects and unpredictable contexts (Norwood, 2010). Qualitative studies are flexible and can mostly accommodate the unexpected or any challenges that may happen during the research (Bryman, 2004). For example, data collection methods can be modified, or new ones added based on the demands of the situation. Research questions can also be amended, for instance, more narrowed, even after the initial stage of data analysis (Norwood, 2010).

Choosing Grounded Theory over Other Methodologies

The challenge for the novice qualitative researcher is selecting the most appropriate methodology to best answer the research question (Richards & Morse, 2012). Additionally, in the case of student researchers, it is important to choose the design that will allow them to finish the study within the available time frame and funding (Fusch et al., 2017). GT was selected as the most suitable method for conducting the study.

GT is the method of choice when little is known about the area of study and when existing theories are insufficient to explain the phenomenon being studied, necessitating the development of a substantive theory (Birks & Mills, 2015; Charmaz, 2014). GT refers to both the research output and the analytic method used to generate it. *Theory* and *process* are two terms that require explanation when discussing GT.

Theory

Birks and Mills (2015) define a theory as “an explanatory scheme comprising of a set of concepts related to each other through logical patterns of connection" (p. 108). Bryant (2009) argues that theories produced by GT research do not have to be universally explanatory; rather, they are context-specific and should wait for further development, such as strengthening to the level of formal theories. In GT, Charmaz (2014) focuses on interpretive theorising, which is based on social constructionist assumptions (explained later in this chapter). The process of developing abstract interpretations based on people's interactions with the world is known as interpretive theorising. GTs usually generate substantive middle-range theories (Morse, 2001).

It was Merton (1949) who first coined the term *middle-range* to describe the relationship between theory and empirical evidence. According to Merton (1949),

> middle range theories deal with delimited aspects of social phenomena, as is indicated by their labels. One speaks of a theory of reference groups, of social mobility, or role-conflict and of the formation of social norms just as one speaks of a theory of prices, a germ theory of disease, or a kinetic theory of gases. (p. 448)

Later, Glaser and Strauss (1967) discussed middle-range theories in their seminal work, *The Discovery of Grounded Theory*. A clear distinction between grand theories and middle-range theories is made by Charmaz (2014). The category *grand theories* refers to theories which have no basis in systematically analysed data, whereas middle-range theories are abstract explanations of specific social phenomena which are grounded in data.

Glaser and Strauss (1967) also describe substantive and formal/grand theories. While substantive theories explain the empirical areas of sociological inquiry and emerge from studying a specific population, setting, or context (e.g., caring for a particular group of patients, professional education, racial relations, etc.), formal theories explain a formal conceptual area of sociological inquiry and are applicable to a wide range of settings and situations (e.g., stigma, social mobility, deviant behaviour, authority, power, etc.) (Glaser & Strauss, 1967; Holloway & Wheeler, 2010; Salsali et al., 2016; Urquhart, 2019). Substantive theory can be developed into a formal theory by studying the same phenomena in a wide range of settings or situations (Glaser & Strauss, 1967). According to Charmaz (2014), the majority of GT studies result in substantive theories because they aim to address problems in specific substantive areas. For instance, the specific area of interest for this study is Indian immigrant children’s and their family carers’ beliefs, practices, and experiences of asthma.

Process

GT facilitates the exploration of psychosocial processes of behaviour and attempts to identify and explain how and why people act in certain ways in various contexts (Birks & Mills, 2015; Charmaz, 2014; Corbin & Strauss, 2015; Glaser & Strauss, 1967; Urquhart, 2019). According to Charmaz (2014), “processes consist of unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks between. The temporal sequences are linked in a process and lead to change" (p. 17). Consequently, a process has a temporal dimension, phases, and key moments.

GT studies do not necessarily include a *basic social process* (BSP). A BSP refers to a process that occurs gradually over time and has the capacity to explain behavioural changes (Holloway & Wheeler, 2010). However, Glaser (1978) noted that the identification and exploration of a BSP in a GT study can be an added advantage. The best approach to understanding a BSP is to view it in terms of a core category (explained in chapter 4). The BSP is always a core category, but not all core categories are BSPs. There is always a core category in a GT study, but the BSP may not always be present. In contrast to core categories, BSPs account for changes over time.

Two major criteria are used to establish whether a process is central to the social phenomenon under study. The first criterion is the extent to which the core process identified in the data can explain a substantial proportion of the variation in behaviours, regardless of their type or degree. As a second criterion, the components of the process should be logically connected. Therefore, GT emphasises the actions, interactions, and substantive processes that occur in specific social contexts (Charmaz, 2014).

Grounded Theory–The Best Fit

GT is well-suited for investigating health patterns in various populations, ethnic groups, and communities as part of a social justice inquiry (Charmaz, 2011). The GT approach can be used as a means to reveal complex and hidden processes that are pertinent to the substantive context of the study. It has been suggested that GT studies have the potential to explain how inequalities are manifested at the structural and interactional levels. Various forms of inequality exist, including those based on age, race, class, disability, and gender. However, these are contested social constructions that are reconstituted and invoked in numerous ways; they cannot be considered as static variables. Using GT, a researcher determines when, how, and to what extent individuals construct and enforce power, privilege, and inequality (Charmaz, 2014).

GTs are derived from real-world settings and are therefore appropriate for guiding practice (Oktay, 2012). In addition, GTs can predict healthcare and practice issues. The flexible nature of the methodology, coupled with constant comparison and theoretical sampling (explained under the *Main Tenets of Grounded Theory* in chapter 4), allows the researcher to modify the research plan to accommodate the topic's diversity (Charmaz, 2014; Groen et al., 2018). Given the limited evidence around my study topic, I chose a GT approach to explore the social processes that Indian immigrant children with asthma and their families were involved in. My decision to select a particular version of GT was guided by my philosophical assumptions. These philosophical assumptions are termed the research paradigm (Guba, 1990).

Research Paradigm

Guba (1990) defines a paradigm as a basic set of beliefs or worldviews that guides researchers’ actions. It includes the abstract beliefs and principles that determine how researchers view the world, interpret it, and act within that world. This worldview is shaped by the personal biographies of researchers, whose perspectives may be influenced by their background, class, race, ethnicity, and gender. Disclosing and describing the study paradigm is important because it influences the researchers' personal conduct, professional practices, and the position they adopt in relation to their research and ultimately impacts their study findings (Brown & Dueñas, 2020; Denzin & Lincoln, 2008; Sudarsan et al., 2022c).

The fundamental beliefs that define a specific research paradigm can be summed up by the answers provided to three basic questions: the ontological question, the epistemological question, and the methodological question (Guba & Lincoln, 1994). Researchers view the world with a set of values, ideas, and beliefs about the nature of reality (ontology) and truth (Denzin & Lincoln, 2008; Lincoln et al., 2011). The ontological question directs researchers to enquire about the form of reality that exists: “a singular, verifiable reality and truth [or] … socially constructed multiple realities” (Patton, 2002, p. 134). Ontology raises questions about the nature of knowledge and how it can be attained (epistemology), and it determines the relationship of the researcher to the researched. It is the epistemological question that guides researchers to rule out “the possibility and desirability of objectivity, subjectivity, causality, validity, generalisability” (Patton, 2002, p. 134). Thus, the researcher’s worldview determines how they plan the research process (methodology). Researchers must select a research paradigm that aligns well with their ontology to ensure a robust research design (Crotty, 1998; Denzin & Lincoln, 2008; Lincoln et al., 2011; Mills et al., 2006).

Ontological Stance

My values, beliefs, and thoughts align with a relativist ontology. The relativist perspective opposes the idea of absolute truth (realism) and considers reality to be subjective, local, and conditional, and therefore capable of taking on different forms according to each individual's ontological stance (Berger & Luckmann, 1991; Lincoln et al., 2011; Sudarsan et al., 2022c).

Social Constructionism: According to Berger and Luckmann (1991), reality does not wait to be discovered; it is constructed by people. People are born into a physical world that is objective in nature, whereby they contribute to it by their subjectivity through social interaction. This concept is termed social constructionism (Berger & Luckmann, 1991; Burr, 2015). People assign meanings to things they come across, and these things become successfully socially constructed when most people in the group or population acknowledge and practise them. In this sense, language, symbols, food, colour, gestures, and even people are socially constructed and become shared realities (Vera, 2016). For instance, the symbol thumbs up indicates “good job.” Another example is food; people assign certain foods specifically for breakfast, and other specific foods for lunch and dinner. This may vary with different groups. Even people are socially constructed. In some societies, women are assigned to look after children and do housework, whereas men are assigned to earn the family's livelihood. However, people are not usually aware of these social constructions, and they take them for granted in their everyday lives (Berger & Luckmann, 1991; Burr, 2015; Gergen, 2015; Vera, 2016).

Moreover, reality differs with people, time, and the social context and is dependent on how people make sense of each and everything (Berger & Luckmann, 1991). For example, what a Tibetan monk considers "real" will not be real to an American businessman. Another instance is that the notion of childhood has undergone drastic changes over time; what was considered to be "natural" for children to do has changed, as well as what parents are expected to do. Hence, reality does not only depend on culture and historicity but also on the particular social and economic environment prevailing in a particular society at a particular point in time (Berger & Luckmann, 1991; Burr, 2015; Gergen, 2015).

Similarly**,** in my view, each participant in this study may have their own construct of their experiences, and this may be influenced by the context, with different issues occurring at various points in time (Berger & Luckmann, 1991; Burr, 2015; Gergen, 2015). Moreover, my relativist ontological stance seemed appropriate to answer the kind of knowledge that is sought by the research question (Charmaz, 2014). Social constructionism and its application to children's research are described in greater detail in the journal article presented at the end of this chapter.

Epistemological Stance

Identifying the epistemological stance is important as it affects how researchers interpret knowledge in the social context they are researching within (Birks & Mills, 2015). The two main epistemological positions are positivism/objectivism and interpretivism/constructionism. While positivists believe in the existence of an external, objective reality that is independent of the individual, interpretivists reject this notion and argue that multiple realities exist based on how each individual uniquely interprets them (Denzin & Lincoln, 2008; Guba & Lincoln, 1994).

Positivism/objectivism emphasises the significance of objectivity in the pursuit of knowledge as well as the existence of a true reality governed by fixed cause-effect laws (Lincoln et al., 2011). The premise of positivism is that reality is neither contextual nor time bound. Therefore, positivist knowledge can be generalised and replicated. In this stance, knowledge about the world is obtained through our senses, and only that knowledge which can be confirmed by our senses can be genuinely considered as knowledge. This necessitates researchers to distance themselves from the researched and wait for the objective truth to emerge (Aliyu, 2015; Lincoln et al., 2011; Rehman & Alharthi, 2016).

On the other hand, interpretivism/constructionism is based on the principle that knowledge is derived not only through observable phenomena but also from subjective values, beliefs, and interpretations (Lincoln et al., 2011). Interpretivism emphasises that knowledge is constructed through the interaction of individuals with others and their environment. For interpretivists, knowledge is derived through examining and exploring the social world of the participants being studied, with a focus on participants' meanings and interpretations. They believe that knowledge is socially constructed by people within a given context (Aliyu, 2015; Al-Saadi, 2014; Lincoln et al., 2011).

According to Guba (1990), in an interpretivist approach, the researchers and the researched are merged into a single entity, and the findings result from the intense interaction between the two. Researchers assume that they cannot separate themselves from what they know, and their identity and views about the world will significantly influence how they understand themselves, others, and the world (Lincoln et al., 2011). Thus, in this tradition, researchers actively engage with the participants by co-constructing meanings and interpretations with them based on their prior knowledge and experiences. Charmaz used the term *constructionist* to acknowledge subjectivity and the researcher’s active role in the co-construction and interpretation of data (Al-Saadi, 2014; Charmaz, 2006; Lincoln et al., 2011).

I believe in subjectivist/interpretivist/constructionist epistemology. The idea of social constructionism aligns well with my perspectives, and I realise that my epistemological stance fits mostly within this research paradigm (Berger & Luckmann, 1991; Burr, 2015; Charmaz, 2014; Sudarsan et al., 2022c). I agree with Berger and Luckman’s (1991) viewpoint of truth as a state of constant revision rather than something awaiting discovery. Therefore, I believe that social phenomena and the meanings assigned to them are constantly being managed by social actors through interaction. Furthermore, people may give different meanings to the same phenomena based on each individual’s perception. Constructionists also hold the view that no one can perfectly understand the participant’s view and that one can only interpret it (Al-Saadi, 2014; Charmaz, 2008).

The terms *constructivism* and *constructionism* are used ambiguously within the research literature (Charmaz, 2014; Ward et al., 2015). Crotty (1998) makes a clear distinction between these two terms, pointing out that constructivism focuses on “the meaning making activity of the individual mind” and constructionism focuses on the “collective generation [and transmission] of meaning” (p. 58). While constructivism is appropriate for studying unique individual experiences, constructionism allows researchers to examine the impact of culture on people's worldviews and their social relationships (Martin & Gynnild, 2011).

A prefix of *social* adds a new dimension to constructivism, situating it within a social context. This shift in focus allows constructivism to appreciate the role of social interaction and cultural norms in an individual’s learning (Ward et al., 2015). Similar to social constructionism, social constructivism also stresses the role of social interaction in knowledge construction. While social constructionism has a collective focus and highlights the influence of researcher to the research and researched, social constructivism takes a more psychological stance. Thus, social constructivism is closely related to social constructionism, or they are a part of a continuum.

Although Charmaz refers to her GT as a constructivist GT, she clarifies her stance in her 2014 book as a social constructionist. Her choice of the constructivist label for her style of GT was a result of her disagreement with some of the approaches of early social constructionists (the absolute relative stance by radical constructionists) (Charmaz, 2014). In other words, her construct of *constructivist* is that of *social constructionist*. Furthermore, Charmaz (2014) acknowledges that her version of CGT incorporates elements of both social constructionism and social constructivism. Social constructionist version of GT enabled my role as an integral part of the research to be acknowledged. Therefore, emphasis was placed on the analysis of participant experiences/constructions and perceptions of phenomena in light of the context in which they exist, along with a focus on the researcher as an integral part of the research process (Charmaz, 2014; Ward et al., 2015). Given that I was researching with children in this study, my choice of social constructionism over constructivism may be questioned, given the latter's synergy with developmental connections to childhood and knowledge acquisition. This question can be addressed by emphasising the continuum along which social constructionism and social constructivism coexist (Charmaz, 2014; Ward et al., 2015).

In this research, given the strong collectivist nature of Indian culture, I believed that the asthma experience of the participants could not be restricted to a merely individual or biomedical context. Indian immigrants' perceptions, beliefs, and practices about asthma may be influenced by multiple factors, including wider structural influences, their sociocultural backgrounds, and social interactions (Hudson et al., 2016; Lakhanpaul et al., 2020; Mehrotra et al., 2014). Reality, according to social constructionists, is a product of both individual and social experience. I confirmed that a social constructionist approach would be a better choice for this study than a social constructivist approach because focusing solely on the individual experience might not provide a complete picture of participants' asthma experiences (Aburn et al., 2020; Ward et al., 2015). Social constructionism is greatly influenced by the concept of symbolic interactionism (SI) (Charmaz, 2014).

Symbolic Interactionism: SI provides the philosophical foundations of GT. SI originates from the pragmatist traditions of George Herbert Mead and his student Herbert Blumer. Mead was the main proponent of the concept of SI. However, the term symbolic interactionism was coined by Blumer (Birks & Mills, 2015; Blumer, 1969; Charmaz, 2014).

According to Mead (1934), the development of an individual’s social self is influenced by members of society and is shaped by their relationships and expectations. First, people try to model themselves after the most influential people in their lives. Then, they act based on others’ expectations, and this shapes their behaviour (Burr, 2015; Holloway, 2008; Mead, 1934). SI focuses on the social meanings people attach to things and the world around them, as well as how they respond to these meanings. The basic assumptions of SI were initially explained by Blumer (1969). The assumptions of SI include: (a) “human beings act towards things based on meanings they have for them” (Blumer, 1969, p.2). These ‘things’ may comprise of self, objects, other individuals, values, beliefs, activities of others, institutions, and situations or any combination of these; (b) the meanings of things arise out of human interactions, and (c) meanings are modified through interpretive processes people use as they deal with things they come across. People are involved in the process of SI throughout their lifespan; they develop meaning from their interactions, and what they observe is understood within the context of this meaning (Blumer, 1969). Pragmatism is the philosophy that underpins SI (Charmaz, 2014).

Pragmatist philosophy is based on the principle that reality and knowledge are based on beliefs and practices that are socially constructed (Chamberlain-Salaun et al., 2013). However, some forms of these social constructions are more helpful for individuals than others. Pragmatists consider reality as true if it allows people to make satisfactory relations with their experiences (Kaushik & Walsh, 2019).

Pragmatism, according to Mead (1936), is a "practical sort of philosophy" (p. 352). Goles and Hirschheim (2000) explain this with an example. Positivistic researchers always consider an object with a flat surface and four legs as a table, regardless of how it is being used. In the case of constructivists, they consider a table as a table if they eat off it, a platform as a platform if they stand on it, and a bench as a bench if they sit on it. However, a pragmatist defines these objects based on their usefulness for them. For example, the object will be defined as a table if they plan to eat off it, a platform if they plan to stand on it, and a bench if they plan to sit on it (Goles & Hirschheim, 2000). Therefore, for a pragmatist, the definition of an object is not based on what it is or how it is being used, but rather on how it helps the pragmatist achieve their purpose (Kaushik & Walsh, 2019). Nursing is a practice-oriented profession, so a pragmatist approach to nursing is most effective.

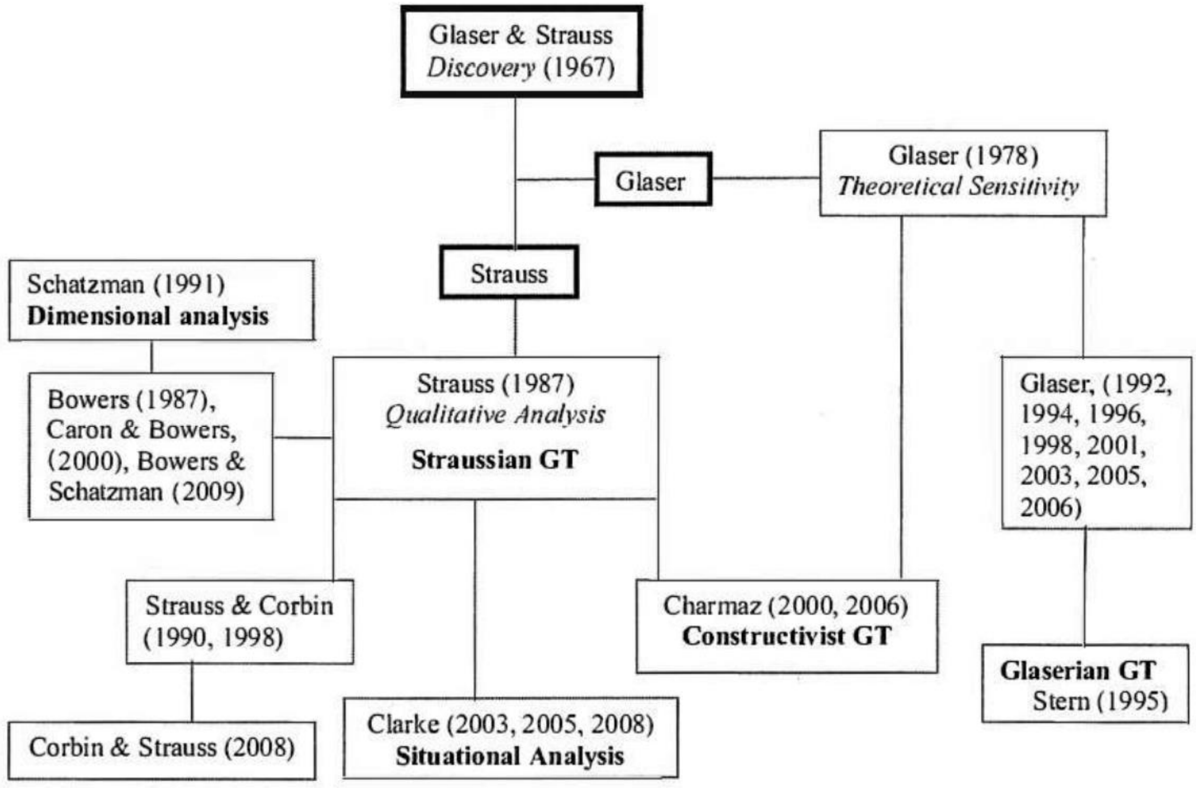
Different Versions of GT

Most researchers use the term *versions* or *variants* when talking about different types of GT (Reichertz, 2019; Rupsiene & Pranskuniene, 2010). There are three distinct versions of GT. These include the perspectives of Barney Glaser, Anselm Strauss and Juliet Corbin, and Kathy Charmaz. These versions differ significantly in three areas: philosophical perspectives, methods of engaging with the literature (refer to chapter two), and coding procedures (refer to chapter 4) (Gibson & Hartman, 2013).

Glaser and Strauss introduced GT in the 1960s when they were doing a collaborative research project entitled *Awareness of Dying* (Glaser & Strauss, 1967). The study examined the process of dying and explored the interactions between medical staff and terminally ill patients in hospices. During the research project, they realised that the formulation of a theory would be more appropriate than testing preexisting theories (Glaser & Strauss, 1967). This led to the development of GT methodology, which they considered efficient enough to bridge the "embarrassing gap between theory and empirical research" (Glaser & Strauss, 1967, p. 2). They defined their new methodology as "the discovery of theory from data" (Glaser & Strauss, 1967, p. 1); it became a major innovation in social research, where the quantitative approach dominated (Thornberg, 2012). Later, they published their seminal book on GT, *The Discovery of Grounded Theory*, to explain the principles of GT methodology (Glaser, 2002).

Figure 12

Genealogy of Grounded Theory: Major Milestones



Note: Reprinted from "Tussles, Tensions and Resolutions," by J. M Morse, In J. M. Morse, B. J. Bowers, K. Charmaz, J. Corbin, A. E. Clarke, and Stern, P. N. (Eds.), *Developing Grounded Theory: The Second Generation* (p. 17), 2016, Routledge. Copyright 2009 by Taylor & Francis.

Glaser and Strauss's initial version of GT, known as *Classical GT/Glaserian GT/Traditional GT*, is based on positivism/objectivism (Birks & Mills, 2015). According to Glaser (1967), reality is independent of researchers and can be discovered only if researchers set aside their personal and professional experiences. Therefore, he wants them to stay as distant observers to allow the data to speak for itself (Glaser & Strauss, 1967). Thus, the GT researchers assume the role of a neutral inquirer (objectivist) who attempts to identify the patterns in the data and discovers the theory that explains the reality grounded in the data (realist) (Singh & Estefan, 2018).

Glaser denied the necessity of having any philosophical orientation while undertaking a GT study (Glaser, 2005). He argued that the philosophical dimensions of the research would be shaped by the research question and the specific context as the study progresses (Glaser, 2005; Singh & Estefan, 2018). However, Thornberg (2012) criticises Glaser’s rejection of the researcher taking any prior philosophical stance by pointing out that his principle of letting data speak for itself is based on positivism/objectivism as its embedded philosophical stance.

While Glaser remained consistent with their version of objectivist classical GT, Strauss later moved away to a more post-positivist version (with a relativist perspective) that acknowledged the existence of multiple realities (Birks & Mills, 2015). Strauss collaborated with Juliet Corbin and made some revisions to the original version of GT. Their revised version of GT came to be known as *Straussian GT,* which they elaborated in their book, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, (1990) and was underpinned by the philosophy of pragmatism and SI (Kenny & Fourie, 2014).

Strauss’ new position was not against Glaser’s realist idea of the existence of an independent reality. Straussian GT is based on the concept that the researchers cannot perfectly apprehend reality; they can only obtain a close representation of it by maintaining an objective and practical stance (Corbin & Strauss, 2015). They acknowledged the influence of the researcher’s background on the research process and devised a more systematic method to conduct a GT study in a way that minimises the subjectivity of the researcher and maximises objectivity (Birks & Mills, 2015; Corbin & Strauss, 2015).

While Glaser used pure induction to develop a GT, Strauss and Corbin included deduction (forming a hypothesis based on the data collected and testing it) during the analytic phase (Birks & Mills, 2015). One of the key contributions of Straussian GT was the development of a highly organised and analytical coding framework, which helps in the systematic deduction of theory from data (Kenny & Fourie, 2014). This coding framework has been cited as helpful for novice GT researchers and those who need more structure to guide their analysis However, their approach received criticism for being overly prescriptive and for restricting the researchers from creatively engaging in the research process (Singh & Estefan, 2018).

Glaser strongly criticised Straussian GT for its prescriptiveness and argued that their method results in forcing the data into preconceived categories rather than allowing the theory to emerge from the data (Glaser, 1992). Glaser expressed his protest against Straussian GT by publishing a book titled *Basics of Grounded Theory Analysis: Emergence vs. Forcing* (Kenny & Fourie, 2014). He claimed that Strauss's book is without conscience, "bordering on immorality" (Glaser, 1992, p. 5). Similarly, Charmaz (2000) also criticised Straussian GT by pointing out that the approach involves an extreme "maze of techniques" (p. 512). She highlighted the axial coding and stated that it results in "awkward scientific terms and clumsy categories" (Charmaz, 2000, p. 525), which deviate from participants' experiences and complicate analysis with excessive jargon (Kenny & Fourie, 2014). However, even before these criticisms were published, Strauss and Corbin had already clarified the use of their coding mechanisms. They recommended that their coding techniques could be adjusted to different contexts and used more flexibly, a recommendation which Glaser and Charmaz overlooked in their critical analysis (Kenny & Fourie, 2014; Strauss & Corbin, 1990).

The restructuring of GT did not end with Glasserian and Straussian GT. Kathy Charmaz, a former student of Glaser and Strauss, developed a third version of GT known as CGT (Birks & Mills, 2015). Charmaz initially discussed the concept of CGT in 1990 when she explained a constructivist approach to the GT research process. She suggested incorporating reflexivity in GT design and reconsidering the relationship of the researcher to the research (Charmaz, 1990).

Charmaz's concept of acquiring knowledge about reality differed from that of Glaser, Strauss, and Corbin. According to Charmaz (2014), the researcher plays an active role during the research by passionately engaging with the participants, whose existing knowledge and previous experiences form the basis of how he or she approaches the research field. Thus, the researcher, instead of taking a neutral position, interprets the data obtained based on her knowledge and experience, thereby co-constructing the knowledge, resulting in constructivist grounded theory (Singh & Estefan, 2018). CGT considers the researcher's position, perspectives, privileges, and interactions as an integral part of research reality. Charmaz (2009) states, "knowledge rests on social constructions. We construct research processes and products, but these constructions occur under preexisting structural conditions, arise in emergent situations, and are influenced by the researcher's perspectives, positions, interactions, and geographical locations" (p. 130). Thus, CGT takes an ontologically relativist, an epistemologically subjectivist, and a methodologically interpretivist approach (Gardner et al., 2012).

Charmaz (2014) argues that each individual constructs their own meaning of reality that makes sense to them and then acts on it according to that meaning. She believes in the possibilities of multiple perspectives on reality in this highly complex social world. Thus, according to Charmaz (2008, 2014), social reality is multiple, constructed, and processual.

The key concept that guides CGT is social constructionism. Something is said to be successfully socially constructed when the majority of people in a group agree on its common meaning. Once these meanings are collectively adopted, social constructs tend to be fixed and can be difficult to change. This makes social constructionism a powerful concept (Burr, 2015; Charmaz, 2014; Gergen, 2015).

According to Charmaz (2014), objectivist grounded theorists aim to arrive at generalisations by separating the developed GT from any contingencies or conditions associated with its data collection and analysis. Therefore, there is the possibility of incomplete, inadequate, or missing information that may undermine the process of developing a robust theory. Charmaz (2006) further argues objectivity as an elusive and debatable concept, especially since researchers' definitions of objectivity may still reflect partial knowledge, specific priorities, and a particular position. CGT, on the other hand, seeks contextualised interpretations of studied phenomena as opposed to oversimplified explanations and generalisations. Due to the inherent reflexivity and relativity of the CGT methodology, constructivist grounded theorists can conduct a more in-depth critical analysis of their own construction of the research process and research participants' construction of their experiences. In CGT, action is an important concept, and it is viewed as the consequence of socially constructed situations and social structures. CGT attempts to answer what and how questions, whereas objectivist GT explicitly aims to answer why questions. Objectivist grounded theorists emphasise abstract comprehension of empirical phenomena and object to the necessity of situating this comprehension within the research context (Birks & Mills, 2015; Glaser & Strauss, 1967).

Charmaz (2014) also did not rely purely on induction and recommended making use of deduction and abduction during analysis to make sense of the collected data. A real surprise in the data causes genuine shock and the search for new explanations. Bryant and Charmaz (2007) define abduction as “a type of reasoning that begins by examining data and, after scrutiny of these data, entertains all possible explanations for the observed data, and then forms hypotheses to confirm or disconfirm until the researcher arrives at the most plausible interpretation of the observed data” (p. 603). Abductive reasoning allows the reunion of the themes of the logic of discovery and the logic of justification, thereby bringing them together into analytical considerations (Bryant & Charmaz, 2007).

The standard approach to abduction starts when grounded theorists come across an unexpected/surprising finding, which leads them to follow these steps: (1) explore all potential theoretical concepts that could contribute to the finding, 2) go back to the field and collect more data to verify these concepts, and 3) accept the most reasonable theoretical interpretation (Morse et al., 2016). According to Charmaz (2014), abduction facilitates further exploration of unexpected observations by prompting data collection in varying directions and allowing reexamination of data, which enriches theory construction. She also recommended going back to the participants to check if the formulated theory makes sense to them (Charmaz, 2014).

Charmaz's version of GT provoked varying responses (Kenny & Fourie, 2014). Glaser (2002), through his article entitled *Constructivist Grounded Theory?* responded by describing CGT as a "misnomer" (p. 1). He argued that CGT lacks the fundamental features of pure GT, such as conceptualisation, abstraction, and systematic theory formulation. Bryant defended Charmaz by arguing that GT researchers actively co-construct rather than neutrally discovering a GT as they would certainly have an interpretive influence over the analysis. Bryant further extended his support by pointing out that CGT "rescues the key ideas of the method" and is "far more potent and coherent" than Classic GT (Bryant, 2003, para. 25).

Strauss died in 1996 before the introduction of CGT; however, Corbin disclosed her acceptance of the new version before his death (Corbin & Strauss, 2008; Kenny & Fourie, 2014). Corbin continued to publish on GT after Strauss's death. She modified the underlying philosophical orientations of Straussian GT and relaxed the prescriptive coding systems (Corbin & Strauss, 2008; Kenny & Fourie, 2015). Later, Corbin wrote about the existence of multiple realities and the creation of knowledge through understanding these multiple viewpoints. She also suggested that data is co-constructed by the researcher and participants. Importantly, Corbin's version of Straussian GT took the methodology in the direction of CGT (Charmaz, 2014; Kenny & Fourie, 2015).

Choice of Constructivist Grounded Theory

As I searched for the version of GT that provides the best ontological and epistemological fit with my philosophical position, the concept of CGT appeared most suitable one. My views aligned well with relativist ontology and constructionist epistemology, which fit well with the philosophical assumptions of CGT. Thus, I viewed the current study through a social constructionist lens (Sudarsan et al., 2022a).

In addition, I believed that my background knowledge and experience could significantly contribute to the current study. My experiences could have an impact on my perspectives on asthma, and they could also potentially influence data collection and analysis. I found it challenging to completely set aside all my assumptions in relation to this research. A CGT approach allowed me to acknowledge and use my personal and professional experience, whereas objectivist grounded theory would have required me to suspend all my assumptions (Charmaz, 2008; Singh & Estefan, 2018; Sudarsan et al., 2022c). I was aware of the significance of being conscious and transparent about these experiences and not assuming that the children and the family carers taking part in this study would share similar experiences and perspectives. My experiences served as sensitising tools that assisted in understanding and exploring Indian immigrant children's and their family carers' experience of asthma (Birks & Mills, 2015).

Throughout this research, I have incorporated my personal and professional interests as I brought my views and experiences to the study. The influence of my previous knowledge and experience, and my values and beliefs related to asthma could not be ignored, and are described elsewhere (Sudarsan et al., 2022c). Furthermore, by sharing a common immigrant background with the participants and being an Indian immigrant mother, my own cultural understanding may have had an influence on the interaction and ultimately on the knowledge produced. I was an outsider in the context that I did not have any children with asthma. Moreover, being an aged care RN in NZ, my primary responsibility was caring for the elderly population. I had no professional experience caring for Indian immigrant children suffering from asthma. However, I had experience working with elderly Indian immigrants with asthma. Thus, in this approach, I examined my position through an ongoing reflexive process, as my experiences might impact the findings of the study. Articulating my feelings about the ability to take an emic (insider) and etic (outsider) perspective as an instrument of research lends transparency to the research process (Birks & Mills, 2015; Hoare et al., 2012b; Sudarsan et al., 2022a, 2022b, 2022c).

Reflexivity, as explained in chapter one, includes two important aspects. The first is explaining researchers' experience with the area under investigation, and the second is discussing how it influences their interpretation of the phenomena (Creswell, 2007). Reflecting on my personal and professional experiences with Indian immigrant children's asthma and my immigrant background, along with the preliminary literature review, enhanced my theoretical sensitivity (Sudarsan et al., 2022c; Thornberg, 2012). Researchers need to engage in a reflexive exercise at the start of the research process to explore their ontological and epistemological positions, and they should maintain reflexivity throughout the research process. To foster reflexivity, I had been writing down my thoughts in the form of memos since I first started thinking about this topic and all the way through the study (Birks & Mills, 2015; Sudarsan et al., 2022c).

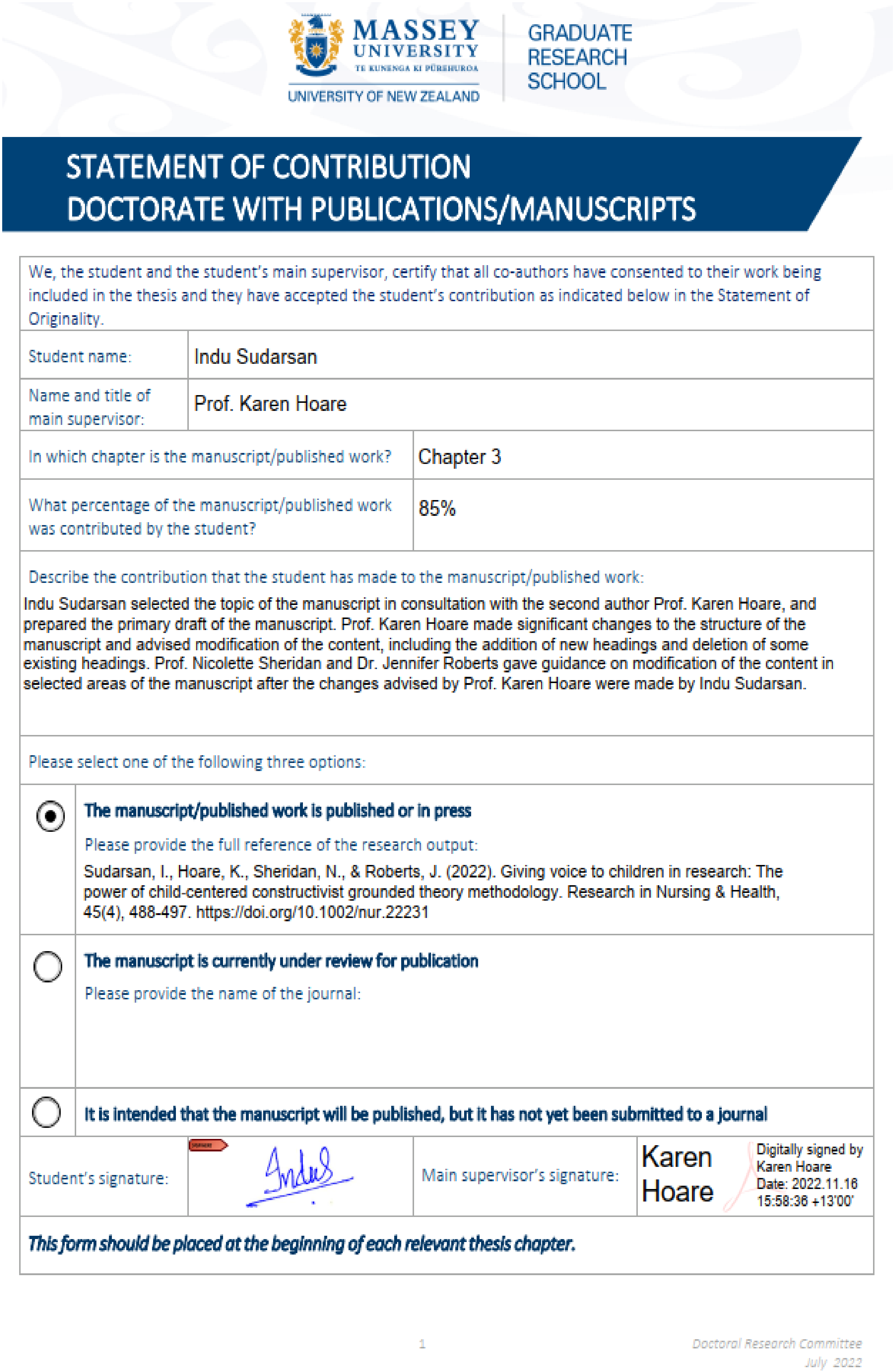
Therefore, the constructionist approach allowed an insider's view and enabled me to develop an interpretative understanding of the participants' beliefs, practices, and experiences within their complex social backgrounds (Charmaz, 2011). The principles of CGT guided me to address the objectives of the present study. CGT is based on the following basic principles: (a) entering into other people's worlds is essential to understand their experiences completely; (b) exploration of the social context in which subjective experiences are located is pivotal; (c) being reflexive is essential; and (d) acknowledgment of differences in power relationships and distinctions between people, as well as societal hierarchies, is important (Charmaz, 2014).

Thus, the CGT approach allowed me to develop intimacy with the research context, interact with the participants while co-constructing their own understanding of their feelings, beliefs, practices, and experiences, and amplify their voices in communicating results from the study (Charmaz, 1990, 2008, 2011, 2014).

The theory generation in CGT takes into account the time, place, culture, and context where the phenomena take place (Charmaz 2003). The CGT approach is useful to understand local problems, which may change over time and as the context changes. Hence, in this study, the adoption of the CGT permitted a rich construction and understanding of the experience of asthma for Indian immigrant children and their families within their local social context (Charmaz, 2014). The current study was conducted in one of the main cities in NZ, in the early 21st century, with the Indian immigrant families and in a situation where asthma was common with active interventions available to reduce the disease severity. This context provided a set of circumstances which has led to specific findings which might not be seen at other times, places, or cultures (Charmaz 2008).

Furthermore, by using the CGT methodology, I was able to focus on Indian immigrant children's and their families' actions based on their definitions of social situations (Charmaz, 2014). I could also explore the implicit meanings of their health behaviours in their relative social contexts and examine the structures that affect these meanings. CGT's utility in understanding immigrant experiences of chronic illnesses has been demonstrated previously (Charmaz, 2011; Dastjerdi et al., 2012; Kim & Hocking, 2018). The adoption of a CGT approach while studying chronic illnesses may assist HCPs to get a better understanding of patients' values, beliefs, and actions than those readily available in healthcare settings (Charmaz, 1990, 2011).

The appropriateness of CGT in giving voice to children is presented in the form of a journal article published in RINAH. This journal has an impact factor of 2.228 (2021).



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STATEMENT OF CONTRIBUTION DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

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Student name:	Indu Sudarsan
Name and title of main supervisor:	Prof. Karen Hoare
In which chapter is the manuscript/published work?	Chapter 3
What percentage of the manuscript/published work was contributed by the student?	85%

Describe the contribution that the student has made to the manuscript/published work:

Indu Sudarsan selected the topic of the manuscript in consultation with the second author Prof. Karen Hoare, and prepared the primary draft of the manuscript. Prof. Karen Hoare made significant changes to the structure of the manuscript and advised modification of the content, including the addition of new headings and deletion of some existing headings. Prof. Nicolette Sheridan and Dr. Jennifer Roberts gave guidance on modification of the content in selected areas of the manuscript after the changes advised by Prof. Karen Hoare were made by Indu Sudarsan.

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1

Doctoral Research Committee
July 2022

Article 3: Giving Voice to Children in Research: The Power of Child-Centered Constructivist Grounded Theory Methodology

Abstract

There has been a growing interest in giving voice to children in response to the introduction of the UNCRC and evolving sociological discourses on childhood. Using child-sensitive methodologies such as CGT enables children's voices to contribute authentic, meaningful, and eventually more actionable data, capable of informing policies and practices in children's best interests. In this article, we discuss how researchers using CGT can privilege children's voices through effective knowledge co-construction by creating a child-sensitive research space and using methods that are appropriate to their abilities and interests. We draw on selected data from the first author's (IS) PhD project that explores Indian immigrant children's and their family carers' beliefs, practices, and experiences of asthma in NZ. We encourage researchers to consider CGT as one of the appropriate methodological choices to explicitly promote the voice of the child.

Keywords: Asthma, children's voices, child-sensitive methods, grounded theory, social constructionism

Introduction

There has been a burgeoning interest in giving voice to children in recent years in response to the introduction of the UNCRC and evolving sociological discourses on childhood (Cudjoe et al., 2021; Cuevas-Parra et al., 2020; Eastham & Kaley, 2020; Lundy, 2018). These models portray children as active and competent social actors who have the right to be engaged in decision-making concerning their lives. Children are thus considered capable of influencing societal issues and policies affecting them. These contemporary models of childhood emphasise the significance of researching *by* and *with* children rather than *on* them, by listening to their words, emotions, actions, and social interactions. Moreover, it has been argued that without their voice, understanding the lives of children would be incomplete (Eastham & Kaley, 2020; Stirrup, 2017).

A social constructionist perspective builds on the principle that children’s beliefs and their knowledge about the world are actively constructed through their interactions with one another and their surroundings (Berger & Luckmann, 1991; Freeman & Mathison, 2009). These constructions are context-specific and cannot be comprehended without a thorough analysis of society, history, and culture. Social constructionists, therefore, challenge the widely held belief that children experience life in a universal manner and claim that their experiences become meaningful when considered in light of multiple contexts (Charmaz & Thornberg, 2021; Greig et al., 2013).

Understanding childhood as a social construction also has an impact on how researchers approach children and position them in the research process (Mah et al., 2020; Smith, 2011). Researchers who follow social constructionist principles view children as competent individuals who can provide researchers with ideas and knowledge, and who deserve to be informed and respected. Moreover, the inclusion of children's voices in research is considered essential to elicit rich, first-hand data on their experiences and perspectives. Supporting children's voices is a challenging and multifaceted task, however. Researchers should undergo a significant paradigm shift in their attitudes, behaviours, and thinking if they are to genuinely support children's voices (Eastham & Kaley, 2020; Peters & Kelly, 2015; Smith, 2011; Tay-Lim & Lim, 2013). In tandem with these developments, there is a growing interest in choosing research methodologies tailored to the rights of children. CGT methodology is one such methodology that is appealing to researchers. CGT, developed by Kathy Charmaz, is an interpretive version of Barney Glaser's and Anselm Strauss's classic GT (Charmaz, 2016; Farragher & Coogan, 2020; Hoare et al., 2017).

While there is a wealth of literature illustrating the wide range of approaches and methods that can be used in research with children, very little is published regarding the use of CGT as a child-sensitive methodology. In this article, we begin by explaining relevant theoretical perspectives of childhood that have informed our argument in favour of using CGT when researching with children, followed by a brief overview of the first author's (IS) current doctoral study that required children's active participation. In the next section, we discuss various rationales for selecting CGT as the methodology to privilege the voices of children for the current study. In the final section, we use selected data from IS's doctoral project to critically analyse how in-depth, semi-structured interviews employing drawing and photography facilitated engagement with children. This section also highlights the importance of ensuring child-sensitive research spaces and techniques in promoting children's voices. Although family carers were also interviewed to provide insights into their child's experiences of asthma, the focus of this article is on how to include children's voices in research.

Theoretical Perspectives of Childhood

Researchers' assumptions about children influence how they conduct research and the knowledge they produce. Children's voices can only be promoted by using methodologies that are based on theoretical frameworks that recognise and respect their assets, competencies, and developmental context (Mah et al., 2020; Smith et al., 2021). We draw on three important perspectives to describe the rights and theories of childhood. These perspectives are: the UNCRC, Vygotsky's sociocultural theory of cognitive development, and childhood studies (Peters & Kelly, 2015; Smith, 2013; UNICEF, 1989).

The UNCRC has significantly influenced children's participation in research as a means of exercising their participatory rights (Cuevas-Parra, 2020). Introduced in 1989, the UNCRC consists of a set of universal standards that were developed to give voice to children and young people. Child participation is one of the core principles of the UNCRC, which advocates the rights of children and young people to freely express their views and participate in decisions on all matters affecting them (UNICEF, 1989). Articles 12 and 13 of the UNCRC demonstrate these rights:

Article 12 (respect for the views of the child) states:

> Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child: the views of the child being given due weight in accordance with the age and maturity of the child. (UNICEF, 1989, p. 4)

Article 13 (freedom of expression) reinforces Article 12 and states:

> The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice. (UNICEF, 1989, p. 4)

Article 12 should be interpreted in conjunction with Article 5 of the UNCRC (Lundy & McEvoy, 2012). Article 5 points out the rights of adults in providing proper guidance and direction to the child which is consistent with the evolving capacities of the child. Adults' rights over the child are expected to gradually lessen and eventually stop as the child matures. The UNCRC acknowledges children's legal status as minors while also enabling adults to act as advocates, mediators, proxies, and interpreters as needed (Ford et al., 2018; Lundy & McEvoy, 2012; Mutambo et al., 2019). Therefore, the people with whom children develop close relationships play a key role in their life as they structure children's lives and give meaning and direction to their experiences. These relationships and the key role they have are commensurate with Vygotsky's sociocultural theory of cognitive development (Smith, 2013).

Vygotsky, a Russian psychologist, claimed that children actively construct knowledge through collaborative activity. He associated the influence of sociocultural environment to children's cognitive development and questioned the notion of universal child development by Jean Piaget (Greig et al., 2013). Piaget's staged account of a child's cognitive development emphasised how children constructed their perspectives of the world through individual activities. His theory received criticisms for restricting understandings of children's capabilities and ignoring the sociocultural influences that shape their development. In contrast, according to Vygotsky's sociocultural theory, a complex interaction of several social, cultural, and historical factors determines how children respond to various situations and may vary with person, place, and time. The focus of Vygotsky's theory is the role that social interaction plays in children's development (Smith, 2011). Social interaction contributes significantly to children's knowledge acquisition; they learn as they interact with their family members, friends, and other members of society. Importantly, children do not just copy what they see around them but actively attempt to make sense of it. At the same time, adults assist children in the development of their higher cognitive functions, such as thinking and problem-solving. Children's development is therefore co-constructed. The term co-construction acknowledges children's active role as competent participants in their own development and adults as those with adequate expertise who guide them. Vygotskian views urge researchers to consider the quality and nature of the child's environment, age, social relationships, culture, and experiences while interpreting their perspectives (Eastham & Kaley, 2020; Greig et al., 2013).

Childhood studies emerged as a critique of the portrayal of children as a social minority group who lack independence, confidence, intelligence, rationality, and autonomy (Smith, 2013). Childhood studies have substantially contributed to recognising children's agency and social construction of childhood. Agency refers to the ability of children to comprehend, actively participate in, and influence the world around them, demonstrating competence in all matters affecting their well-being (Cudjoe et al., 2021; Ford et al., 2018; Mutambo et al., 2019). Furthermore, childhood is viewed as a social construct that changes through time based on values, beliefs, philosophies, and cultures, even within the same society. The way society constructs childhood can have a significant impact on how children participate in various aspects of life. Importantly, with the evolution of childhood studies, the concept of childhood is embraced in a way that ensures the best interests of children and affirms that children's voices are not ignored or that the access of dominant discursive realms to them is not limited. For example, children who were previously classified as highly vulnerable, such as those with chronic medical conditions, are now considered knowledgeable about their illness experience. It is argued that these children's viewpoints can only be elicited from them, and their viewpoints are likely to differ from those of their adult caregivers, who usually talk on their behalf (Mah et al., 2020; Mutambo et al., 2019).

The Doctoral Study

Childhood asthma is one of the major health issues among Indian immigrant children in NZ (Mehta, 2012; Scragg, 2016). Despite the lower prevalence rates compared to other minority ethnic groups, the potentially avoidable hospitalisation rates due to asthma among Indian immigrant children are higher than their NZ counterparts. Moreover, asthma is the first leading cause of PAH among this group, whereas dental conditions and ear, nose, and throat infections are placed second and third, respectively (Mehta, 2012; Plunket, 2015; Wong & Tsang, 2018). Despite the steadily growing population of Indian immigrants in NZ, little research has been conducted on childhood asthma. In contrast, among the limited international studies on childhood asthma, most of the studies focus on the experiences of family caregivers and health professionals; relatively few studies examine children's perspectives.

NZ ratified the UNCRC in 1993 and is obliged to align the laws and policies of the country to the convention's standards, which are in the best interests of children (Dalli & Stephenson, 2010). The progress of incorporating the UNCRC into policies, laws, and processes, however, has been slow over the last 25 years (The Children's Convention Monitoring Group, 2018). Additionally, one of the priority child rights issues identified by the UNCRC Monitoring Group in NZ is “Piecemeal approach to gathering the views of the child” (UNCRC Monitoring Group, 2015; p. 1). The Ministry of Vulnerable Children (2017) is therefore actively seeking the input of experience of children and young people to improve the current health services.

The underrepresentation of Indian immigrant children with asthma in research has led to a discrepancy in knowledge to inform practice. As children are the only ones who can provide the most accurate information about their experiences, it is imperative to listen to their perspectives regarding their experiences of asthma. However, in some cases, it is equally important to consider the adults' perspectives on their child's condition to gain a comprehensive picture of the situation. For example, Indian family caregivers' beliefs on chronic conditions such as asthma shape the context in which they provide care to their children (Lakhanpaul et al., 2019; Mehrotra et al., 2014). Moreover, Indian children often identify themselves in reference to the people around them and the social circumstances they find themselves in. Change can only occur with the help of those with whom the child interacts the most. This may be because of their collectivistic cultural orientation, where familial, and community preferences are given more importance than individual preferences (Benuto et al., 2014).

The challenges of including children in decision-making and making their voices heard are acutely marked in the Indian context (Chadda & Deb, 2013; Raina et al., 2020). Children are considered inferior to adults, who have the absolute authority to make decisions on their behalf. Adults also do not expect children to challenge their decisions. Additionally, in authoritarian parenting, which is popular among Indian families, children are expected to obey, depend on, and work together with parents and other elder family members in all matters affecting them. Parents may use a system of strict guidelines to develop, regulate, and evaluate their children's behavior. While authoritarian parenting does not imply a lack of compassion on the part of the parents, it emphasises the culturally rooted nature of Indian parenting, which can create a power imbalance between parents and children. Indian immigrant children's power to participate in research, contribute meaningfully, and influence decisions that affect their lives are highly influenced by their parents or family carers (Kuppens & Ceulemans, 2019; Sondhi, 2017). Therefore, eliciting Indian family carers' insight into their child's asthma experiences and their experiences of being a carer to a child with asthma are extremely important.

According to Mah et al. (2020), there is no problem in relying on adult perspectives, nor is it problematic to combine adult-generated with child-generated data. The reliance on adults' views becomes problematic when their observations are used instead of children's own voices as the only evidence of a child's experiences. Thus, IS framed the study's central aim as exploring the beliefs, practices, and experiences of asthma among Indian immigrant children and their family carers.

Constructivist Grounded Theory: A Child-Sensitive Methodology

To answer the research question, the authors required a methodology that enabled exploration of the social construction of childhood and that acknowledged its complexity, plurality, multiplicities, and diversities. This demanded a methodology that was open and flexible so that the child participants could gain ownership and control over the research process (Kyritsi, 2019; Poku et al., 2019). CGT as an interactive methodology was chosen and data were obtained through in-depth semi-structured interviews. There were other specific rationales for choosing CGT. First, CGT was chosen as it is best suited to study a topic about which little is known. Second, CGT is an appropriate methodology to explore interactions between people and their social settings and to investigate the complex social processes involved. For example, CGT has been proven as an excellent methodology for studying the experiences of people who are negotiating a new social environment, such as immigrants, or who are in the process of adapting to a recently diagnosed chronic illness. Finally, CGT can be used to undertake social justice inquiry and to investigate the relevant established impressions afresh (Birks & Mills, 2015; Charmaz, 2014; Oktay, 2012).

In CGT, children take a more active part in the co-construction process, collaborating with researchers to select those aspects of their experience that are most meaningful to them. Therefore, CGT gives authority and respect to the voices of children (Abma & Schrijver, 2019). The key to knowledge co-construction is the concept that the lived experiences of both children and researchers always influence the knowledge generated throughout the research. Hence, CGT assumes that researchers cannot completely set aside or bracket their knowledge and experience and can be utilised in the co-construction of knowledge during the research (Charmaz, 2016; Hoare et al., 2012b; Mah et al., 2020).

In the current study, IS occupied a complex position in relation to studying Indian immigrant children's asthma experiences. Being an Indian immigrant parent in NZ and a former Indian paediatric nurse, she occupied an insider (emic) position. Moreover, she knew many Indian immigrant children with asthma in NZ through social networking. However, she was also an outsider (etic), as she did not have any children with asthma or had nursed any Indian immigrant children with asthma in NZ. IS reflected on her position as the researcher, co-constructing knowledge with the participants, and how she could potentially move along a continuum between an emic and etic researcher at different stages of the research process (Charmaz, 2016; Hoare et al., 2012a). Reflection not only entails exploring the researcher's assumptions, knowledge, and experiences about the phenomena under investigation but also determining how these factors influence their interpretation of those phenomena and interactions with participants. Listening to children's needs based on self-reflection and co-constructing children's experiences through shared interaction helps to address the power imbalances between the adult researchers and children, facilitating children's genuine involvement in research (Poku et al., 2019; Roa, 2019).

To foster reflexivity, IS had also been recording her thoughts in the form of memos from the early stages of the study. Memoing is an integral part of grounded theory and is an informal written record of the researcher's thoughts on the collected and analysed data.

Memos explain how and why decisions for all the actions taken associated with research, and thus they stimulate analytic thoughts and are the key to conceptualisation (Birks & Mills, 2015).

Research Description

Ethical approval was granted by the Massey University Human Ethics Committee. The study sample included Indian immigrant children (8−17 years old) and their primary caregivers. This age range was chosen based on the evidence that research with children aged 7 years and older is most effective in eliciting meaningful data (Eastham & Kaley, 2020). The recruitment occurred through multiple channels based on the inclusion and exclusion criteria (see Table 5); these included general practices and schools from selected suburbs of Wellington and through various Indian cultural associations.

Table 5

Participant Inclusion and Exclusion Criteria

Participant Type	Inclusion Criteria	Exclusion Criteria
Child	• Indian immigrant children (8−17 years of age). • Diagnosed with asthma for at least 1 year. • Residing in NZ for at least 1 year. • Able to speak and comprehend English. • Able to understand what the research involves and give assent or consent to it	• Too unwell to take part. • Having other long-term illnesses (except eczema and allergic rhinitis). • Children with food allergy as well as asthma.
Family Carers	• Having child or children (8−17 years old with asthma) • Able to speak and read English.	• Unable to speak and read English.

Potential participants were given adequate time to consider whether they wished to participate in the study, allowing them to make a fully informed and voluntary decision. While the children had the option to select the venue for the data collection, the interviews occurred in an environment of the family caregivers' choice where they felt their children would be most comfortable, a potential reflection of the collectivistic nature of Indian families. Simultaneously, IS ensured that children were comfortable in the setting chosen by their family caregivers. The study initially employed a purposive sampling technique. In-depth open-ended semi-structured interviews were conducted with children and their family carers which were digitally recorded and transcribed verbatim.

IS employed participatory data collection methods such as drawing and photography to facilitate interviewing younger children under 14 years. She was flexible in using these child-sensitive data collection methods. For instance, some children preferred both drawing and photography, while others preferred neither. With the latter case, IS tried different methods based on the child's interests, such as storytelling and puzzles. Older children may consider these methods inappropriate for their age or babyish (Stirrup, 2017). Nevertheless, there was also the option for them to choose these child-sensitive methods or any other if the situation deemed it necessary. Concurrent data collection and analysis took place accompanied by memoing and theoretical sampling.

Using theoretical sampling (Charmaz, 2014), IS was able to gain a deeper understanding of the participant's contextual and cultural interactions. For instance, during the initial stages of analysis, we realised that most children and their family carers were concerned by the negative judgment of asthma by others in the Indian community. Based on our analysis and follow-up memos, we understood that social stigma had a major impact on the participants' asthma care decisions, thus making it an early potential category titled *fear of shame, blame, and discrimination*. We added new questions and probes to the future interviews to further explore this category using theoretical sampling. Further exploration of this category took place by selecting participants from diverse backgrounds, such as family carers with and without asthma histories, Indian children raised in NZ and children who migrated from India, younger and older children, and family carers with and without professional healthcare backgrounds.

Giving Voice to Children through Co-construction of Data

In CGT, the success of giving voices to children depends largely on the researcher's ability to employ the data co-construction technique properly (Farragher & Coogan, 2020; Poku et al., 2019; Tay-Lim & Lim, 2013). CGT researchers may, however, face challenges in co-constructing data with children, including implementing child-inclusive techniques, and providing a child-sensitive research environment. Researchers who fail to unlock the potentials of children as constructors, thinkers, and communicators within the construction process can disempower children, and tokenise their status as autonomous agents (Eastham & Kaley, 2020; Tay-Lim & Lim, 2013). Hence, methods that provide children with shared control over language and concepts are critical for ensuring that their voices are heard effectively. To accomplish effective data co-construction, children should be provided with the appropriate assistance they need to develop and express their opinions and should be placed in a social environment that fosters effective communication (Freeman & Mathison, 2009; Smith, 2013).

IS ensured an informal and flexible interview atmosphere for children to have their say. Special attention was taken to use developmentally appropriate vocabulary that makes sense for children to elicit knowledge about their beliefs, practices, and experiences about asthma. Children were not forced to answer questions or take part in activities that they did not want to do, and their verbal assent was sought on an ongoing basis. Additionally, verbal cues such as splutters, laughter, and nonverbal cues (eye-contact, silence, gestures, body language, and facial expression) were also collected to best gauge their response to different questions and to monitor their interest in the interview (Carter & Ford, 2013; Due et al., 2013; Peters & Kelly, 2015; Webber-Ritchey et al., 2021).

The duration of the interview varied with each child depending upon their attention span. Attempts were made to engage children by diverting them to another activity or a different topic if they seemed to lose interest in the conversation. If these attempts failed, interviews were terminated pleasantly. The interview was also paused as required; sometimes the child got distracted with other children in the house or seemed to have nothing more to contribute. IS invited family carers to accompany the children throughout the interview because she felt their presence would help to balance the researcher-participant power dynamics. Furthermore, if the interview occurred at home, not giving children the opportunity to have their parents present seemed inappropriate. While the carers' presence may enhance the child's narrative as they can assist in memory recall of events, it may restrict some children from expressing their views freely as there is a high chance that they can potentially dominate during the interview and the children's voices may remain unheard (Melton et al., 2014; O'Reilly & Dogra, 2016).

To minimise interruptions during the interview, family carers were informed of the objective of interviewing children separately to allow them to give their opinions and to listen to their voices. Despite this effort, there were interruptions during the interview when parents disagreed with children contradicting or correcting them or vice versa, making it more challenging for the children's voices to be heard. Interestingly, interviews conducted in children's homes provided the opportunity for other family members to add their thoughts and comments after the interviews. These incidental interactions provided valuable information about their attitude towards the child's condition and their asthma care experiences with the child (Eastham & Kaley, 2020; Melton et al., 2014).

Drawing and Photography: Reflecting on the drawings and photographs at the start of the interview enhanced co-construction beyond what was possible with interview methods alone, allowing for a richer and more complex understanding of children's experience of asthma (Mah et al., 2020). Children chose what they wished to draw about their asthma and were given the option of guiding discussions about it. Most children enjoyed these techniques, which facilitated the establishment of rapport between IS and the children. IS did not employ any strict guidelines when it came to discussing their drawings. While some children talked as they drew, others talked about their pictures once they finished. Drawing enabled the elicitation of either abstract or tacit information. Some examples from the study included seemingly mundane activities and emotional insights that were difficult to elicit. Additionally, these techniques allowed IS to focus on what was important to them during their illness journey (Driessnack, 2006; Mah et al., 2020; Poku et al., 2019).

The study also included photography, in which children were encouraged to photograph anything about their asthma experiences that they felt significant. This method acknowledged children's agency as it allowed children to take photographs of their own choice and to lead the conversation based on the photographs they produced. As children are the most knowledgeable about the photos since they are the ones that owned them, they are more likely to speak confidently about their pictures and lead the conversation, ensuring a more effective co-construction process. (Poku et al., 2019). However, IS was conscious of the potential influence of family members and friends on the capturing of the photographs, as they may guide them about what to take or which photographs to be shared for the research.

While data collection methods such as interviews demand timely responses, creative activities such as drawing and photography may be more leisurely, allowing children to think more critically about the response that they provide (Freeman & Mathison, 2009). As the proverb says, *A picture paints a thousand words*, some pictures yielded a comprehensive idea of children's asthma experience (see Figures 13 and 14). Pseudonyms and participant codes are used for participants' names throughout the article to protect their anonymity (see Table 11 [p. 205, chapter 5] for participant demographics).

During subsequent discussions about photographs/drawings, IS was able to capture their excitement, which often led to unique data regarding the children's asthma experience; their symptoms, how they felt emotionally, as well as their support network and management tactics. For example, Sruti's picture (see Figure 15) exemplified the vital role her family played in supporting her during asthma flare-ups. Additionally, sometimes the most mundane images ignited valuable discussions that IS did not anticipate (Carter & Ford, 2013; Due et al., 2013). For instance, the image of oranges (see Figure 17) was taken by Shika, a 13-year-old girl, who had been eating oranges daily as a part of her mother's asthma control strategy. The photograph prompted an in-depth and lively conversation about various natural remedies that Indian immigrants commonly used to manage asthma.

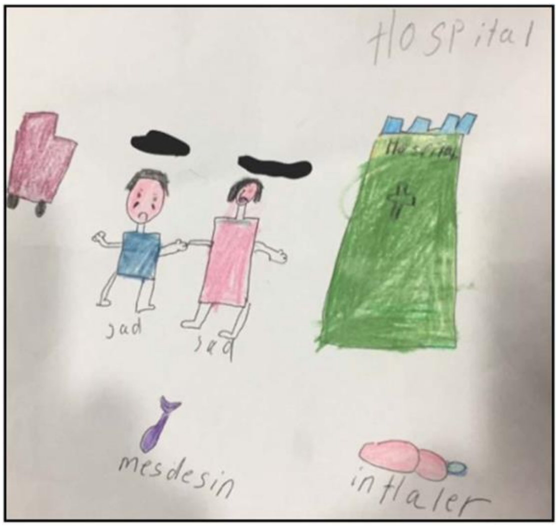
Figure 13

Drawing by Nidhi (C6/9Y/F)

Note: The name *Lucy is a made-up name by the participant

Figure 14

Drawing by Krishna (C5/9Y/M)



As mentioned earlier, without children's explanations, the images would have been meaningless (Peters & Kelly, 2015). By giving children the option to draw or photograph what they like and allowing them to have their say on it, they become an active part of the co-construction process. Furthermore, when analysing visual data, researchers run the risk of interpreting the data that are not congruent with what the children meant. The need to obtain an explanation from the child before the researcher interprets the visual data was repeatedly demonstrated during the project (Driessnack, 2006; Due et al., 2013). The following excerpt is taken from the interview with an 8-year-old girl, Nidhi, who describes her drawing (see Figure 13).

> Researcher: Mom took Lucy to the doctor, and the doctor gave the blue inhaler?
>
> Nidhi: Yes, because we can't use the orange inhaler.
>
> Researcher: Why?
>
> Nidhi: Because that means you are feeling good.
>
> Researcher: Ok.

Figure 15

Drawing by Sruti (C10/12Y/F)

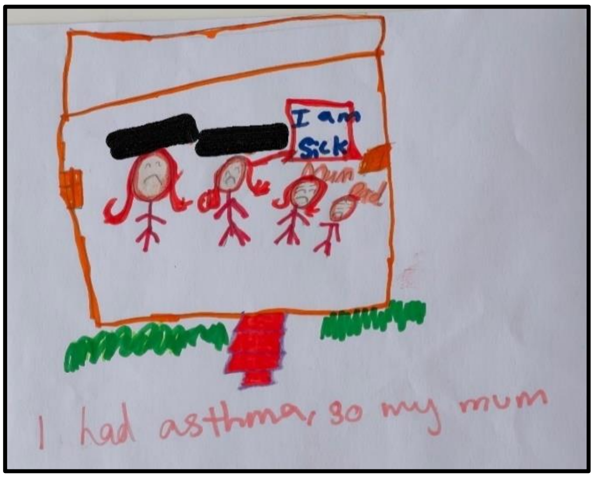


Figure 16

Drawing by Simon (C1/8Y/M)

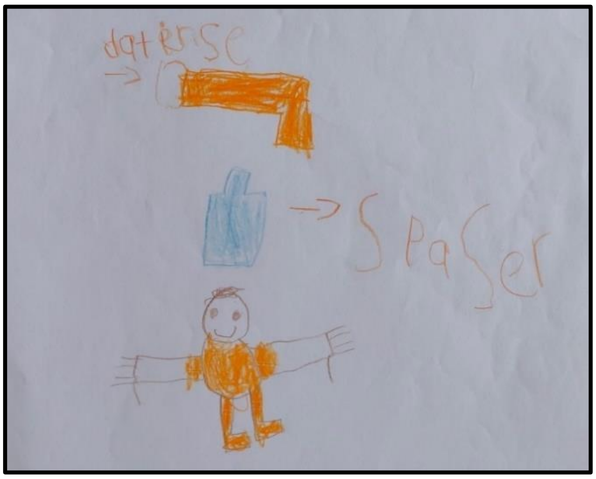


Figure 17

Photograph by Shikha (C9/13Y/F)

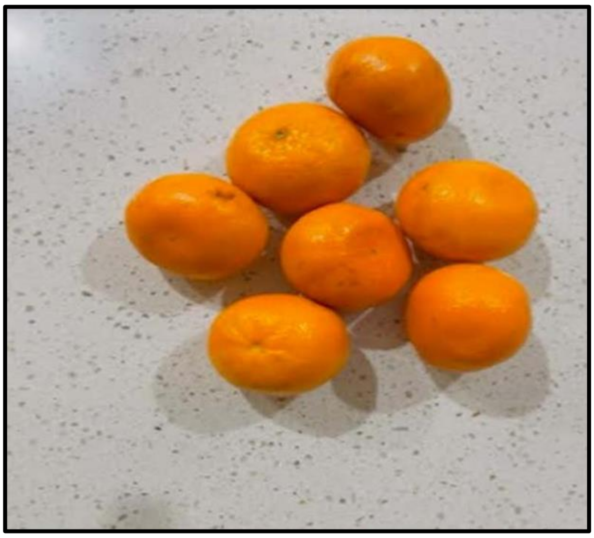
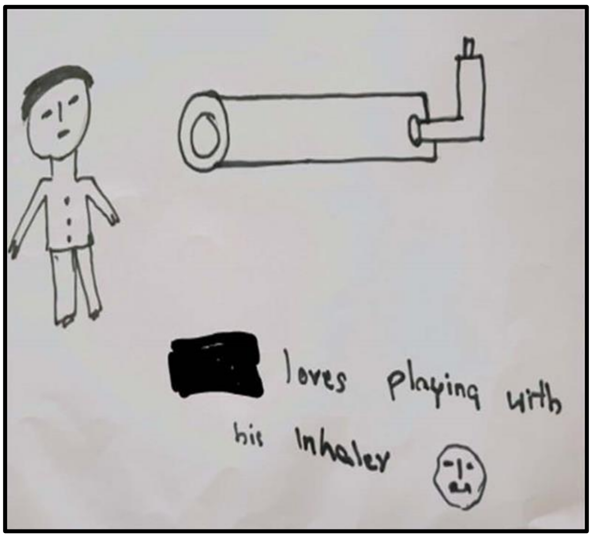


Figure 18

Drawing by Ryan (C8/8Y/M)

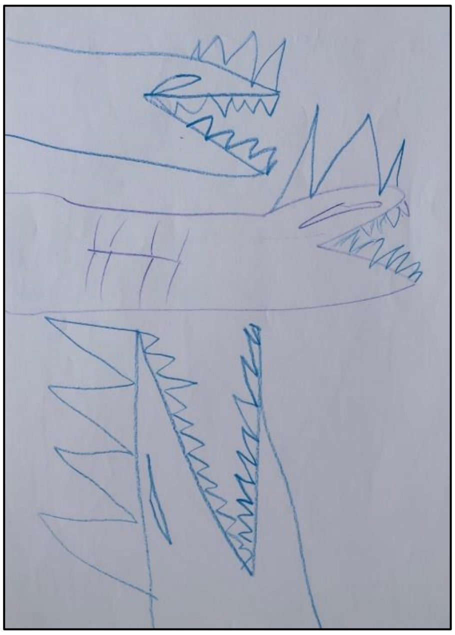


As can be seen in the excerpt, the child shared her thoughts about the preventer inhaler (orange inhaler) when she explained her picture; she mistakenly believed that preventer inhalers should never be used during acute flare-ups. This was a significant finding which the nurse researcher might have missed if the child had not been given the option of discussing her picture. Allowing them to explain about their pictures/photographs also helped to redistribute power in the researcher-child relationship (Mah et al., 2020).

IS also took time to clarify data collected from children as required since it was essential in ensuring rigor by enhancing the reliability of data collected (Due et al., 2013). Many children, for example, drew pictures of inhalers, and the stories behind each picture varied (see Figures 13, 14, 16, and 18). Simon drew a picture of a preventer inhaler (see Figure 16). Through his drawing, Simon showed how the preventer inhaler, which he initially refused to use due to severe side effects such as painful mouth sores, had become his best friend. Simon claimed that he felt much better after starting the preventer inhaler, which was why he drew the happy face. Ryan too drew a picture of his inhaler (see Figure 18), but the picture provided a different account; he explained how his mother had eventually consented to his choice of using the inhaler despite her preferences. Rekha, his mother, was originally hesitant to start the inhaler for her child because she was concerned about the adverse effects. Despite her constant attempts at various traditional asthma management methods, he refused to follow them and preferred to utilise the inhaler instead. During the interview, Ryan showed the researcher his inhaler decorated with stickers. He treated the inhaler as if it were a toy.

Figure 19

Drawing by Nehan (C4/8Y/M)



There are, however, some drawbacks to using these techniques. As a researcher, one has no control over what images children might capture, so they may use the camera inappropriately, and some may consider taking pictures that have no relation with your research topic. In the case of drawing, a child may draw what is easy for them to portray. For example, Nehan drew a picture totally unrelated to the topic (see Figure 19). However, he was so interested in the activity of drawing that he wanted IS. and his mother to guess what he was drawing when he was doing it. Nehan was shy at the beginning of the interview, but the drawing activity facilitated the establishment of rapport between us, and he took the lead throughout the whole interview process from the start.

On the other hand, the use of photographs as research data may present concerns about confidentiality, privacy, and copyright. To address this issue, children and their parents were informed of the purpose of using children's photographs, how it would be stored and used in the future, and how any identifiable features would be anonymised. Despite the drawbacks, these techniques are considered as an effective and quick way of obtaining a significant amount of information in a relatively short period of time (Fargas-Malet et al., 2010; Poku et al., 2019).

Discussion

Children are not a homogeneous group: they vary in their age, class, ethnicity, literacy, sexuality, cultural and religious background, level of articulacy and sociability, and the amount of adult assistance or monitoring they receive. These variables are interactive, dynamic, and complex (Freeman & Mathison, 2009). The same heterogeneity can be seen even within the same social or ethnic group, which was evident in the current study sample of the Indian immigrant children. Charmaz's philosophy is consistent with the new sociology of childhood, which views children as contextually subjective, dynamic, and self-determining beings. She claims that her position aligns with the ideologies of Lev Vygotsky, and emphasises the role of social contexts, social interaction, interpretive understanding, and sharing viewpoints in exploring a phenomenon of interest (Charmaz, 2014; Greig et al., 2013).

Research with children has the potential to highlight surprising or unexpected findings which necessitate critical inquiry (Charmaz, 2016). While most qualitative research is inductive and emergent, CGT differs from other approaches and enhances critical inquiry in two ways. First, CGT integrates critical issues systematically into the analytic process. For example, in all versions of GT, including CGT, the researcher analyses the initially collected data before moving to further data collection. Concurrent data collection and analysis also involves constant comparative analysis, in which the researcher constantly engages with the data and compares each piece of data with others (Charmaz, 2014). Second, researchers who use CGT, design, and adapt data collection to further explore avenues to pursue. For instance, the iterative data collection process which involves inductive, deductive, and abductive reasoning along with theoretical sampling, ensures an in-depth exploration of the phenomena of interest. While inductive reasoning involves arriving at generalisations based on the data collected, deductive reasoning involves exploring a known phenomenon or theory and determining if it makes sense in the given research context. On the other hand, abduction enables the researcher to promptly address and investigate any contradictory piece of data. Abduction entails considering all potential theoretical explanations for the surprising findings and then evaluating those explanations against new empirical evidence from the field (Charmaz, 2016).

Conclusion

CGT methodology, using child-sensitive data collection methods, enables children's voices to contribute authentic, meaningful, and eventually more influential data capable of informing policies and practices in children's best interests. A CGT approach was chosen to study the asthma experiences of Indian immigrant children and their family carers and to develop an interpretative understanding of their beliefs, practices, and experiences within their complex social background. In this article, we have discussed how CGT researchers can privilege the voices of children through effective co-construction of knowledge by creating a child-sensitive research space and using methods that are appropriate to their abilities and interests. We have also highlighted the significance of gaining a comprehensive understanding of children's physical, social, and cultural circumstances to promote their health and well-being. These authors encourage researchers to consider CGT as one of the appropriate methodological choices to explicitly promote the voice of the child.

Postscript to the Manuscript

In this article, the authors propose CGT as a valuable approach for designing and implementing research that explicitly integrates and empowers young participants as co-producers of knowledge. The article illustrates how CGT methodologies can produce high-quality data when conducting research with children. The use of child-sensitive data collection methods may provide children with a sense of agency during the research process.

As a result of the emergence of the UNCRC and the latest sociological models of childhood, children who were previously considered vulnerable are now expected to be knowledgeable about their health and to take part in research that will benefit them (Cudjoe et al., 2021; Cuevas-Parra et al., 2020; Eastham & Kaley, 2020; Lundy, 2018). The exclusion of children with chronic illnesses from research was based on the assumption that it was difficult for them to understand complex issues and make informed decisions. This assumption has been challenged and it is now recognised that children have a right to make decisions about their own health. As mentioned earlier, the new sociology of childhood has been influential in this transition as it holds that children are both social agents and individuals in their own right, not merely subordinates to adults (Freeman & Mathison, 2009; Mah et al., 2020).

It is increasingly recognised that children are expert participants in contemporary research, capable of comprehending their own experiences and recounting them regardless of their disabilities or impairments (Mah et al., 2020). It is now known that children are capable of making informed decisions and defending themselves when they have access to reliable sources of information. Consequently, researchers are now seeking to involve children in the research process, allowing them to take part in the design and decision-making of research process. This shift has been driven by a growing recognition of the rights of children and the importance of their voices in the research process. It has also been inspired by the fact that children are often the focus of research, and they should have a say in how the research is conducted (Cudjoe et al., 2021; Cuevas-Parra et al., 2020; Eastham & Kaley, 2020; Lundy, 2018).

Summary

Chapter three takes the reader through a methodological tour of the study. I utilised a social constructionist framework to investigate the asthma experiences of Indian immigrant children and their family caregivers, emphasising the significance of sociocultural context. To accomplish the study objectives, a CGT methodology was employed. In my opinion, practising solely on the basis of experience is insufficient, as we need a theoretical knowledge base to guide our actions. I developed my research as a way to bring about social change based on the ideas of pragmatists, interactionists, and constructionists. The chapter ends with a published article encouraging researchers to consider CGT as one of the best methods for explicitly promoting children's voices. Chapter four explicates the steps involved in collecting, analysing, and developing the substantive theory of navigating asthma—the immigrant child in a tug-of-war.

Chapter 4–Methods and Ethical Considerations

Research is to see what others have seen and to think that no one has thought

—*Albert-Szent Gyorgyi*

In this chapter, I explain how the study was conducted in accordance with the methodological principles outlined in the previous chapter. The first section describes the procedures used for participant identification and recruitment. This is followed by an explanation of various ethical requirements and how they were met. Next, I will discuss the main tenets of GT and demonstrate how they have been rigorously applied in this study. The chapter incorporates several examples from the study, such as memos, codes, and diagrams, to demonstrate the systematic methods that were used to ensure that the developed theory is grounded in the data.

Participant Identification and Recruitment

I invited various gatekeepers, including the managers of general practices, Indian community associations, and school principals from selected suburbs in the Greater Wellington region, to participate in the study. For those who expressed interest, I sent them a letter (see Appendix A) explaining the proposed study, along with flyers (see Appendix B), participant information sheets (see Appendices H and I), and assent/consent forms (see Appendices E, F, and G). These gatekeepers informed potential participant family carers about the study. Family carers received an invitation letter explaining the study along with the information sheets. They were invited to contact me by email if they wished to participate. Following this, the family caregivers were contacted by phone to discuss the study and schedule the face-to-face interview. Family carers who failed to respond within two weeks were contacted by phone to check if they were still interested. If they did not respond, further contact was not made in order to avoid coercion.

The research process was discussed again during the initial meeting with the participants to obtain informed consent. I provided the family caregivers and children with separate information sheets and explained the study in detail. For children, I read the information sheet aloud and provided them with adequate time to express their thoughts regarding the study and clarify any doubts they had about their participation. In order to clarify any fears or concerns, children and their carers were given considerable time to discuss the study independently. They were requested to contact me if they still wished to participate within two weeks. I arranged a second meeting if the child was not present at the initial meeting to explain the study and obtain informed assent/consent.

The child and family carer each signed a separate consent form if they consented to participate. Informed consents/assents were obtained from children. Participants were informed that family caregivers had the option of attending the interview with the children. Although the presence of family caregivers may prevent some children from freely expressing themselves, they may not only enhance children's narratives by assisting them in recalling past events but also make them more relaxed (O'Reilly & Dogra, 2016; Sudarsan et al., 2022a). A copy of the consent forms was given to both children and caregivers. The family carers were asked to complete a demographic form (see Appendix J) once informed consent had been obtained. This was followed by a face-to-face interview with the family carers, after which the interview date with the children was scheduled.

Children below 14 years of age were given either a drawing pack or a disposable camera on the first visit, depending on what they were interested in. I planned to conduct follow-up telephone interviews with family caregivers two to three weeks after the first interview if any clarifications were required. During the initial interview, participants were informed of follow-up interviews, and their consent was obtained in advance. While I had planned for telephone follow-up interviews with family caregivers, face-to-face follow-up interviews were planned for children since I believed they might not respond well to telephone interviews.

Challenges in Recruitment

Recruitment of participants through specific gatekeepers began on December 13, 2020. I contacted 61 GP practices, 60 schools, and four community associations in the Greater Wellington region to invite them to participate in the study. One of the major barriers to recruiting participants was the stigma associated with asthma. During my recruitment efforts through Indian community associations, the most frequently asked question was, “Who will say that their child has asthma?” The other question was, "I know someone, but how will I ask them?" Some responses from potential participant family caregivers included, "He does not have asthma but uses an inhaler as a precaution." Several people denied their child's condition was asthma, stating that the child used inhalers only occasionally. There were many potential participant family carers who claimed that their child did not have asthma despite having been prescribed preventer inhalers for many years. Despite being a former Indian nurse, I was not aware of the stigma associated with asthma within the Indian community.

Sampling Strategy

Participants were initially chosen by a purposive sampling method. Given that there is limited research on the experiences of Indian immigrant children and their families with asthma, it was imperative that the data collected reflect both the broad range of experiences as well as the nuances and patterns present in the data. Therefore, I used maximum variation sampling as part of a purposive sampling strategy. I ensured that the participants I selected reflected a wide range of asthma experiences.

The preliminary literature review served as a guide for identifying the best sample of potential information sources. There were several characteristics that I considered important enough to use as a guide to select participants. These characteristics included severity of asthma (mild, moderate, or severe), diagnosis (recent diagnosis versus long-standing diagnosis), immigration status (recent immigrants versus long-term immigrants), region of India from which the participants came, and religious affiliation (Lakhanpaul et al., 2014;

Mehrotra et al., 2014; Ravindran & Myers, 2012; Zechella & Raval, 2016). Furthermore, I used snowball sampling if the participants recommended someone who was eligible for the study and willing to participate. Purposive sampling followed by theoretical sampling enabled an accurate reflection of the participants' experiences and assisted me with my quest for further clarifications (Charmaz, 2014; Glaser & Strauss, 1967).

Sample Size

In GT studies, theoretical saturation is the primary factor in determining the sample size (Charmaz, 2006). In this study, theoretical saturation was attained after 19 interviews. It is noteworthy, however, that experts differ in their perspectives on the number of samples needed to achieve theoretical saturation. According to Charmaz (2006), 25 interviews may be sufficient for small studies. Creswell (2007) recommends 20 to 30 interviews, whereas Morse (1994) suggests 30 to 50.

Data Collection Methods

Participants received a reminder text message the day before the scheduled interview requesting confirmation about the time and location of the interview. This gave the participants the option to reschedule the interview if necessary.

GT studies require rich data that is detailed, focused, and comprehensive. Rich data provide insight into participants' thoughts, emotions, intentions, and behaviours, as well as their sociocultural contexts. To ensure a rich and thick description of the data, I conducted intensive interviews, took extensive field notes, collected photographs and drawings from younger children, and consulted relevant literature (Charmaz, 2014).

Challenges in Data Collection

Participant recruitment and data collection took place between December 15, 2019, and December 15, 2020. In NZ, the first case of COVID-19 was reported on February 28, 2020. The government implemented a four-tiered alert system on March 21, 2020, in an effort to control the COVID-19 outbreak. Following a two-month nationwide lockdown, from

March 26 to May 27, 2020, a regionalised alert level change was enacted (Unite against COVID-19, 2022). I was able to acquire a pool of potential participants by the time the lockdown was implemented. I had already conducted six interviews prior to the lockdown.

Lockdowns, alert level changes, social distancing regulations, and university research restriction policies greatly impacted face-to-face interactions, such as in-person interviews. I did not conduct any in-person interviews during the lockdown. I offered the participants the option of online video interviewing using the videoconferencing platform Zoom if they wished to participate during this period. To minimise in-person contact, I offered Zoom interviewing for all the participants from my seventh interview onwards. Since people with asthma are especially susceptible to COVID-19 and its associated health complications, I informed those who had already consented to the study that they could opt-out if they did not feel comfortable with the evolving pandemic situation. Those who preferred in-person interviews were given the option of waiting until the alert level measures were relaxed before scheduling interviews. I ensured that all the interviews followed COVID-19 isolation precautions.

Only two participants preferred online Zoom interviews. They received an email containing the details of the online meeting, including the date, time, and instructions on how to access the video conferencing platform. In order to ensure the privacy and confidentiality of the information that was collected, several procedures were put in place. For instance, each meeting had a unique meeting ID and password. Furthermore, at the beginning of each meeting, the session was locked. The meeting was thus protected from interruptions by uninvited guests (i.e., Zoom raiding or Zoom bombing) (Eigege et al., 2022). At the beginning of the Zoom interview, I obtained participants' consent to audio record the interview. Participants were informed that their video would not be captured and that the interview would be recorded using an audio recorder instead of Zoom. It is not possible to record audio alone during the Zoom video conference (Zoom, 2022). Therefore, to comply with ethical standards, I chose to record the Zoom interviews with an audio recorder instead of Zoom.

Face-to-Face Interviews

To explore the asthma experiences of Indian immigrant children and their family caregivers, I was required to immerse myself in their worlds. The primary method used to enter the participants' worlds during this study was the use of intensive interviews. Charmaz (2014) recommends intensive interviewing as a primary method of interviewing in GT studies.

Intensive Interviews: A typical intensive interview is a one-sided, gently guided conversation designed to explore a person's extensive experience with the study topic (Charmaz, 2014). Intensive interviews were an effective method for collecting data in this study since I sought to examine participants' language, meaning, actions, interactions, body language, and emotions. I conducted semi-structured, online, and face-to-face, intensive interviews with the participants that were audio recorded.

All efforts were made to help the participants feel at ease during data collection. This allowed them to speak freely, thereby removing any unreasonable expectations regarding what might be expected of them as research participants. Family carers were interviewed for a maximum of one hour. Typically, children were interviewed for 30 minutes, or for an hour if they were quite talkative. The children were gifted with a *koha* (gift), and the family carers were offered a $20 grocery voucher as a token of appreciation for their time and effort. In intensive interviews, participants are likely to express a range of responses, such as their current concerns, justifications for their past actions, and reflections (Charmaz, 2014).

Use of Interview Guides: There were separate interview guides for children and family carers, which served as a framework for the interview (see Appendices K and L). Some GT researchers advise researchers to adopt an unstructured interviewing technique to allow the interview to be fluid and spontaneous (Glaser & Strauss, 1967). However, conducting an interview without a detailed work plan may be fraught with potential difficulties, particularly for novices. There is a possibility that this approach could lead to inappropriately timed, intrusive questions being asked by researchers with unquestioned preconceptions. Thus, it is often advantageous for novice researchers to develop a comprehensive interview guide to provide them with a quick reference in case of forgetfulness or nervousness (Charmaz, 2014).

Using an interview guide facilitated a comprehensive and systematic exploration of the research topic and kept the interview on track and focused. The questions that I formulated were open-ended, broad, and nonjudgmental. I did not adhere rigidly to the interview guide. The questions were not asked in a set order, which varied depending on the responses of the participants. I always stayed attentive to the main concerns expressed by the participants, remained open to new information, and searched for and clarified key patterns and processes in the data. As a result, the interview guide was frequently modified throughout the data collection process (Birks & Mills, 2015; Chenitz & Swanson, 1986). After a few interviews, I became more comfortable disregarding the interview guide. When participants had completed their stories, I asked probing questions. Additionally, I carefully reviewed the interview guide and ensured that nothing had been missed. The use of this strategy prevented me from ignoring the participants' reality in order to meet my own agenda (Charmaz, 2014; Chenitz & Swanson, 1986).

Interview Techniques: Interviewing intensively served as a fluid method of discussion that provided an area in which ideas and concerns could arise and be addressed immediately following their emergence. Listening carefully, observing sensitively, and encouraging participants to speak were the strategies I employed. I was aware that participants could exert control over the content of the interview by avoiding areas that might prompt probing questions. Particularly, this problem occurs when sensitive topics are discussed during the interview or when participants believe that the interviewer will negatively view them. In such situations, I used my judgement and interviewing skills to create an environment in which participants felt comfortable discussing their experiences and perspectives (Charmaz, 2014; Foley et al., 2021).

Several simple social queries, such as "how are you?" and "how has your day been?" helped establish rapport prior to the interview. I used both silent probes and neutral probes throughout the interview. Silently listening to the participants' answers, pausing, and waiting for their responses, allowed participants to proceed in the direction of their choice. By using neutral probes, "hmmm," "I understand," and "I see," I could indicate to the participants that they had been heard. I also took note of non-verbal cues given by them and any contextual inconsistencies (Brinkmann & Kvale, 2018; Chenitz & Swanson, 1986).

As a constructionist, I sought to understand participants' interpretations of terms, circumstances, and events, as well as their assumptions, implicit meanings, and tacit rules. I utilised both funnel and inverted funnel approaches to elicit specific information from the participants (Chenitz & Swanson, 1986). A funnel-like approach to interviewing begins with a general question and is followed by more specific questions. This technique may be employed by researchers when they wish to uncover unexpected responses or when the participant wishes to describe a situation or incident in detail, or when researchers wish to avoid imposing their own perspective on participants. Contrarily, the inverted funnel approach starts with specific questions before moving to a more general approach. Inverted funnel methods are advantageous in situations where participants are reluctant to speak spontaneously, present their experiences as unimportant to the researchers, or when the researchers wish to arrive at a conclusion in light of the participants’ specific experiences. The inverted funnelling approach proved especially useful while interviewing children (Chenitz & Swanson, 1986).

Additionally, I applied informational and investigative interviewing strategies (Charmaz, 2014). Informational interviewing is designed to gather facts. I asked demographic questions as well as questions related to specific events. These included clarifications regarding chronologies, places, and people involved. Investigative interviewing, on the other hand, also aims to obtain accurate information, but the purpose is to expose hidden intentions and actions or to reveal practices, and policies and their implications. The use of investigative interviewing is generally associated with specific research projects such as social justice studies (Brinkmann & Kvale, 2018; Charmaz, 2014).

There were certain topics that required special attention both during the interview planning process as well as during the actual interview. Participants disclosed personal experiences that they never imagined sharing. As an example, shortly after the interview had concluded, Surya, one of the family caregivers, began describing how her asthma diagnosis ultimately led to the rejection of her marriage proposal. The audio recording had already been stopped because she indicated that she had nothing further to contribute. Nevertheless, she continued to talk casually after that. She revealed significant information about the stigma associated with asthma in the Indian community as she continued to speak. Examining topics such as stigma may raise the issue of intrusiveness with some participants.

I was conscious of questions that could elicit an emotional response from the participants. My technique was to use ‘door openers’, which encouraged participants to open up. For instance, "you must have had a difficult experience," "many people have gone through similar experiences," and “how did you feel about your experiences?" By empathising with participants and pointing out that others had experienced similar difficulties, I hoped to convey the impression that their concerns were valid and important (Brinkmann & Kvale, 2018; Chenitz & Swanson, 1986).

A few questions that helped me to conclude an interview involved: 1) What would you tell a friend or family member who has recently found out that they have asthma? 2) Is there anything else you would like to tell me? 3) Do you have any questions you would like to ask me? These questions evoked participant reflection, which often resulted in useful data (Chenitz & Swanson, 1986). Additionally, I asked specific questions about conceptual relationships based on developing concepts, relevant literature, or hunches in the data before concluding the interview. For instance, I used language such as "others have said that" "have you had a similar experience?" or "the studies support." I used this approach to determine how the content of the interviews should be changed over time (Schreiber et al., 2001).

Cultural Sensitivity: It is imperative to respect the cultural beliefs, values, and practices of participants when conducting cross-cultural research (Memon et al., 2021). As an example, I used greetings such as *Namaste* (a respectful way of saying *Hello* in Indian culture) when I first met participants. I always removed my shoes before entering a participant's home. Additionally, whenever I saw seniors, I stood up and bowed to them.

Nurse's Hat Versus Researcher's Hat: Wearing a nurse's hat versus a researcher's hat might pose challenges for novice nurse researchers. I was aware that how participants identified me would influence what they shared with me. The nurse's image may assist in gaining the trust and confidence of the participants. Participants may reveal sensitive health information to nurse researchers, which they are reluctant to share with others (Charmaz, 2014; Chenitz & Swanson, 1986).

However, the nurse component of the role raises its own ethical issues. The participants may expect that the nurse researchers will advocate for them or intervene on their behalf or address their concerns. The strategy I used to address this issue was to inform the participants clearly about how my role as a researcher differed from that of a nurse in the study. For instance, one of the participants requested my opinion regarding the use of preventer inhalers for her child. Given that I was not in a clinical role, I did not comment on the use of medications. However, I recommended that she consult with her GP in order to clarify her concerns. Clearly, the researcher and nurse roles are being conflated here. Therefore, while a nursing background is advantageous, the researcher must act predominantly in the researcher's role to maintain maneuverability and versatility (Chenitz & Swanson, 1986).

However, in certain situations, it may be appropriate to remove the hat of the researcher and put on the hat of the nurse. In one instance, one of the family caregivers had an incorrect understanding of the content of the Ventolin (Salbutamol) inhaler and expressed his concern that it had a high steroid content. In the course of the interview, I did not attempt to establish accurate information, as this would have affected subsequent responses or given the participant the perception that they did not possess accurate information. In this case and similar context, I asked a sensitive and nonjudgmental question at the end of the interview to clarify their misunderstanding. Furthermore, the family carer was also directed to various online asthma education resources, as well as to the child's GP, for further clarification (Chenitz & Swanson, 1986). I also referred the participants to relevant support networks when further guidance was required. A family caregiver, for example, was unaware of the asthma action plans in schools. I recommended that they contact the school staff for further guidance.

Interviewing Participants with English as a Second Language: If researchers do not speak the participants' languages, they may employ interpreters. The translation may, however, distort or obscure the meanings of the participants' perspectives. There are many languages spoken in India. I am only familiar with my regional language. Therefore, I chose participants who are fluent in English in order to eliminate the need for interpretation and translation. All the child participants spoke English fluently. While most family caregivers were fluent in English, there were a few times when I had to pay close attention to the language. If participants cannot be understood clearly, the richness of the data collected can be limited. In these situations, I requested the participants to repeat their responses to ensure that their intended meaning was accurately captured.

Interviewing Participants from the Same Ethnic Background: Interviewing people from similar ethnic backgrounds was helpful. Regular memoing and discussions with my supervisors allowed me to guard against forcing of my received knowledge and experience into the developing theory. The process of writing about my experiences and the knowledge I learnt also allowed me to critically examine my assumptions and uncover blind spots. I became aware of how my research might be influenced by previous ideas and findings and was cautious when these influences happened. Additionally, fieldnotes, and constant comparative methods accompanied with line-by-line coding ensured grounding of the theory in the data.

I found it relatively simple to establish rapport with the participants and gain their trust. Some participants said they felt comfortable disclosing things to me they would not have discussed with anyone else. It was clear from their talk that they were confident in my ability to understand their experiences and emotions better than researchers of a different ethnicity would. They used phrases such as, "You will understand, but others (HCPs from other ethnic groups) won’t," "You already know that,” and “We, Indians, we do that."

Furthermore, I ensured that I elicited explanatory commentary from those participants who might have assumed that I knew what they meant. During these conversations, I watched for the red flags such as "You know", "We know", etc. These situations required me to use effective interviewing techniques, such as using open-ended questions, probing, prompting, seeking clarifications, etc. As the research progressed, I also asked specific questions about conceptual relationships based on developing concepts, related literature, or hunches in the data before concluding the interview if they had not already identified them. As an example, I used phrases such as "others have said this," "have you had a similar experience?" or "the studies support." By using this approach, I was able to modify the content of the interviews over time or to do theoretical sampling.

Conversely, it is possible for the opposite effect to occur when a participant interacts with a researcher who is from a similar ethnic group. There may be concerns related to confidentiality and privacy issues, such as the leakage of their personal information into their community. Participants might also worry that their answers will be secretly assessed. Participants may alter their answers in order to reflect the preferences of the researcher.

Follow-up Interviews: Conducting multiple interviews with participants has been shown to provide significant benefits to GT research for numerous reasons. It is necessary to build a relationship of trust with participants in order to obtain reliable and accurate data. This process may take time. Furthermore, it is impossible to predict what concepts will be constructed from later interviews. Having several interviews allow researchers to revisit and gain a different perspective regarding previously collected data (Charmaz, 2011).

Telephone interviews are one of the most effective methods of collecting data, as they provide rich descriptive information that can enhance the understanding of human experience (Ward et al., 2015). Aside from being cost-effective, it also encourages a more relaxed discussion and a more open exchange of information and permits participants from a wider geographical area to engage. A significant disadvantage, though, of telephone interviews is that the researcher cannot observe the social cues of the participants (Ward et al., 2015). I intended to gain a deeper understanding of the participants' experiences, related concepts, and processes through this second interview. Two follow-up telephone interviews were conducted with family caregivers to gain further insight into the core category of *clashing cultures* (explained in chapters 4 and 5).

Field Notes

I took field notes throughout the data collection and did regular memoing to obtain a description of the participants' behaviour and their environment, processes happening in their environment, and anything that the participants found disturbing. Field notes were used during the data analysis (Birks & Mills, 2015).

Ethical Considerations

This study received ethical approval from the Massey University Human Ethics Committee (See Appendix C).

Anonymity and Confidentiality

Both privacy and confidentiality are essential to ethical research practices (Polit & Beck, 2021). Confidentiality was maintained by not revealing the participants' or organisations' names when reporting findings and by properly storing research data (Gerrish & Lathlean, 2015). I used participant codes and pseudonyms in order to maintain anonymity. Following each interview, the transcripts were coded, and access to the raw data was restricted to myself and my supervisors. When including interview excerpts in the reports, any parts that could compromise participants' confidentiality were removed (Polit & Beck, 2021). During the recruiting and data collection process, I used a password-protected computer to store research-related data. The completed consent forms, data storage devices, and other hardcopy data were securely stored in a locked filing cabinet in my home during the research. In accordance with Massey University's policy, all the relevant data will be stored in a locked cabinet for a minimum period of six years, and access will be restricted to myself and my supervisors (Massey University, 2017; Massey University, n.d.).

Informed Consent/Assent

A written informed consent/assent document was signed by all participants. Family carers and children above 16 years of age gave consent. Children under the age of 16 had a separate assent form. In order for the study to proceed, both the child and the family caregiver needed to give informed consent/assent (Massey University, 2017; Polit & Beck, 2021). The consent was obtained from the caregiver first. This included consent for family carers' participation in the study as well as their consent for their children's participation in the study. Permission to record the interview was also obtained shortly before the interview. The participants were free to opt-out of recording any part of the interview or to stop it at any time (Polit & Beck, 2021).

In NZ, children aged 16 and older are legally entitled to consent. In the context of research involving children, consent is often a controversial issue. Many debates exist regarding children's ability to give consent depending on their age (Medical Council of New Zealand [MCN], 2011). The *Code of Health and Disability Services Consumers' Rights* does not state any specific age for consent in the case of minors and assumes that all healthcare consumers are competent to give informed consent and make an informed choice unless there are particular circumstances in which they are not able to do so (MCN, 2011). Furthermore, research with children suggests that chronological age and competence are not related. Children are more likely to make informed decisions if they receive adequate information in terms they can understand (MCN, 2011; van Rooyen et al., 2015). Nine children under the age of 16 were included in the study, and informed assent was obtained from them.

Children and family carers were informed that they did not have to take part in the study if they did not wish to, and that their treatment would not be affected in any way by this decision. It is also likely that children may be too frightened to say "No" due to power imbalances between adults and children (Davidson, 2017). If a child declined to participate in the study, their rights were respected regardless of whether their caregivers wanted them to participate or not. Furthermore, I informed the participants of their right to withdraw from the study at any time during the study (Corbin & Strauss, 2015).

Participant Safety and Well-being

My experience as an RN made me proficient in both therapeutic communication and conducting interviews. I was able to assess and monitor participants' well-being throughout the interview process. If a participant became upset or distressed during the interview, I had a plan ready to give them a break, end or reschedule the interview, or give them the option to withdraw from the study. As part of the interview, time was allocated for debriefing (Brinkmann & Kvale, 2018). I had the plan to seek immediate assistance from the family carers if the children became distressed. The purpose of allowing family carers to participate in their child's interview was to ensure their child's comfort during the interview. In this study, participants did not exhibit or report any distress during the interviews.

Researcher Safety

There are safety concerns for the researcher when the interview is conducted in a private location chosen by the participants, such as their homes (Sanjari et al., 2014). My supervisors were given complete details of the interview schedule, including the time, location, and details of the participants, and were notified by text message before and after each interview. In addition, I made sure that my cell phone was easy to access throughout the interview.

Main Tenets of Grounded Theory

The fundamental elements deemed essential to every GT study include: 1) initial coding and categorisation of data; 2) concurrent data collection and analysis; 3) constant comparative analysis; 4) intermediate coding; 5) identification of a core category; and 6) advanced coding and theoretical integration (Birks & Mills, 2015). These core elements play a significant role in ensuring that GTs are grounded in data and are not just a reflection of researchers' ideas or theories. Applied diligently, these elements will also assist GT researchers to move their analysis beyond the realm of description to the development of a fully integrated, robust GT.

Initial Coding and Categorisation of Data

Initial coding is the first step in data analysis, in which the researcher breaks down data into small parts and then groups these according to what each part represents. Initial coding involves studying each fragment of data closely, by words, segments, lines, and incidents, and labelling these as codes (Birks & Mills, 2015; Charmaz, 2014; Charmaz, 2017). Charmaz (2014) recommends researchers “keep your initial codes short, simple, and spontaneous and analytic. The rest will fall in place” (p. 161). Depending on the version of GT, different types of codes are generated. Thus, GT researchers perform coding procedures differently, and the terminologies used may be confusing as well (see Table 6).

Table 6

Comparison of Coding Terminologies in Different Versions of GT

	Initial Coding	**Intermediate Coding**	**Advanced Coding**
Glaser 1978	Open coding	Selective coding	Theoretical coding
Strauss & Corbin 1990, 1998	Open coding	Axial coding	Selective coding
Charmaz, 2014	Initial coding	Focused coding	Theoretical coding

Note: Reprinted from *Grounded Theory* (2nd ed., p. 91), by M. Birks and J. Mills, 2015, Sage Publications. Copyright 2015 by Melanie Birks and Jane Mills.

Although time-consuming, transcribing the interviews myself provided me with an additional opportunity for self-reflection and allowed me to stay close to the participants' voices. I vividly recall the anxiety I felt when I began coding my first interview transcript. Initially, I chose the antiquated method of pen and paper for coding data. It quickly became apparent that this was an arduous task, so I began my initial coding process using Microsoft Word (Saldaña, 2021). The photographs, images, and field notes were also coded. Additionally, coding may become challenging when the researchers' first language is not English. For instance, coding might go more slowly (Tarozzi, 2013). I experienced similar problems when I attempted to raise my level of abstraction during the advanced coding phase. My supervisor, Prof. Karen Hoare, encouraged me to think in English as a strategy to resolve this issue.

Line-by-Line Coding: In the initial coding phase, I used line-by-line coding, as is the recommended practice for novice researchers, particularly in the early phases of data analysis (Charmaz, 2017; Glaser, 1978; Strauss, 1987). The line-by-line coding enables a closer analysis of the data (see Table 7).

Table 7

Line-by-Line coding

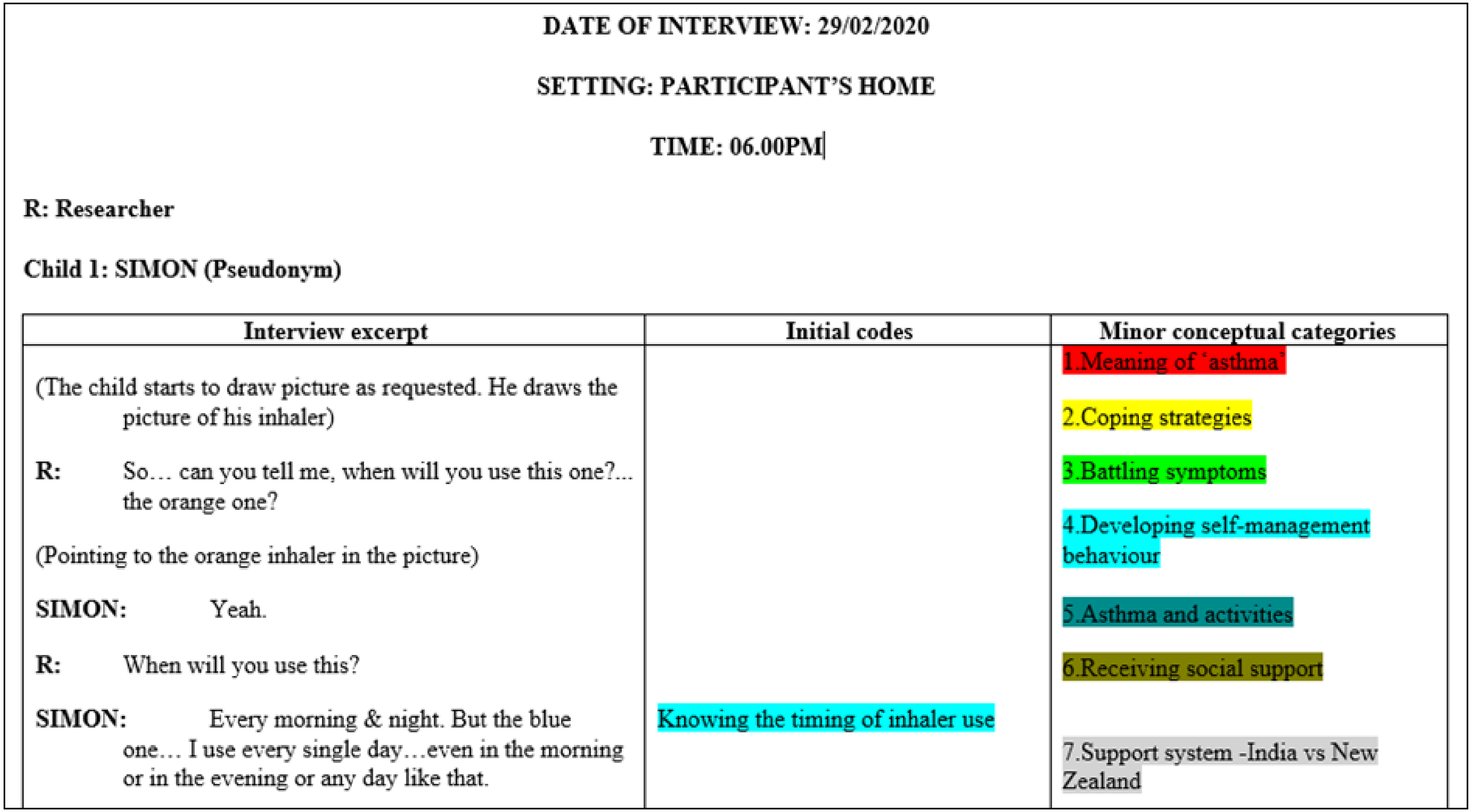
Interview Excerpt	Initial Line-by-Line Coding
• Researcher: So, from that time onwards, do you have both inhalers? Or, did they start with the blue ones? • Mandeep: I think the orange one is the primary one and the other one [blue] as well. I don’t use the orange one because I have to use it every day.	• Receiving an orange inhaler as the primary one. • Having a blue inhaler. • Not using the orange inhaler. • Difficulty in daily use.

Following Glaser's recommendation (1978), I regularly questioned the data: What exactly was going on in the data? How did the data relate to the study topic? I did the coding quickly and stayed as close to the data as possible. Initially, I assigned codes to all the data, regardless of its perceived importance, since I did not know where the data would ultimately lead me. I adopted this strategy to avoid forcing data into a specific focus (Charmaz, 2014). Furthermore, I paid close attention to coding phrases that evoked strong emotions. Children with asthma may experience a wide range of emotions and behaviours. They may ignore, minimise, fight against, embrace, or adapt to the symptoms. Asthma experiences may vary between children and over time within the same child (Trivedi & Denton, 2019). Furthermore, I checked for red flags, such as phrases with assumptions (never, everyone knows, always). I kept in mind that line-by-line coding may not be appropriate in all circumstances. As the analysis proceeded, I utilised existing codes whenever possible and added new codes when new, uncoded data became available (Charmaz, 2014; Corbin & Strauss, 2015).

Minor Conceptual Categories: In the beginning, as coding progressed, it became evident that certain codes could be grouped together. Initial line-by-line codes were subsequently merged into *minor conceptual categories* as a first step before moving into the focused coding phase (discussed later in this chapter). Minor conceptual categories should not be confused with high-level categories, which are constructed following the development of focused codes. A minor conceptual category is a low-level category that may be developed during the initial coding phase (Oktay, 2012; Qureshi & Ünlü, 2020; Willig, 2008). These low-level categories consisted of related codes that appeared consistently in the data and shared similarities. The newly constructed initial codes were then classified into these minor conceptual categories. This strategy helped me advance to the next cycle of coding. Focused codes, or the next level of codes, were developed from the initial codes grouped under these minor conceptual categories (Oktay, 2012; Qureshi & Ünlü, 2020; Willig, 2008). As a novice qualitative researcher, I found this approach effective for managing the large amount of data generated by the initial interviews (see Figure 20). In order to indicate the various codes and their corresponding minor conceptual categories, I used different coloured shadings.

Figure 20

Minor Conceptual Categories and Colour Shading



DATE OF INTERVIEW: 29/02/2020

SETTING: PARTICIPANT'S HOME

TIME: 06.00PM

R: Researcher

Child 1: SIMON (Pseudonym)

Interview excerpt	**Initial codes**	**Minor conceptual categories**
(The child starts to draw picture as requested. He draws the picture of his inhaler) **R:** So… can you tell me, when will you use this one?... the orange one? (Pointing to the orange inhaler in the picture) **SIMON:** Yeah. **R:** When will you use this? **SIMON:** Every morning & night. But the blue one… I use every single day…even in the morning or in the evening or any day like that.	Knowing the timing of inhaler use	1.Meaning of 'asthma' 2.Coping strategies 3.Battling symptoms 4.Developing self-management behaviour 5.Asthma and activities 6.Receiving social support 7.Support system -India vs New Zealand

Descriptive versus Analytical Coding: One of the challenges for novice GT researchers is developing expertise in framing analytical codes rather than using descriptive codes. However, most novice grounded theorists often begin with descriptive codes before moving on to analytic ones (Urquhart, 2013). Initial codes generated after my first few interviews appeared descriptive to me. On reflection, they were later modified into more analytical codes. As an example, at first, I used the code *experiencing stigma* (see Table 8) to refer to the experience that one of the family caregivers had regarding the rejection of her marriage proposal.

Table 8

Example of Descriptive Versus Analytical Coding

Interview Excerpt	Initial Line-by-Line Codes	Initial Codes–Ist Cycle	Initial Codes–2nd Cycle
Surya: He kept the phone, and two days later, I got a call saying that they were not interested in this marriage proposal anymore. Then they didn't contact us anymore. They really got scared after hearing this [about her asthma] that how will we be able to manage if she has got 'asthma' [stressing the term], and I mean, they took it as a 'very big thing' [stressing the words]	• Receiving a call • Rejection of marriage proposal • Not contacting them anymore. • Being fearful of asthma • Considering it as a "big thing." • Not wanting to marry a girl with asthma • Communicating with parents • Expecting her to be a burden after	• Experiencing stigma	• Being a victim of stigma

like I don't want to marry a girl with ‘asthma’ [stressing the term], and he shared this with his parents. Then, they also said she is going to be a burden for us.	marriage		

Experiencing stigma is a descriptive code that appeared to be an excellent starting point. Table 8 shows only a small portion of the transcript. As I completed coding the entire transcript, I was able to think about some of these originally descriptive codes in a more analytical manner. Here are some questions I asked myself to improve my analytical thinking: What was the meaning of this experience for the family caregiver? How did it affect her? Were there any other similar experiences? Is she experiencing similar issues with her child? Due to my perception that the family caregiver was ultimately becoming a victim of stigma, I changed my initial code from experiencing stigma to *being a victim of stigma*, an analytical code.

GT researchers get involved with multiple cycles of coding. Initial codes are provisional and comparative codes that are firmly anchored in the data (Charmaz, 2014). Codes are provisional in the sense that they may require modification over time to better reflect or fit the data. Part of the fit lies in the degree to which these codes can convey meanings and actions in a concise manner. It is expected that the initial codes will be more concrete, while later codes will become more specific and abstract (Birks & Mills, 2015; Charmaz, 2014). By illustrating multiple initial codes (as shown in Table 8), I was able to demonstrate that GT analysis is an interactive process. The initial coding phase acted as a foundation for larger codes as I decided what was important and moved from initial descriptions to analytical priorities.

In vivo Codes: I employed in vivo codes wherever possible to stay close to the participants' experiences. In vivo codes incorporate participants' own words to specify a concept (Birks & Mills, 2015; Charmaz, 2014). As an example, one of the family caregivers with a history of asthma described her first impression of the condition as “a big disease kind of feeling.” I used her words as an in vivo code for reflecting the participant’s perceptions of the social stigma associated with asthma. As the analysis progressed, my understanding of her description of a “big disease kind of feeling” became obvious. This interview demonstrated that the social stigma associated with asthma had a significant impact on the family caregiver's attitudes towards her child's asthma. The usefulness of in vivo codes in the later, more integrated analyses, depends on how researchers treat them analytically. For instance, in every interview, the notion of stigma was a recurring theme. So, the initial in vivo code, *big disease kind of feeling*, which surfaced during the second interview, was elevated to the subcategory of *fear of blame, shame, and discrimination,* in the final GT.

Use of Gerunds: Whenever possible, I used gerunds (verbs ending in -ing), another coding technique recommended by Charmaz, to identify actions and processes found within the data (see Table 8) (Carmichael & Cunningham, 2017; Sbaraini et al., 2011). Saldaña (2021) refers to this form of coding as *process coding* and explains its significance, in part, by pointing out its ability to reflect conceptual actions such as change and growth alongside observed actions. The code *being a victim of stigma*, for example, reflects the actions and processes associated with this code, which would not have been apparent if the code had been titled *stigma victim* instead.

Categories, Properties, and Dimensions: In the course of the analysis, similar concepts were assigned the same codes, and groups of related focused codes (explained later in this chapter) formed categories. Each category was defined in terms of its properties and dimensions. Properties are the common attributes of all the codes within a category, whereas the dimensions refer to the variations of a property (Chun Tie et al., 2019).

As the next step in initial coding, I began identifying the dimensions and properties associated with categories. GT coding begins to differ significantly from other qualitative methods at this point. Some grounded theorists consider this step to be a part of second-level or focused coding. However, I was able to clearly see various properties and dimensions of different categories in the initial coding phase itself. Throughout my analysis, I relied primarily on two approaches to identify various properties and dimensions of different categories: asking questions and making comparisons.

The properties and dimensions of categories became apparent as I began to compare different scenarios, cases, or incidents. For example, considering the initial code, being a victim of stigma, I asked myself the following questions: What does stigma mean to each person? What are the factors that contribute to stigma? What are the various manifestations of stigma? What types of stigmas do participants experience? How does stigma affect the child and the family carer? What is the child's attitude towards stigma? Is the child stigma coached? What are the participants' strategies for dealing with stigma? I asked myself further questions: Can I identify any of the dimensions of stigma? For instance, are the participants conscious of the stigma existing within the Indian community? To what extent are they conscious of this stigma? (i.e., it may range from *not being conscious of stigma* to *being extremely conscious of stigma*). Would you describe stigma as evident? (Is it *explicit* or *implicit*?) Does stigma have a *temporal* and *spatial* component? (For example, do participants' perceptions of stigma change over time or as they relocate?) Table 9 illustrates the properties and dimensions of the code—being a victim of stigma—that I developed following my second interview with a family carer who had endured several negative experiences due to her asthma diagnosis.

Table 9

Properties and Dimensions of the Code Being a Victim of Stigma After the Second Interview

Initial Code	Properties	Dimensions
Being a victim of stigma	**Stigma related to/ Stigmatising experiences** • The disease: Incidents: Marriage proposal [rejection], college excursion [exclusion] • Cause: Heredity [blame] • Use of an inhaler • Use of steroids **Causes of stigma** 1. Historical/Cultural 2. Poor knowledge **Types of stigma** • Perceived stigma • Public/Social stigma • Felt stigma/Self-stigma/Internalised stigma • Courtesy stigma • Vicarious stigma **Source/Context** • Self • Family • Friends	• Stereotyping • Prejudice • Discrimination • Non-disclosure • Temporal versus Spatial • Stigma coaching • Stigma consciousness

	• Public • Institutional/College **Stigma practices** • Imposition of restrictions [physical activities, sports] • Inhaler/steroid phobia **Consequences** *Impact on the child:* • Feeling of being different/feeling discriminated • Low self-esteem • Being stigma-coached • Poor knowledge about the disease • Poor management strategies • Poor healthcare utilisation • Self-stigma • Poor disease control *Impact on the caregiver:* • Caregiver stress • Increase in caregiver burden **Coping strategies** • Becoming an advocate • Fighting stigma	

	• Normalising asthma **Factors influencing stigma** • Health literacy • Social influence **Stigma towards asthma** India versus New Zealand	

In GT, categories are perfectly framed when further data collection neither provides new theoretical insights nor reveals new properties and dimensions for the categories. This is known as theoretical saturation. In order to establish theoretical saturation, the data analysis must result in codes that only fit into existing categories, and these categories must be adequately explained in terms of their dimensions and properties. It is at this point that the researcher stops collecting further data (Birks & Mills, 2015).

Clarifying the Concepts of *Concepts, Codes,* and *Categories* in Grounded Theory: The terms used by grounded theorists, such as *concepts*, *codes*, and *categories*, may initially seem confusing to novice grounded theorists until they realise that they generally represent the same or similar things. The term concept is often used in GT studies. According to Holloway (2008), a concept is defined as “an explanatory or descriptive idea, its meaning embedded in a word, label, or symbol” (p. 43). The concepts must be analytic and sensitising (Glaser & Strauss, 1967). A code is a type of concept that condenses meanings and actions to facilitate interpretation and understanding. Urquhart (2013) describes categories as higher-level concepts that unify concepts or codes with similar characteristics.

In his advice to novice GT researchers, Oktay (2012) states, "Don't worry whether something is a ‘code,’ a ‘concept,’ or a ‘category.’ It is somewhat arbitrary, based on how important or central the concept is to your developing theory. What is important is that you need to go from a large number of codes to a relatively small number of categories that will make up the heart of your theory” (p. 60). I learnt more about these concepts, asked questions about them, and developed tentative answers, which I later refined as I collected more data. By using the main tenets of GT methodology as a guide, I successfully developed concepts from a low-level to a higher level.

Concurrent Data Collection and Analysis

The unique characteristic of GT that distinguishes it from other research designs is the concurrent data collection and analysis (Birks & Mills, 2015). Concurrent data collection and analysis provides the basis for a robust GT, as it facilitates the development of theory by sequentially elevating the level of abstraction. My interviews were planned in such a way that I had ample time to transcribe and analyse the data before moving on to the next interview. Conceptual insights that were constructed from the ongoing analysis guided the selection of participants and determined the type of data to be collected next (Carmichael, & Cunningham, 2017; Charmaz, 2014). Concurrent data collection and analysis, accompanied by memoing, leads to new levels of inquiry due to increasing theoretical sensitivity. Memoing and theoretical sensitivity are discussed in the following sections.

Memo Writing: Memos are usually documented in the form of research notes or diaries (Birks & Mills, 2015; Charmaz, 2014). According to Remenyi (2014), memos are analogous to cement in the way they bind together various building blocks of GT research. Memos served as records of how my thinking evolved over the course of this study. The content of my memos ranged from a simple description to a detailed analysis. The journal article presented in the first chapter contains some examples of reflective memos that I composed prior to conducting the data collection. Throughout this thesis, I have incorporated a variety of memos written during various phases of this study. The following is a simple, descriptive memo that I wrote after my interview with the first child participant regarding the challenges I encountered during the interview.

Memo 03/03/2020: Challenges in Interviewing Young Children

I realised the challenges of interviewing an 8-year-old child right from the start of the interview. I wanted to elicit the child's thoughts and feelings about his condition in the best possible manner. However, as I started the interview, I realised how challenging it was to get into the child's mind and elicit his thoughts. He was cracking jokes and was very talkative until I started my questions on the condition. I tried to be very informal and ensured that my tone was appropriate so that he did not feel that he was being tested or questioned. I started with the question, "What do you feel at that time when you have breathing difficulty?" His answer was that he did not feel anything. Then, I asked him about the potential feelings he might have, such as if he felt some chest tightness or if he felt unwell, etc. He was so involved in playing with colour pencils that his response to my later question was "Hm." I changed the topic and asked about his interest in drawing to make him more comfortable and later returned to the same question. This time, he said that he found it hard to breathe and explained further about his symptoms.

Although the child was cooperative and talkative, sometimes the answers were irrelevant, or the child was more focused on playing with the colour pencils that he gave a different response when the same question was asked later. Eliciting thoughts and feelings may be challenging in the case of younger children. But, at the same time, some older children may behave like young children and vice versa, and I must keep this in mind while interviewing children. In this interview, at times, the family carer was giving the child prompts as he was not responding properly to my questions or was getting distracted. I think it might be a good idea to involve the family carer if the child is not responding appropriately to make the situation more comfortable for the child. In this case, this approach worked well, and in the end, I asked the family carer if she had anything to ask the child about the condition. I also realise that, sometimes, the presence of family carers could also restrict the *child from revealing things. I look forward to my upcoming interviews to see how I can better get into the children's minds and elicit their thoughts and feelings. Next, I have planned to interview a child who is 10 years old, and I want to analyse his way of responding to questions during the interview.*

Memos explain the *how and why* of the decisions taken regarding various stages of the research process (Chun Tie et al., 2019). Regular memoing during data analysis assisted in forming tentative connections and identifying relationships among categories. It illustrated how I used constant comparison, theoretical sensitivity, and theoretical sampling in the multistage GT process. Furthermore, memoing assisted me in identifying the attainment of theoretical saturation. I dated, titled, cross-referenced, and filed the memos. Throughout the study, I revisited, reviewed, and revised my memos with a critical eye (Birks & Mills, 2015; Charmaz, 2014; Schreiber et al., 2001).

Theoretical Sensitivity: A theoretically sensitive approach reveals the importance of openness and flexibility for GT studies. I used several analytical tools to increase my theoretical sensitivity, including reviewing the literature, initial coding, category construction, and reflecting in memos. Following this, I doubled back on data collection once further avenues of inquiry had been explored (Hoare et al., 2012a). The more I immersed myself in the data, the more theoretically sensitive I became (Birks & Mills, 2015; Gibson & Hartman, 2014; Oktay, 2012). For example, as data collection and analysis progressed, I discovered instances in which a family caregiver's perception of a child's asthma symptoms differed from the child's perception. This is described in the following memo, which demonstrates my increasing theoretical sensitivity:

Memo 08/03/2020: Discrepancy between the Child's and Family Caregiver's Statements

Rakesh, Hari's father, claimed that Hari presented with asthma flare-ups only when he had a fever. Hari, on the other hand, explained how his asthma affected his daily life, including his sleep, physical activity, and speech. I had already interviewed Hari and analysed his interview before interviewing Rakesh. Therefore, I attempted to elaborate on the points Hari had made. Hari added that his symptoms were so severe that he required a preventer inhaler. Fear was evident from his talk as he explained his symptoms. Yet the child's description of how asthma affected his daily life contradicted Rakesh's statement.

Surprisingly, Hari's caregiver refused to allow him to carry his inhalers to school, despite being aware of the school's asthma management policy. Hari's parents claimed that their son did not require an inhaler at school and denied that the child experienced regular breathing difficulties. The family caregiver also indicated that they preferred to keep the child at home rather than send him to school if the child was unwell.

What is the significance of the family carer's ignorance of the child's nature of the illness? 2) Is stigma a possible culprit in this instance; both the stigma surrounding the disease (disclosure of the disease/severity of the disease) and inhaler usage? Rakesh consistently stated that his son's asthma had no effect on his daily life, including his physical activities. Has Rakesh misinterpreted and underestimated the severity of his son's asthma? Or, was he trying to conceal the severity? Or, was there a communication breakdown between the child and the family caregiver?

Communication between the child and the family caregiver is essential, as the family caregiver may serve as the child's voice during a healthcare visit, particularly for young children. Moreover, children often may not engage in open communication with HCPs as they do with their families, especially when they are sick. This highlights the necessity of listening to children's voices.

Theoretical sensitivity and analysis influence each other. Moreover, ongoing theoretical sensitivity is paramount to achieving analytic precision in theory generation (Charmaz, 2014). Additionally, the above memo emphasises the importance of collecting and analysing data concurrently, as it enables the timely identification and elucidation of similar issues, which can then be investigated through theoretical sampling.

Constant Comparative Data Analysis

Concurrent data collection and analysis involves constant comparative analysis, which continues until a GT is completely integrated (Birks & Mills, 2015). This requires constantly engaging with the data and comparing each piece of data with another until the attainment of theoretical saturation (Charmaz, 2014; Glaser & Strauss, 1967). Comparisons were made between data from the same interview, across interviews, and across different types of data, which was essential to exploring and understanding the variation in the data. For instance, one of the initial codes was *battling symptoms*. As a result of constant comparative analysis, I identified an overarching emotion of fear being reflected in the participants' talk as they communicated regarding their symptoms. Thus, in the final GT, the initial code of battling symptoms was elevated to the category of *being fearful*. The following excerpts demonstrate, how constant comparative analysis was used to identify participants whose responses could be included under the category of being fearful based on the initial code of battling symptoms.

Children expressed their fear in different ways. Most children described asthma symptoms as fear-provoking. Some children used terms such as "scary," "afraid," or "fear."

> It is really scary for me when I vomit. I cannot stop coughing, and I vomit. (C10, 12Y/F)

Shika's fear was indirectly reflected in her talk.

> I feel like something heavy is in my chest [deep sigh]. I can't express how you feel at that time. (C9, 13Y/F)

The emotion of intense fear was evident in his tone as Hari talked about his experience of symptoms.

> I feel like... I can't breathe. I cough. If I don't cough, then I will stop breathing. It happens…it happens…it happens…it hurts like….it happens……when I run. And when I need a breath, I get it. It happens even worse. And when I need to breathe, I can't… I have to cough so much, and then it becomes difficult to cough. (C2, 10Y/M)

Simon was fearful of falling during flare-ups, and he said that he holds his father’s hand to prevent falling.

> Well, I have to hold my dad's hand, and that is why I don’t fall because I take deep breaths. (C1, 8Y/M)

Family carers reported their child’s asthma episodes as frightening.

> It is the hardest time–getting shortness of breath. It is hard to see when a child is struggling for breath. So yeah, it is hard. What I can say…I don't want children to suffer like that…because they are not like grandparents or old people. (P8/Mother)

Some family carers expressed their concerns about the uncertainty arising from not being able to predict the future course of the disease.

> I don't know, like, how long it is going to be. Whether it is curable or not, or how her future is going to be with asthma. (P6/Father)

Family carers were fearful of various triggers and alerted their children to situations where they could be exposed to triggers.

> So, I used to tell him not to go to his friend's house because they have cats, and not to touch them. (P7/Mother)

Personal experience, either having asthma or family history and knowledge of asthma-related struggles, further aggravated parents’ fear.

> I told you since I had asthma, I know how hard it is to breathe at that time. (P1/Mother)

Thus, I went back and forth between new and already analysed data, constantly made comparisons to generate new concepts, and then collected more data to further expand the concepts and verify them (Oktay, 2012). I made use of deductive and abductive reasoning to move back and forth between data and pre-existing theories or knowledge. I made constant comparisons and interpretations while searching for patterns, relationships, and the best possible explanations (Carmichael & Cunningham, 2017; Charmaz, 2017; Thornberg, 2012). The constant comparative technique is utilised to identify similarities and differences in the data and to continuously refine concepts and theoretically significant categories (Chun Tie et al., 2019). Thus, it ensures that all possibilities are considered, and that the theory constructed is grounded in the participants' data rather than predetermined by the investigator (Birks & Mills, 2015; Charmaz, 2014).

Corbin and Strauss (2015) recommend specific types of questions that are useful when doing constant comparative analysis. Sensitising questions help researchers explore the possible meanings of data (what is happening in the data? who are the people involved?). Theoretical questions help researchers to recognise the processes and variations within the data and to make connections between concepts (what is the relationship of one category to another? what would occur if…). Practical questions provide direction for theoretical sampling and help with the development of the structure of the theory. Guiding questions guide the interviews, observations, document gathering, and analysis. This type of questioning continues until the similarities and differences between cases are clear. By using these questions, researchers are making comparisons at the sub-categorical and categorical levels. The subcategories of a category evolve—that is, the properties of that category (Corbin & Strauss, 2015).

Ultimately, constant comparative analysis results in high-level conceptually abstract categories, which provide an explanation of variance to categorical dimensionalisation (Birks & Mills, 2015). For example, considering the above-mentioned category of being fearful, I asked many questions: "What does fear mean to each participant? What do they fear? What may the conditions be when a participant presents with little fear? What are the factors that alleviate or aggravate fear? What are other causes of fear? Are there any other hidden fears? What are the strategies taken to overcome fear? Who are the actors involved? How does it affect the participants or their families?" (Chenitz & Swanson, 1986). As the analysis progressed with these questions being asked, I could see other sub-categories, such as *fear of blame, shame and discrimination,* and *fear of treatment side effects*, being developed under the category of being fearful.

Theoretical Sampling

Theoretical sampling is another hallmark of GT research, in which the researcher selects samples or modifies the interview questions based on the type of data that needs to be collected next (Glaser & Strauss, 1967). The use of theoretical sampling in conjunction with constant comparative analysis enhances the conceptual levels of analysis and guides the process of data generation (Chun Tie et al., 2019). In their work, Glaser and Strauss (1967) describe theoretical sampling as the process by which different "slices of data" (pp. 65–69) are combined to develop a theory. The purpose of theoretical sampling is mainly twofold: 1) to obtain slices of data to expand relevant categories and relationships, and 2) to limit and integrate the theory by specifically defining the core category and its relationships with other categories. It is essential to carefully develop the theoretical scope by working with different groups at various levels of generality. Additionally, theoretical sampling should be based on a variety of social units rather than solely on the viewpoints of individuals (Hoare et al., 2012b; Gibson & Hartman, 2014).

Novice GT researchers may confuse the concept of theoretical sampling with the iterative process of GT. I started with purposive sampling and moved to theoretical sampling once there were some preliminary categories in place and as the data showed gaps and hunches which needed to be filled. In other words, I selected the participants based on their potential contribution to the theoretical concepts evolving from the collected and analysed data (Charmaz, 1995; Corbin & Strauss, 2015; Glaser & Strauss, 1967). In the following memo, I explain why I selected Shekar for the study among the other potential participants.

Memo 2 /8/2020: My Next Participant, Shekar

Next, I plan to interview Shekar, who is a 15-year-old boy. Shekar migrated to NZ two years ago, when he was 13. Mandeep, the 16-year-old girl whom I interviewed before, was born and brought up in NZ. Her perspectives on asthma were mostly based on NZ experience, although her talk reflected the impact of Indian cultural beliefs on asthma management decisions. Having immigrated recently, I expect Shekar to contribute more about his experiences with asthma in India versus NZ. Although I have interviewed children who migrated from India, they moved at a young age, and thus, they could not explain in detail or recollect much about their experiences in India.

I am also interested in knowing how independent Shekar is with his asthma management decisions and the influence of the family caregivers/extended family members on his asthma management behaviour at this age. I expect to hear from Shekar about various evolving concepts in the data, such as the stigma about the condition, attitudes towards inhaler use, hot-cold beliefs, sources of support, cultural beliefs, healthcare system differences, etc. I expect that he would be able to greatly contribute to my evolving categories.

As initial coding progressed, I applied theoretical sampling to explore and validate the concepts that were identified in the early analytic phase (Charmaz, 2014). I utilised theoretical sampling in order to verify and elaborate the boundaries of the categories and to specify the relationships among them. Variation within a category became apparent when I conducted theoretical sampling. Thus, theoretical sampling helped me to broaden and refine categories by developing the properties of each category until no new properties evolved. I regularly revised my guide to include a few focused questions to learn more about my categories. The following is a section of a memo which I wrote after my sixth interview.

Memo 6/5/2020: Questions Prompting Theoretical Sampling

- *I would like to find out how families from different immigration backgrounds experience asthma (that is, short-term versus long-term immigrants, children who are immigrants versus NZ citizens).*
- *I also look forward to interviewing families who come from different parts of India and have different religions, as these may have an influence on how they approach the condition. I can see this already in the data.*
- *What might be the difference in attitude and practice between those caregivers who have experienced asthma and those who have not? Or, what might be the difference between the attitude and practice of a caregiver who already knows about asthma and a caregiver who learns about the disease from their child's experience? Or, what might be the difference between the attitude and practice of a caregiver who has not experienced asthma but knows about the condition or has come across the condition from a family member or a friend?*
- *I think 'stigma' is an important concept (a big barrier to effective asthma management), which could be a potential category, and I have to explore more regarding this concept in my upcoming interviews. This seems to be an area where HCPs will have to do more work. I would also like to explore the child's perspective on this aspect and whether or not they are impacted by the stigma.*
- *I would like to find out how other participants seek support and their strategies for*

choosing appropriate support systems.

- *I would like to see if other participant family carers are imposing restrictions (diet/activities/hot-cold restrictions) on their children or if they provide any other special care to their children in managing asthma. Also, I want to explore how children feel about these restrictions.*
- *The role of CAM is another area that needs further exploration.*
- *The literature reviewed also indicates a similar fear existing about steroid/inhaler use among South Asian communities. Thus, this is another area which has to be explored further.*

Theoretical sampling is based on abductive reasoning and is described elsewhere (Sudarsan et al., 2022a). Theoretical sampling also involves asking previous participants for further information or gathering information regarding experiences that were not discussed in the initial interview (Charmaz, 2014).

Doing theoretical sampling poses several practical challenges. Researchers may not be able to gather data whenever, wherever, or with whomever they choose. During the course of a research investigation, there are always limitations to what can be accomplished. Researchers should make the best use of available resources and acknowledge their limitations. For example, the current study was conducted during the COVID-19 pandemic. During my analysis, I found that extended family members played a crucial role in determining attitudes towards asthma among family caregivers and their children. Specifically, I was interested in collecting data from extended family members who played the role of primary family caregivers. Despite my efforts, I was unable to find any of the extended family carers who were primary caregivers. I assumed that the current immigration policies of NZ might be one of the reasons for this situation. The COVID-19 pandemic restricted the entry of non-citizens/ NZ residents from overseas to NZ. NZ had also temporarily suspended visas for *parent* categories in the recent past. All the family carers I interviewed or identified as potential participants were the children's parents. Some of the participant children had previously lived with their grandparents, who had been sent back to India due to the uncertainty of the pandemic situation.

Intermediate or Focused Coding

Intermediate coding is the second stage of data analysis (Birks & Mills, 2015). Charmaz used the term *focused coding* to refer to the intermediate coding method. Focused codes are those codes that appear most frequently in the initial codes or have a greater significance. Focused coding allows researchers to synthesise, analyse, and conceptualise large sections of data (Charmaz, 2014). Hence, focused coding refines and condenses the collected data while also igniting the central concepts of the ongoing analysis.

One of the objectives of focused coding is to determine the adequacy and conceptual strength of initial codes. The assessment of initial codes involves comparing them with the data and identifying those codes with greater analytical potential. Table 10 shows how I have developed the focused code of *learning through trial and error* by constant comparative analysis.

Table 10

Development of the Focused Code of Learning through Trial and Error

Data	Initial Code	Focused Code
She [her mother] asks me to do steam inhalation with Vicks when I get it [asthma flare-ups], then oranges, warm food, and water. Gives me cough syrup when I get it, but no inhalers. (C10, 12/F)	Personalising management strategies	Learning through trial-and-error

We don't use that regular [preventer] one anymore. But if we see any change, then we will. (P4/Father) They [her parents] told me that, it [dairy products] might be one of the reasons for asthma because we don't know what is causing it. So, we have stopped giving him dairy products as a trial. (P5/Mother). I put ginger in tea and give it to him. Sometimes, I add like a little bit of pepper as well. So, it is not really spicy, but I feel like it gives that soothing effect. (P7/Mother) She [his mother] gives me hot food all the time, never gives me cold food, and she asks me to do yoga. Yoga, it does help. (C7, 15Y/M)		

Furthermore, the focused coding phase involves comparing codes with one another and considering those codes that may represent promising tentative categories. It is also common to see the development of subcategories within the broader categories. After exploring the experiences represented by each category, I divided them into subcategories and defined the relationships between them. I organised the subsequent categories, subcategories, and links based on how I interpreted the data. For example, based on the initial code and the focused code listed in Table 10, I developed the sub-category *striving for control*, which was included under the main category of clashing cultures.

During this phase, some initial codes were later identified as dimensions or properties of a category. For instance, one of my initial codes, *experiencing stigma*, underwent multiple revisions as the analysis progressed. With further thoughts, the code was ultimately titled *fear of blame, shame, and discrimination*, to reflect a variety of stigmatising experiences ranging from *experiences of being blamed* to *experiences of discrimination*. These varying experiences served as one of the properties of this code under the heading *stigmatising experiences*. Finally, the code of fear of blame, shame, and discrimination became a sub-category within the broader category of being fearful.

During the focused coding phase, relationships between categories are established, and individual categories are fully developed through the interconnection of subcategories and the development of all their properties and dimensions (Birks & Mills, 2015; Charmaz, 2014). I was able to identify some strong analytic directions during my focused coding phase. I chose those initial codes that made the most analytical sense in relation to categorising my data comprehensively and precisely. I reviewed existing categories, subsumed similar or related categories under one category, and refined the properties and dimensions of existing categories. My theoretical memos provided me with a broad perspective on the relationships between categories and what might be an important finding (Urquhart, 2013). According to Glaser (1978), theoretical memos are the “bedrock of theory generation” (83). The following is an example of a theoretical memo that I wrote to illustrate the relationship between categories.

Memo 07/07/2020: Relating the Categories: 'being influenced,' 'making sense,' and 'developing personalised management strategies.'

The challenge for the novice GT researcher in the focused coding phase is to move to a more abstract level of analysis by developing relationships between categories. This can be accomplished by linking categories using properties and dimensions. For example, my initial analysis uncovered three significant categories: 'being influenced,' 'making sense,' and 'developing personalised management strategies.' To explore the relationship between these categories, I considered how the source and power of various influences impacted the participants' attempts to make sense of asthma. For instance, during the initial coding, I found various 'sources of influences', such as history, culture, friends, family members, HCPs, etc., which was one of the properties of the initial code 'being influenced'.

During the focused coding phase, I hypothesised that participants developed 'personalised management strategies' based on the way they made sense of asthma, depending on the power of various influences on them. These types of relational statements have the potential to explain the processes or actions apparent in the developing GT. This type of hypothesis generation is initially fairly speculative.

To verify my hypothesis, I used these ideas to guide my next round of data collection using theoretical sampling. I tried to seek out various sources (properties of the category 'being influenced') and level/power/extent of influences (dimensions of the category 'being influenced'), and how participants' attitudes towards asthma changed based on these influences and the different types of impact of these influences on the development of asthma management strategies. I also explored the outcomes/consequences of these strategies. I tried to verify that this relationship was backed up by many different instances in the data and examined those instances to further define that relationship. I also looked into the literature to check for similar relationships.

My analysis indicated that some processes occurred between the phases of 'making sense' and 'personalising management strategies.' This can be explained as follows: As the participants attempted to make sense of asthma based on the information gathered from multiple sources, they were often confused. Related concepts were coded under the term 'feeling conflicted.' I could observe the participants engaging in a process of negotiation (both inter-personal and intra-personal) to overcome this state of confusion. As a part of this process, the family caregiver and the child worked together with HCPs and other significant people in their life to develop asthma management strategies that would work best for the child. Ultimately, the family carers developed a personalised management plan for their child based on an intra-personal negotiation. There was then a process of educating the child regarding these plans. Following this, children engaged in a process of internal negotiation after which they made their final decision. Families' and children's asthma management strategies, therefore, were the result of various internal and external negotiations. The codes related to these negotiations were subsequently added to the code 'making negotiations.'

It is also important to ensure that the names assigned to the focused codes are meaningful and accurately reflect their contents. As the focused coding phase progressed, I elevated the earlier code of 'personalising management strategies' into a more abstract code of 'striving for control' as I observed the participants adopting multiple trial and error strategies to attain control over the condition.

The analysis generated a significant number of codes as a result of the coding method used, whereas the final GT should only include a few codes or core categories so as to be functional and elegant. I was aware that I had the freedom to disregard insignificant codes and concentrate on those that proved effective in advancing the theory (Charmaz, 2014). During the next step of analysis, I used this testing of ideas to help me identify the core category or categories.

Identifying a Core Category

A key feature of GT is the identification of one or more core categories during the focused coding phase (Charmaz, 2014). The core category indicates the main concept that has evolved during data analysis. In other words, the core category represents the central phenomenon or main concern of the studied population. It should encapsulate the essence of a pattern of behaviour observed in the data and summarise what is occurring (Schreiber et al., 2001).

Strauss (1987) observes that a core category should be abstract and broad enough that it can be drawn upon in future research, which should also be able to produce a formal theory. For example, Glaser and Strauss developed a formal theory of status passage based on their core category (patients changing status from living to dying) (Holton & Walsh, 2016). I consciously worked to raise my theoretical sensitivity, critically evaluated categories before declaring them theoretically saturated, and selected a core category that encapsulated the developing GT. As a result, I was able to efficiently progress to the advanced coding phase of theoretical coding, the final phase of GT analysis. Theoretical coding is the method for integrating all data, codes, categories, and the core category into a unified theory (Schreiber et al., 2001).

The Core Category of Clashing Cultures: The core category of clashing cultures condensed the key features of all the categories in a concise way, and it became evident in all the aspects of the constructed theory (Birks & Mills, 2015; Charmaz, 2014). Conventionally, when the core category is a BSP, a gerund is used to denote it. The use of a gerund conveys the concept of change over time and illustrates the action of the participants (Charmaz, 2014). One of the simplest ways for researchers to identify the core category is by asking the question, “What is this study about?” As the study progressed, I repeatedly returned to this question (Charmaz, 2014; Chenitz & Swanson, 1986).

Sometimes, the core category becomes apparent early in the research process. Participants may or may not be aware of the underlying process while it is occurring, or even afterward. Similarly, participants may be aware of what is occurring, but lack an understanding of the process as a whole. It is the analyst's responsibility to present the analysis to the reader in a manner that accurately reflects the experiences of the participants (Charmaz, 2014; Chenitz & Swanson, 1986).

The core category of clashing cultures was visible early in the data. However, it took some time for me to identify the process and name it. I used the metaphor of a *tug-of-war* to describe it. Next, I reviewed each interview to determine if the core category could accommodate the stories that each participant had shared with me. In the following memo, I explain how I identified the core category of clashing cultures.

Memo 14/06/2020: The Core Category of 'Clashing Cultures.'

In the interviews, codes such as 'being a victim of stigma,' 'navigating through stigma,' 'being stigma coached,' 'feeling different,' 'feeling conflicted,' 'being blamed,' 'imposing restrictions,' 'receiving special care,' 'holding onto culture,' and 'personalising management strategies' consistently came up. Early on, I had already identified relationships between 'navigating through stigma' and these codes. I realised that stigma had a significant influence on how children and their family carers developed their attitudes towards asthma. I chose to focus more on understanding the underlying processes of stigma than developing an explicit analysis. However, the concept of stigma kept recurring in subsequent interviews. I asked myself: Do I have something related to stigma as a core category? Frequently, people spoke about their experiences of being stigmatised, and I could relate it to other categories. There were many related codes that came from similar experiences. The codes matched the data. However, I asked: Did these codes actually reflect the underlying processes involved? If *not, what else was going on? Where were these codes leading the data to? What meaning did participants intend with their stories represented by these codes?*

Constructing the code of clashing cultures was a defining moment for me. I quickly realised that this code explained much more than what I had attempted to explain through the concept of stigma. Additionally, this code answered my earlier questions. The code of clashing cultures provided a more comprehensive analytic view of all the related codes. Using this code, I was able to express what I had inferred and understood but could not conceptualise. I could not find a suitable term to explain the stories I heard from the participants before the development of this code. This code explained a number of the earlier codes and described the incidents those codes represented. I found out that this category subsumed a number of initial codes describing the participants' feelings of shame, blame, and/or discrimination. I was also able to establish a clear connection between the concepts of shame, blame, and/or discrimination and the idea of clashing cultures.

Glaser and Strauss (1967) suggest that saturation is not essential for all categories; however, saturation is critical for what they refer to as core categories. After identifying the core category, theoretical sampling was limited to collecting data that would theoretically saturate the core category and its related subcategories. By following this method, I was able to refine and fully integrate each theoretical component, which resulted in a higher level of conceptual abstraction (Birks & Mills, 2015). As more data were gathered, I compared concepts and codes with the core category and with each other to determine consistencies, differences, and the theory's parameters. The data collection continued until I was confident that my theory was conceptually dense and that I had reached theoretical saturation. Thus, in the later stages of analysis, data gathering became highly focused (Birks & Mills, 2015; Charmaz, 2014; Chun Tie et al., 2019).

Furthermore, in the later stages of the study, I actively sought out cases, situations, and events which did not fit the core category as a means of testing my theory. This is known as negative case analysis or divergent case analysis. Identifying negative cases can assist in identifying new variables or providing alternative explanations to the developing theory (Birks & Mills, 2015; Charmaz, 2014). The examination of negative or deviant cases prompted me to develop a more comprehensive, abstract understanding of the phenomenon. For example, early data analysis revealed that stigma had a negative impact on asthma management practices among participants. Therefore, I sought out participants who would have possibly encountered the opposite circumstances. Specifically, I searched for participants who had lived in NZ for an extended period of time or children who were NZ citizens. I also looked for family carers who were qualified health practitioners whose attitudes towards the condition may have been different (Schreiber et al., 2001). Surprisingly, this was not the case with any of my participants.

I was unable to identify a case that contradicted my theory, and the final round of data collection supported the developing theory and the core category. The source of negative cases and the researcher's method of employing them will largely determine their degree of concordance with GT. Negative case analysis satisfies GT's emphasis on variation in a category or process and its analytic density (Birks & Mills, 2015; Charmaz, 2014).

Use of Metaphors: The use of metaphors allows abstract or difficult concepts to be better understood by comparing them with more familiar ideas. Researchers may use metaphors to help the public better comprehend complex and abstract ideas (Harrington, 2012; Semino et al., 2017). According to Turner (1974), “[m]etaphor is, at its simplest, a way of proceeding from the known to the unknown. It is a way of cognition in which the identifying qualities of one thing are transferred in an instantaneous, almost unconscious, flash of insight to some other thing that is, by remoteness or complexity, unknown to us” (p.

25). Patients consider clinicians who use metaphors and analogies to explain illnesses to be much more effective communicators. In addition, the development of a shared language may facilitate a greater understanding of the clinical situation, thereby enhancing the therapeutic relationship (Harrington, 2012).

In this study, I used various metaphors to better reflect the experiences of participants. Some of the metaphors used in the analysis included *journey through diagnosis*, *navigating stigma*, *battling symptoms*, *being a victim of stigma*, etc. In the advanced stages of analysis, the metaphor of tug-of-war was used to represent the theoretical code of clashing cultures since there was a good fit between the tug-of-war metaphor and the developing theory (Birks & Mills, 2015). This metaphor assisted me in explaining the relationship between the major categories and enhanced the explanatory potential of the developing theory. The following memo describes how my supervisors assisted me with the theoretical integration phase.

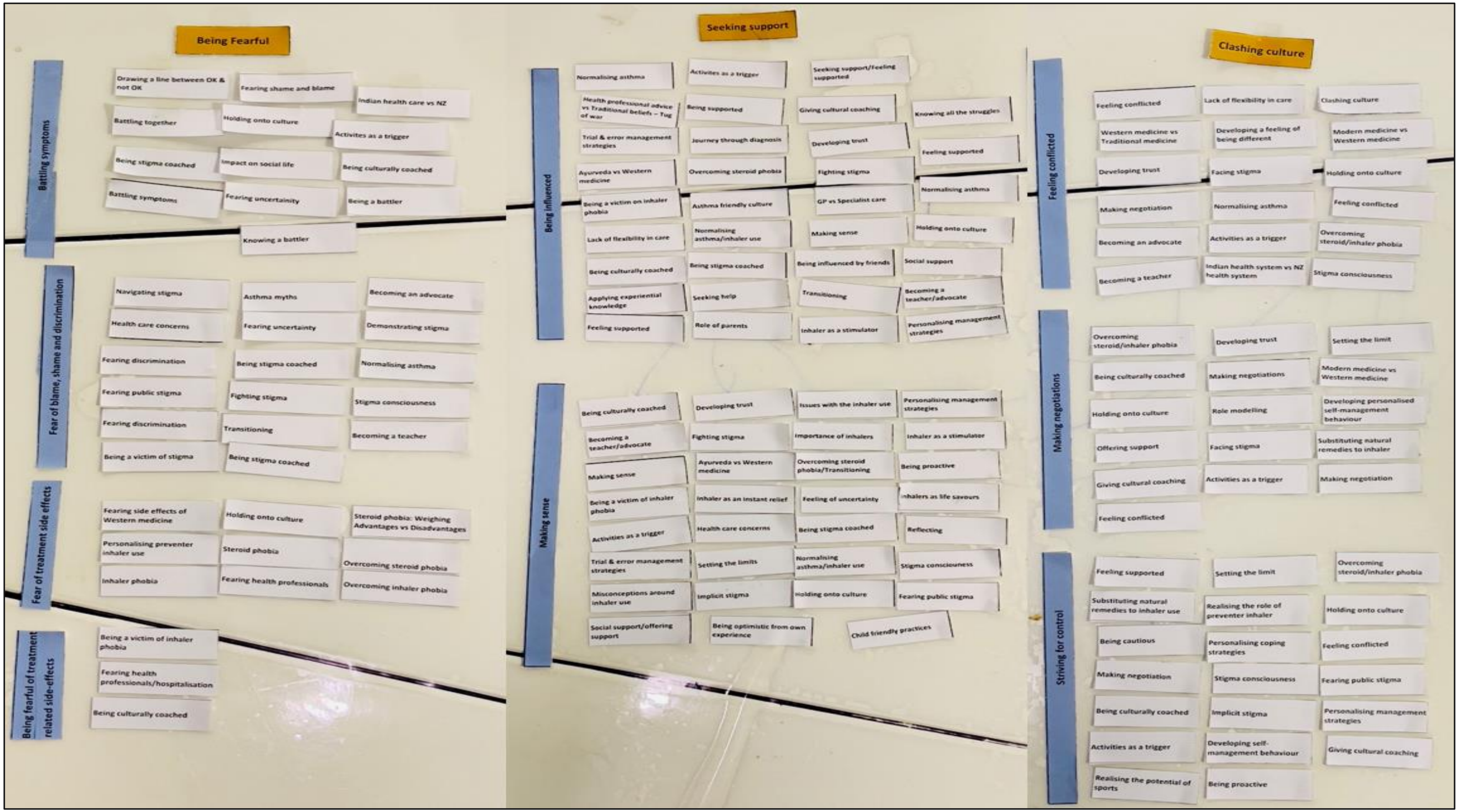
Memo 10/05/2020: My 'Aha' Moment

As a neophyte GT researcher, I had difficulty with the theoretical integration phase of my analysis. I was able to identify patterns and processes, but even with all the memos sorted and sitting in front of me, I had difficulty making the last analytic jump to integration. GT experts suggest novice grounded theorists seek the assistance of an experienced GT researcher to assist with theoretical integration. As the analysis progressed, my supervisor, Prof. Karen Hoare, asked me to write a storyline as a first step to identifying the principal categories and their relationships. I wrote five pages to explain my story, along with a diagram to illustrate it. During the follow-up meeting, we sat together, and she asked me to explain my storyline briefly. As I explained, I used the metaphor of a tug-of-war to explain the general pattern seen in the data. The metaphor of tug-of-war slipped off my tongue as I explained the storyline, and I did not have it written anywhere before. This was an "Aha!" moment. She suggested it could be a potential term to explain the BSP of clashing cultures, *and I too felt the same. I went back to my data and compared the metaphor against the raw data, doing a kind of high-level comparative analysis. It was a pleasure to see how the term explained most of the cases.*

Mapping all the focused codes highlighted other significant initial codes, such as *personalising management strategies, holding onto culture, being a victim of stigma, being culturally coached, providing special care, imposing restrictions, developing a sense of being different, being influenced, being stigma coached*, etc., which were explored further in the upcoming interviews. During the mapping process, it became obvious that all these codes and associated categories could be related to the theoretical code of clashing cultures or the metaphor of tug-of-war. Figure 21 illustrates this pattern.

Figure 21

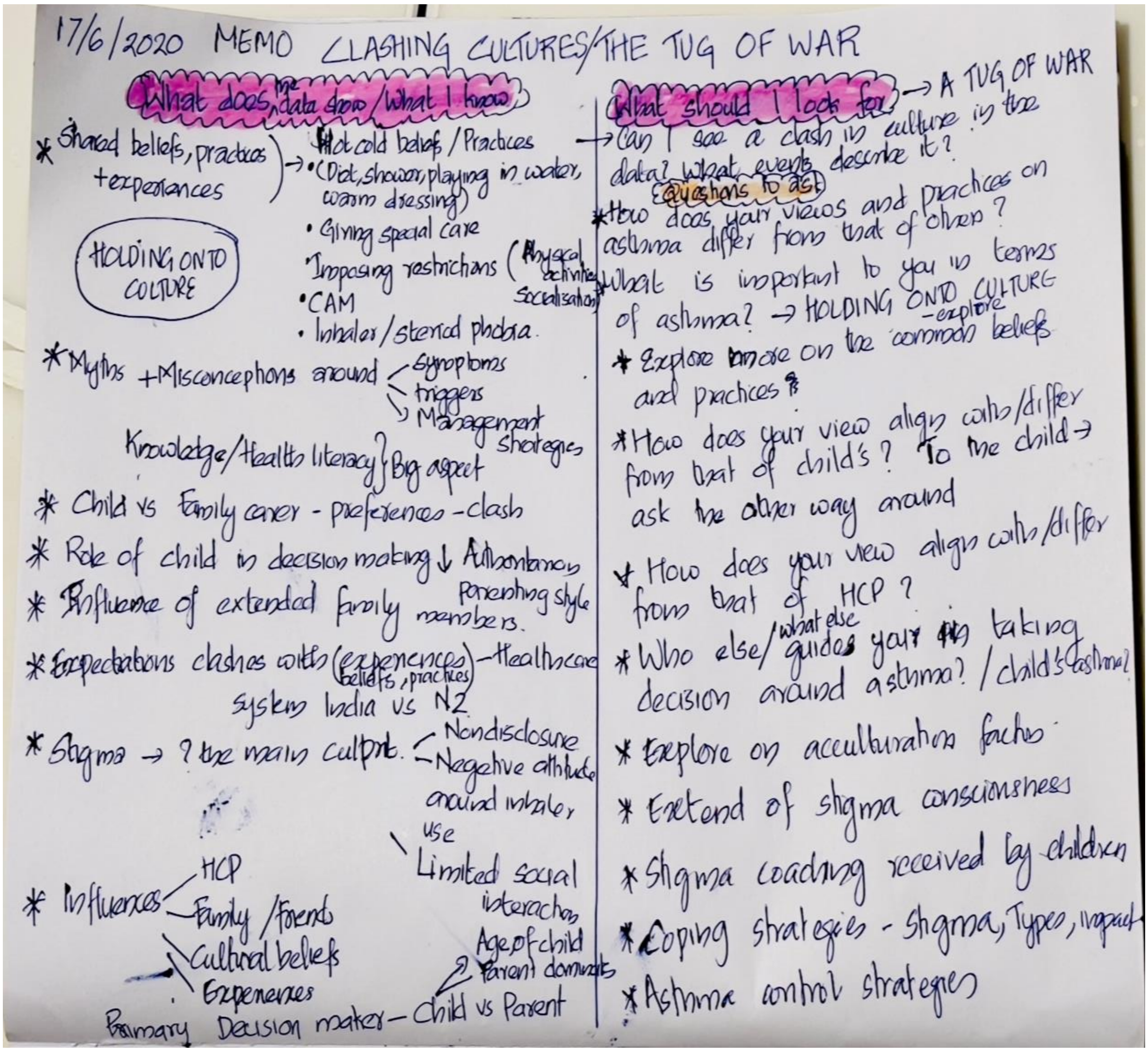
Mapping Process of Clashing Cultures/Tug-of-War



Clashing cultures was therefore developed as a core category following a multifaceted process which included additional interviews, constant comparison with initial codes, and comparison of codes with categories and categories with categories. I then went on to write a memo (Figure 22), in which I examined what I already knew about the core category from the data, as well as what required further exploration. In this way, the theoretical leads were identified, which in turn determined the questions to be addressed in subsequent interviews. Figure 23 illustrates the final discussion of the analytic work.

Figure 22

Memo 17/6/2020 The Immigrant Child in a Tug-of-War



17/6/2020 MEMO CLASHING CULTURES/THE TUG OF WAR

What does the data show/What I know

* Shared beliefs, practices + experiences → Hot cold beliefs / Practices
- (Diet, shower, playing in water, warm dressing)
- Giving special care
- Imposing restrictions (Physical activities Socialisation)
- CAM
- Inhaler/steroid phobia.

HOLDING ONTO CULTURE

* Myths + Misconceptions around
- Symptoms
- triggers
- Management strategies

Knowledge/Health literacy } Big aspect

* Child vs Family carer - preferences - clash

* Role of child in decision making ↓ Autonomy

* Influence of extended family members. Parenting style

* Expectations clashes with (experiences beliefs, practices) - Healthcare system India vs NZ

* Stigma → ? the main culprit.
- Nondisclosure
- Negative attitude around inhaler use
- Limited social interaction

* Influences
- HCP
- Family /friends
- Cultural beliefs
- Experiences

Primary Decision maker - Child vs Parent
- Age of child
- Parent dominants

What should I look for → A TUG OF WAR

→ Can I see a clash in culture in the data? what events describe it?

Questions to ask

* How does your views and practices on asthma differ from that of others?

* What is important to you in terms of asthma? → HOLDING ONTO CULTURE - explore

* Explore more on the common beliefs and practices

* How does your view align with/differ from that of child's? To the child → ask the other way around

* How does your view align with/differ from that of HCP?

* Who else/what else guides your taking decision around asthma? / child's asthma?

* Explore on acculturation factors

* Extend of stigma consciousness

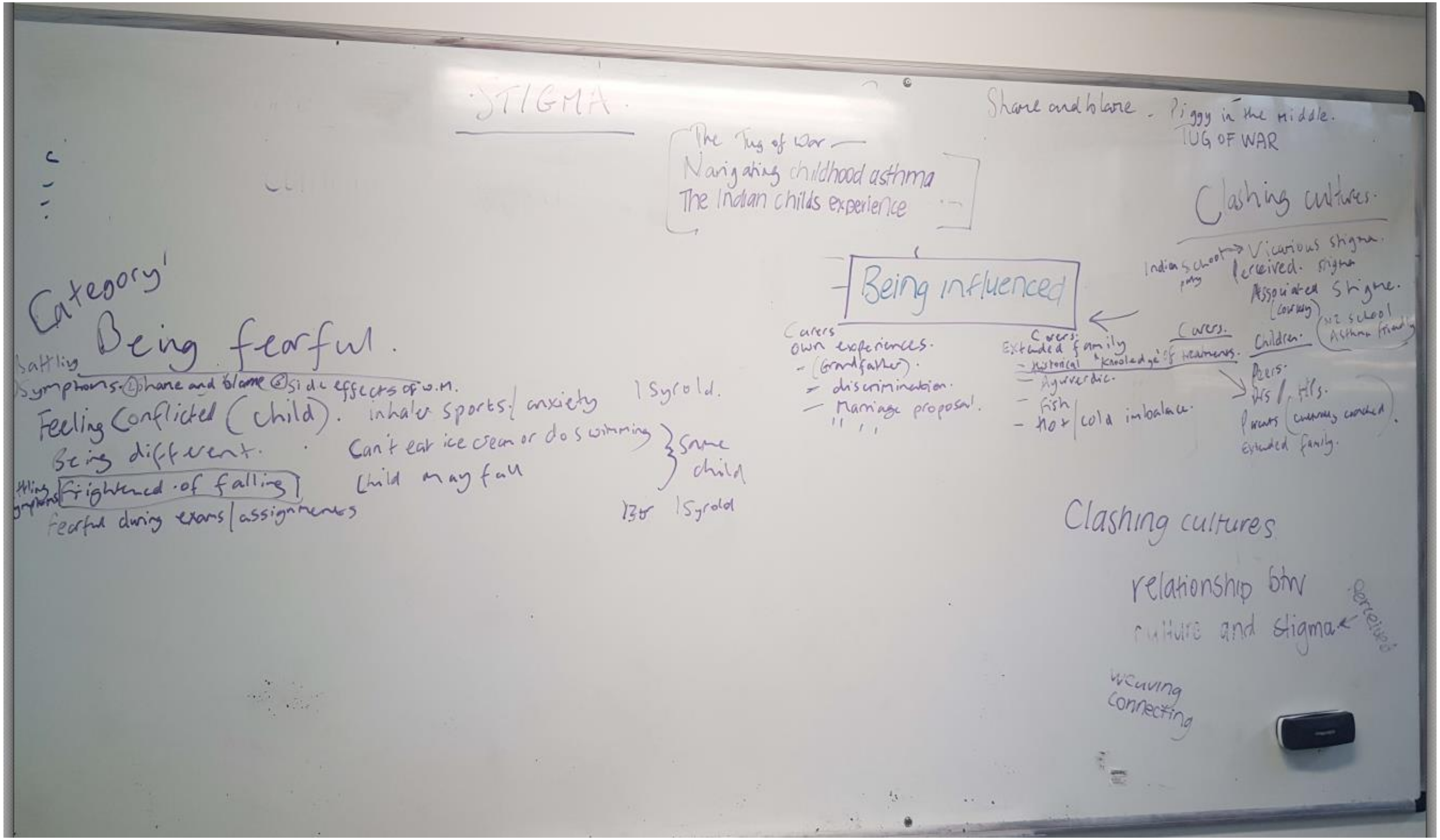
* Stigma coaching received by children

* Coping strategies - Stigma, Types, impact

* Asthma control strategies

Figure 23

Final Analytic Work



Advanced Coding and Theoretical Integration

In order to achieve theoretical integration, advanced coding is an important step, which involves raising the developing theory to a higher level of abstraction. (Birks & Mills, 2015) Charmaz (2006) uses theoretical coding during the advanced coding phase. In theoretical coding, the fragmented data will be woven back together into a well-organised theory. Generally, theoretical codes are integrative and thus give greater clarity to the focused codes, as long as the codes match the data and substantive analysis. It is expected that at this stage, relationships between the identified categories will become more abstract as they start to assume the characteristics of a theory (Charmaz, 2014; Chun Tie et al., 2019). Sorting, comparing, and integrating memos becomes critical during this stage. The quality of the final theory depends on the researcher's ability to move conceptual renderings from the level of processes identified at the beginning of the research towards a working integrated theory (Birks & Mills, 2015).

According to Birks and Mills (2015), three factors are required to integrate a GT: 1. identification of a core category; 2. theoretical saturation of core categories; and 3. a bank of analytical memos. In this phase, I primarily focused on integrating the theory and delimiting it (Gibson & Hartman, 2014). Additionally, I conducted an integrative literature review during data analysis to advance my theoretical sensitivity which served as a source of ideas to enhance my theory. I used literature both against and in support of the theory. The process of integrating my GT with the extant literature in the field enabled me to identify how it contradicted, confirmed, or extended existing ones. The findings and discussion section of the integrative review best reflects my developing theoretical sensitivity. In chapter six, I have discussed and explored further findings of the review which shows the integral role an integrative review could play during and after data analysis in a GT study. The overlapping processes of coding, theoretical memoing, and the integrative literature review enabled me to enrich the theory. Furthermore, I employed diagrams to illustrate my theory.

Integrative diagrams are commonly used in GT (Strauss, 1987). According to Urquhart (2013), “an integrative diagram gives a clear picture of where we have come from after data collection, coding, and memoing. It puts together in a larger form a lot of otherwise scattered materials” (p. 114). There may be multiple versions of these diagrams that build upon one another through testing and questioning. At various stages of the theory development, I drew a series of diagrams representing an approximation of what was attempted to be captured by the theory. Drawing and redrawing diagrams enabled me to conceptualise the evolving theory, which could then be compared with data (Schreiber et al., 2001). An early diagram, for example, may not contain crucial information, but it may indicate areas that require further investigation.

Similar to memos, early diagrams are often messy, complex, incomplete, and provisional. Diagrams also evolve, are sometimes negated, and probably expand upon previous configurations. In the intermediate and advanced stages, however, they become simple, organised, and easy to follow. Figure 24 represents a messy diagram that I created during the initial phase of focused coding.

Figure 24

A Messy Diagram Drawn during the Focused Coding Phase

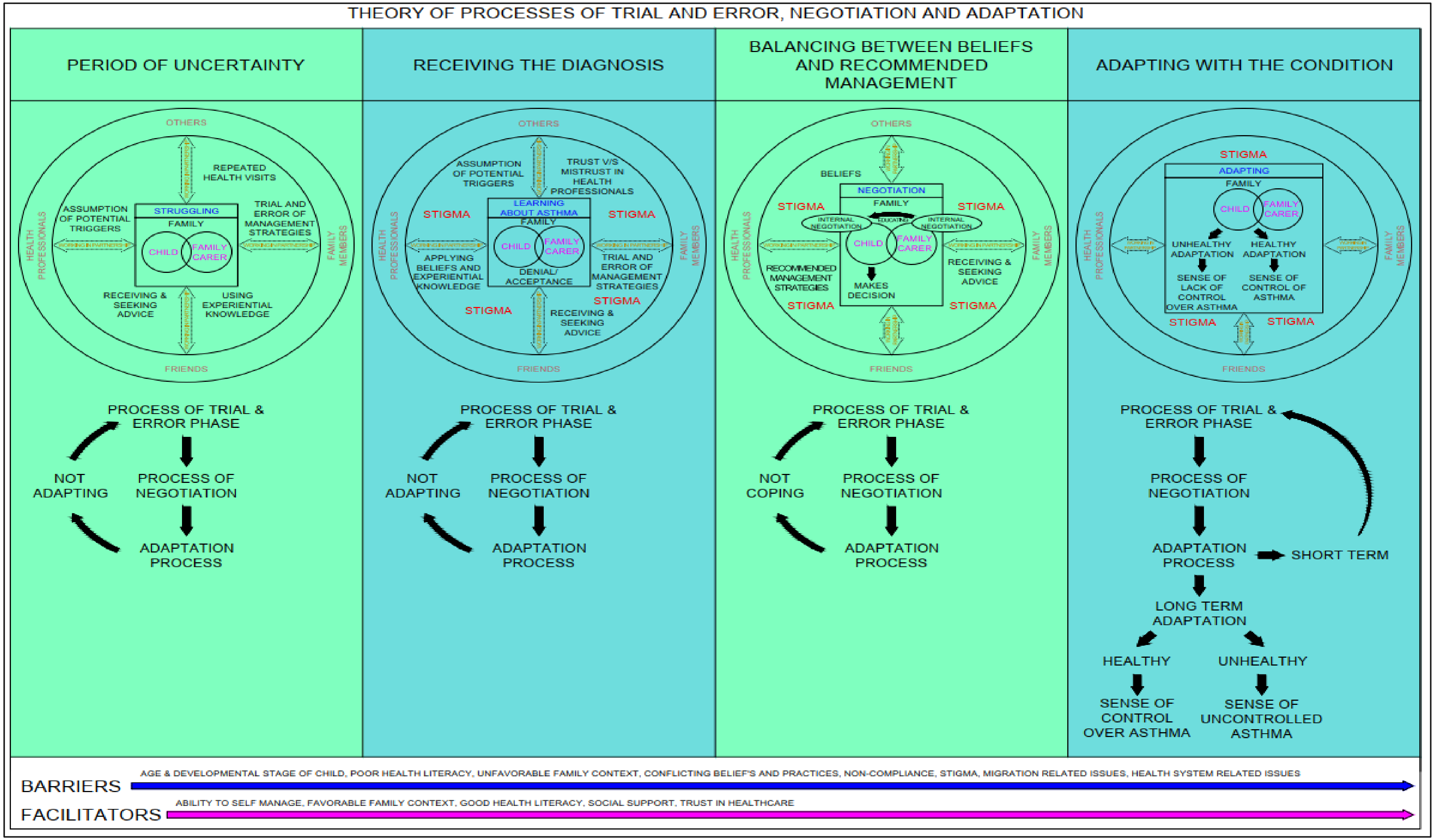
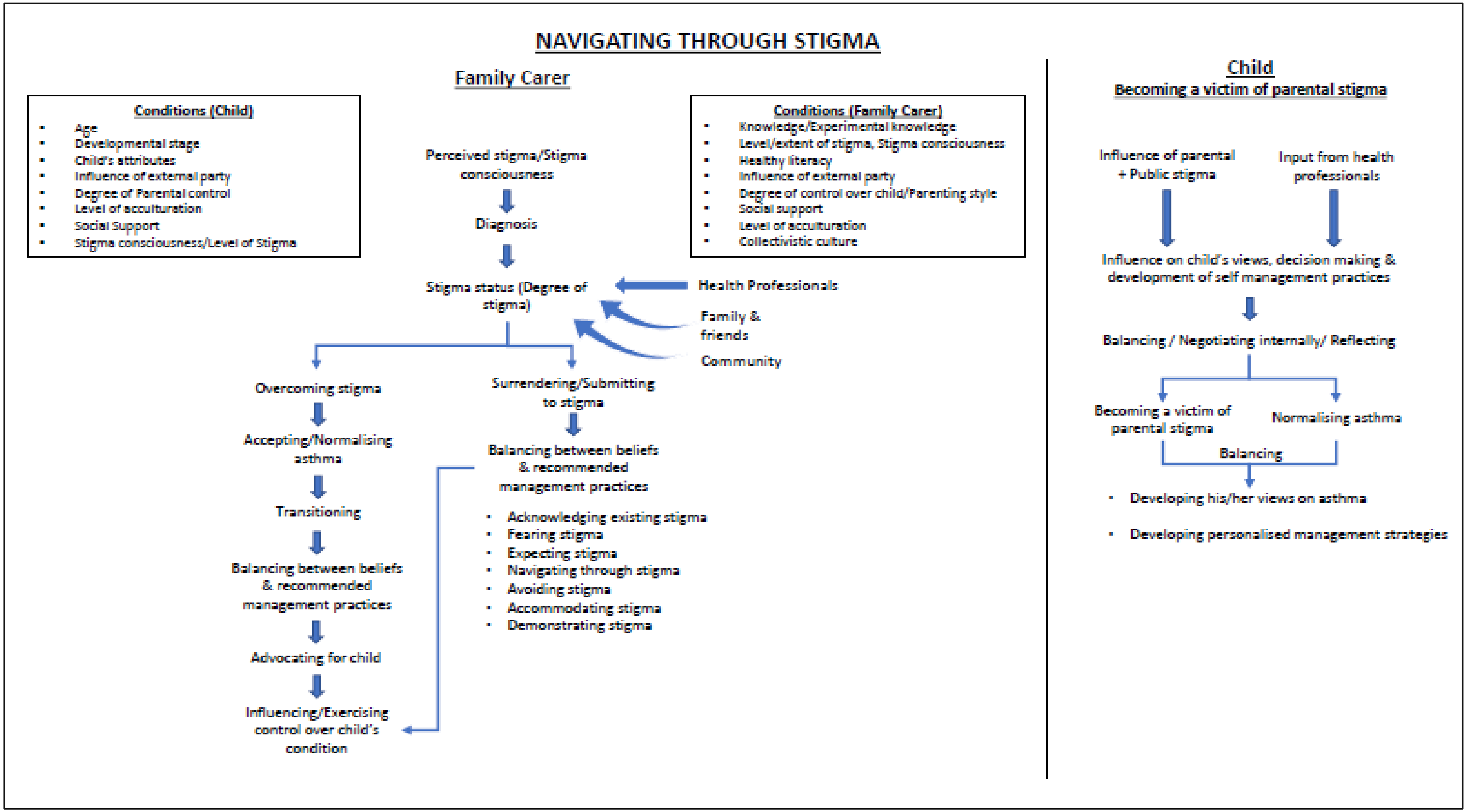


Figure 26 in chapter five shows the diagram representing my final GT. In the final GT, I used diagramming to illustrate the relationships between the core category and the other categories. Additionally, diagrams can be employed to identify the properties and dimensions of categories and subcategories. Figure 25 shows how I attempted to conceptualise the developing concept of stigma.

Figure 25

Diagramming to Develop the Concept of Stigma



According to Charmaz (2006), theoretical codes will take the form of a coherent analytic story. I used the storyline as a tool to assist with theoretical integration. and it is described elsewhere (Birks & Mills, 2015; Strauss & Corbin, 1990; Sudarsan et al., 2022b). This method facilitated the development of a story that connected the categories logically and generated a comprehensive collection of theoretical propositions (Chun Tie et al., 2019). The storyline technique (discussed in chapter five) allowed me to easily identify the core category as well as achieve theoretical saturation as I progressed through various stages of analysis. Additionally, it allowed me to give an interesting outlook to the theory produced that otherwise might not be appealing to the audience (Birks & Mills, 2015).

Good GT research aims to develop a parsimonious theory with interconnected concepts and explanatory relationships that, by accounting for data variation, explains how participants resolve their fundamental social problem (Birks & Mills, 2015). The theory should be abstract —frequently a metaphor—but must be immediately recognisable to participants, consistent with the data, and powerfully illuminating the action and interaction surrounding the phenomenon under investigation. Taking a reflexive approach to data analysis allowed me to avoid inadvertently applying pet theoretical codes during initial coding while simultaneously enhancing my theoretical sensitivity. I assessed the completeness, internal consistency, and logic of the theory. I was able to explain the central processes of the study using the concepts and interrelationships of the theory (Charmaz, 2014).

Strategies and Tactics to Assure Rigour:

In research, rigour refers to the quality of the findings, as well as their robustness, accuracy, and reliability. Rigour is key to ensuring that research findings are unbiased and trustworthy, and that they truly reflect the phenomenon under study. A rigorous approach not only involves being consistent and systematic in the planning and execution of research but also being transparent and open about the methodology, methods, and results (Birks & Mills, 2015; Charmaz, 2014).

Researchers' expertise, methodological congruence, and procedural precision are important quality considerations for a GT study (Birks & Mills, 2015). Since I was a novice grounded theorist, I read seminal books on GT before I began my study and attended GT workshops in order to gain sufficient knowledge about the methodology. I ensured that my PhD supervisory team included expert grounded theorists. A further important quality consideration is the transparency regarding the methodology and methods used during the study. If a study claims to be a GT study, it is important for it to demonstrate the use of main tenets of the methodology such as coding (initital, focused, and advanced), the constant comparative method, concurrent data collection and analysis, memoing, and theoretical sampling (Birks & Mills, 2015; Charmaz, 2014). Several examples have been presented in the current chapter to illustrate how I adhered to the main tenets of GT.

Several other strategies were used throughout the study to ensure rigour. I adopted purposive sampling initially to obtain a diverse sample based on various factors such as the child's age, immigration status, duration of diagnosis, religious affiliations etc. I chose this sampling approach to ensure varied perspectives and avoid the potential for homogeneity of the sample. I transcribed all interviews verbatim to ensure accuracy. As a result, I was able to capture nuances and contextual information that would have been lost if someone else had done the transcription. Moreover, self-transcription enabled me to stay close to the data and make more accurate conclusions based on it. Memos, fieldnotes, and constant comparative methods accompanied with line-by-line coding ensured grounding of the theory in the data. These methods also ensured that I did not impose my own preconceived notions on the developing theory. Along with regular memoing, the use of diagrams and regular discussions with my supervisors assisted me in refining and clarifying key concepts as my analysis progressed, as well as providing an audit trail of the theory development.

Furthermore, theoretical sampling enabled participants to implicitly participate in the verification of conceptual ideas that were developed during theory generation and confirm that the interpretation of the data was consistent with their experience and understanding. Abductive reasoning also served as a valuable tool for generating and evaluating ideas, which enabled me to ensure that the resulting theory was meaningful and would have real-world applications. By engaging in this iterative process, my theoretical sensitivity was enhanced, and I ensured that the developing theory was valid and reliable. Moreover, the developed theory resonated with participants and other people from similar circumstances which demonstrated that my interpretations reflected participants' intentions. Thus, the theory appeared to be plausible, applicable, and accurate.

This study also applied Charmaz's (2014) four criteria for evaluating quality, which included credibility, originality, resonance, and usefulness. The criterion of credibility establishes that the constructed theory is a true interpretation of the participants' views. Originality is attained through the discovery of new knowledge and insights into the topic under investigation. (Charmaz, 2014; Korstjens & Moser, 2018). The criterion of resonance can be established by developing a theory that makes sense to people in similar circumstances. Usefulness refers to the contribution of new knowledge as filling the existing knowledge gap and enhancing existing healthcare systems. Usefulness also refers to the capability of the GT to be utilised in various fields, including health care, education, administration, and future research (Charmaz & Thornberg, 2021). It is likely that the final theory will have a higher resonance, usability, and value in the future if the researcher is successful in meeting the criteria of originality and credibility (Charmaz, 2014). These criteria will be discussed in more detail in the conclusion chapter once the results and theoretical model have been presented.

Use of NVivo 20

NVivo 20 was primarily used for data management and not data analysis. NVivo was used to organise, reorganise, and manage voluminous interview data. I utilised many of the functions, including data recording, sifting, and sorting, which allowed me to focus on the critical thinking required for quality analysis (Corbin & Strauss, 2015). The interview transcripts were formatted in Microsoft Word to facilitate importation into NVivo.

Summary

Chapter four presents the research methods, including ethical considerations, data collection, and analysis. The chapter outlines how I recruited participants and collected data in accordance with GT's main tenets. I have explained the complex iterative process of coding and how I used various GT techniques to gradually raise the level of abstraction during the theory development process. With a detailed description of the steps taken in the research process, this chapter provides support for the validity of the findings by demonstrating the degree of rigour in my research. The final GT is presented as a storyline in the next chapter.

Chapter 5–Findings: Navigating Asthma—The Immigrant Child in a Tug-of-War

Stories give life to data, and data gives authority to stories

—*Wendy Newman*

The previous two chapters have discussed the GT methods used in this study. The procedures of data collection, analysis, and theory formation were explained in depth. In the first section, this chapter will discuss the storylining technique used in the study. Next, the findings are summarised in two sections: 1) the final theory, *"Navigating asthma—The immigrant child in a tug-of-war*," is explained using a storyline and is presented as a journal article published in the *Journal of Clinical Nursing* (JCN*)*; and 2) barriers and facilitators to effective asthma management among Indian immigrant children. The theory explains the process by which Indian immigrant children and their family carers navigate asthma and is comprised of three categories: *being fearful*, *seeking support*, and *clashing cultures.*

Storyline

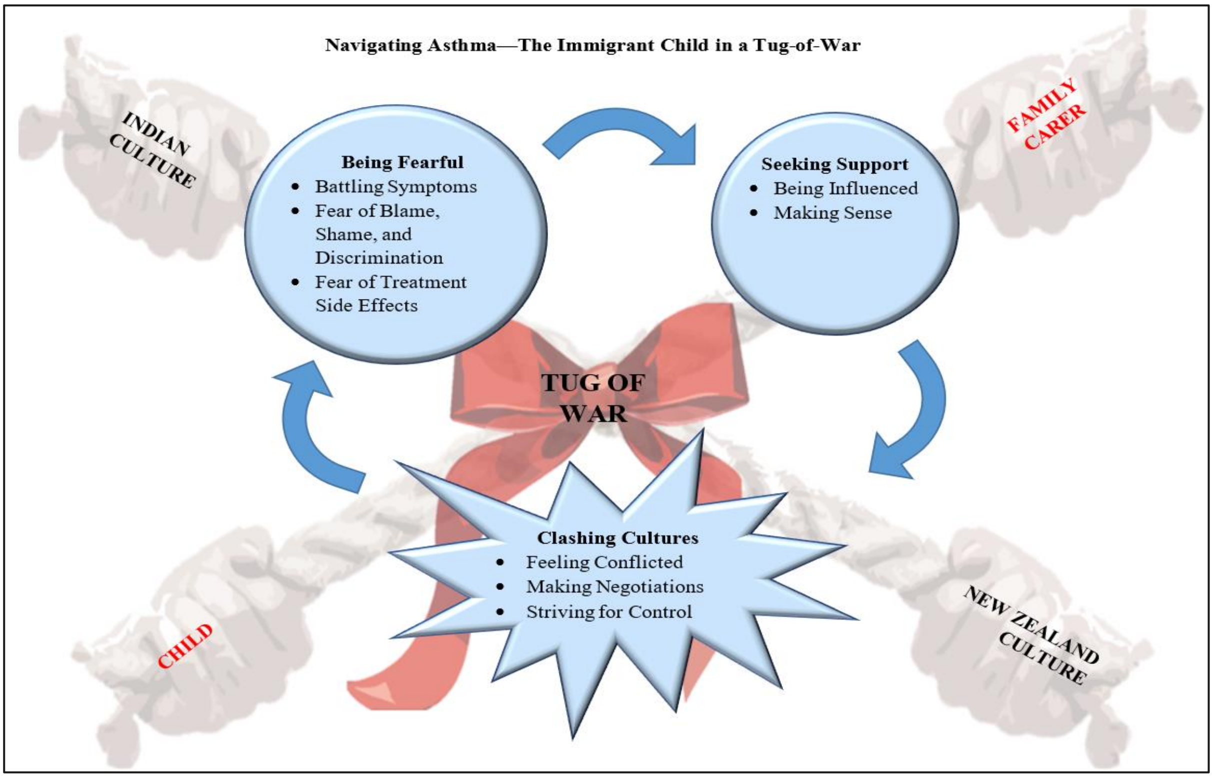
Rigorous application of GT methods can reveal any stories hidden in the data. Additionally, the use of storylines facilitates the development of theories that are grounded in the data and uninfluenced by preconceived ideas (Birks & Mills, 2015). Storylines are integral to all phases of GT research and may take different forms at various stages. As I engaged in constant comparative analysis during the early phases of data generation, I was able to discern the storyline forming. At first, writing the storyline allowed me to identify the gaps in the developing theory, and refine and expand categories. To address these gaps, I iteratively revisited the data, went back to the field to collect more data, and then modified the storyline. Once the storyline was established, raw data was added to support it. Storylines written during the phase of focused coding assisted me in identifying the core category, associated categories, and their relationships (Chun Tie et al., 2019; Freshwater, 2009). The account that follows outlines the theory of *navigating asthma—the immigrant child in a tug-of-war*.

The Theory: Navigating Asthma—The Immigrant Child in a Tug-of-War

The theory constructed from the study is *Navigating asthma—The immigrant child in a tug-of-war*. Figure 26 depicts the theory's main categories and subcategories.

Figure 26

Navigating Asthma—The Immigrant Child in a Tug-of-War



Note: Reprinted from "Navigating asthma— the immigrant child in a tug-of-war: A constructivist grounded theory," by I. Sudarsan, K. Horae, N. Sheridan, and J. Roberts, 2022b, *Journal of Clinical Nursing*. [Online ahead of print]. (https:// doi: 10.1111/jocn.16521). Copyright 2022 by Wiley Publications.

The asthma journey of Indian immigrant children can be divided into three main phases based on the three main categories derived from the data analysis. The phases, represented as the blue shaded portions in the diagram, include *being fearful*, *seeking support*, and *striving for control*. In all the three phases, a tug-of-war is evident. As depicted in Figure 26, two types of tugs-of-war are present: one between two cultures, the native Indian and the host NZ culture, and another between the family caregiver's preferences and that of the child. The first tug-of-war, which involves the clash between the cultures of two nations, lays the foundation for the second tug-of-war. The second tug-of-war often occurs when parents tried to incorporate their beliefs and practices into their children's asthma control strategies, which often conflicts with those of the children.

The categories and subcategories of the theory are italicised in the following summarised storyline.

Being fearful: Participants often expressed a sense of ongoing fear, which is the first category of *being fearful*. Fear was centred around *battling symptoms*, *blame shame, and discrimination* and *treatment side effects*. It is not uncommon for children and their parents to experience fear in the case of childhood asthma. Nevertheless, the immigrant status made the experience of fear more challenging. For example, participants' fear of asthma was influenced by several factors, including conflicting traditional beliefs and practices regarding asthma, lack of extended family and wider community support, a lack of trust and familiarity with the host healthcare system, language barriers, financial constraints, and changes in gender roles, etc.

The first sub-category within the category of being fearful is the *fear of battling symptoms*. For instance, a common finding under this subcategory is the fear of cold, considering it as a trigger. Most participants believed in the hot-cold theory of illness. This belief is derived from Ayurveda, India's traditional medicine. Participants believed that anything that cools the body triggers asthma. The triggers listed by them included cold foods, weather, showers, and other factors that cause the body to cool. It is important to note that cold foods do not only refer to items that are physically cold but also to those that have a cold base, for instance, milk, bananas, grapes, etc. There was a strong tendency among children to follow these beliefs, and many believed that cold triggered their asthma. However, many of the children expressed that they felt different from their peers due to the necessity of adhering to these restrictions, whereas their peers with asthma were not required to do so. In addition, parents questioned the medical system in NZ that does not restrict patients with asthma from consuming cold foods. Furthermore, there was a fear of physical activities and sports as asthma triggers. Some family caregivers restricted their children from participating in sports activities out of concern that asthma flare-ups would occur.

One of the most concerning findings of the present study was the stigma associated with asthma, which was classified under the subcategory of *fear of blame, shame, and discrimination*. The stigma associated with asthma in Indian communities impacted children's health behaviour, health seeking behaviour, and ultimately their health outcomes. Participants discussed their experiences with stigma as well as their fears associated with it. Participants received stigma coaching. Parents were advised that disclosing the diagnosis would negatively affect their child's marriage and future employment prospects. They were discouraged from using inhalers for their children as Indian society had negative views of children using inhalers. These children’s sports and physical skills were underestimated. Parents and other family members provided stigma coaching to the children. Children, for instance, were advised not to discuss their condition or use of inhalers even with close family members. Some family carers preferred not to inform school staff about their child’s asthma. Although it was the school's policy, family carers did not give the inhaler to the school since it made the child's asthma more visible. Children were also forced to hide their inhalers, not use them in public, or use them only as a last resort.

Furthermore, there were serious concerns about the treatment side effects, which leads to the next subcategory of *fear of treatment side effects*. The most common fears among participants were inhaler phobia and steroid phobia. Many of them feared becoming addicted to inhalers. It was surprising to find out that parents who were also HCPs expressed similar views. The children, on the other hand, became confused as they observed their NZ counterparts using inhalers and having a different attitude towards asthma in contrast to their own. Some preferred to use reliever inhalers instead of preventer inhalers due to their concern about adverse effects associated with steroids present in the latter. It was common for participants to substitute inhaler use with CAM practices.

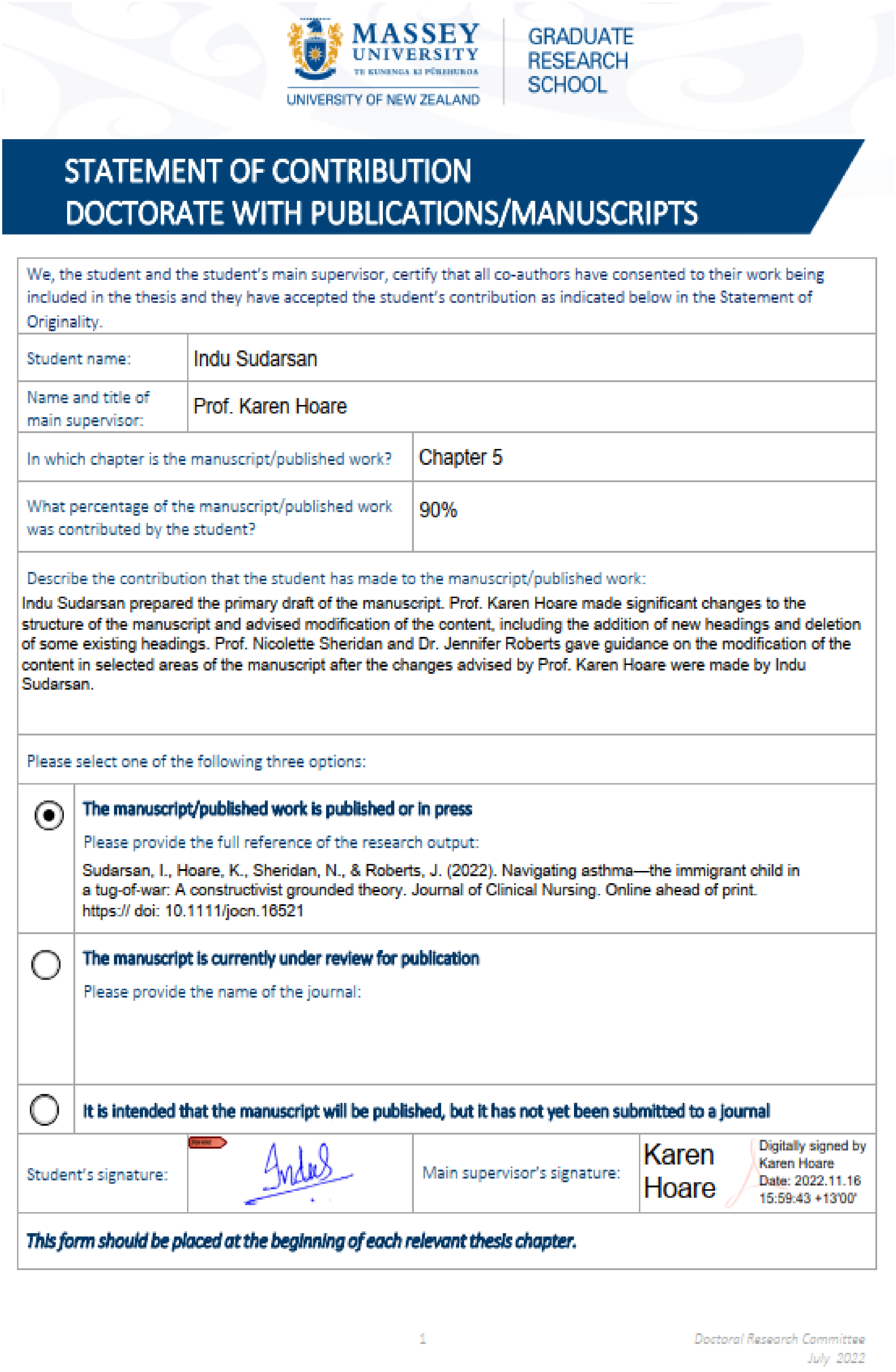
Seeking Support: The participants sought support regularly to overcome their fears, which became the next phase of *seeking support* with two subcategories of *being influenced* and *making sense*. Several people in the society constantly influenced the participants; they were overwhelmed with information from a variety of sources, such as parents, extended family members, health experts, peers, the internet, etc. In addition, their personal experiences and cultural beliefs were another important influence on their asthma care decisions. Although participants received disease-specific information from HCPs, they considered the advice they received from their family members and friends as equally valuable or superior to that provided by HCPs. When they attempted to make sense of the information obtained from various sources, participants reported feeling pulled, pushed and dragged. The strength of the pushes and pulls varied according to the power of various influences. This leads to the final phase of *clashing cultures.*

Clashing Cultures: Clashing cultures, the core category, is comprised of three subcategories: *feeling conflicted*, *making negotiations*, and *striving for control*. Tensions arose as family members tried to integrate their cultural expectations into the child's plan of care, which frequently differed from the child's preferences. Parental beliefs had a significant impact on the child's attitude towards asthma. Although parental influence is expected, the influence appeared to be more pronounced due to the authoritarian parenting style of Indian parents and their collectivist culture. Family caregivers had the challenge of keeping up with societal and cultural expectations which often conflicted with biomedical explanations. For children, the struggle was to maintain the normalcy of childhood while simultaneously attempting to control the disease and meeting parental expectations regarding the management of the illness. This resulted in a tug-of-war and was evident in every phase of their asthma journey.

Making negotiations is another major phase under the category of clashing culture. Children and their family caregivers worked together to make asthma management decisions; however, the final decision often resulted from negotiations based primarily on the preferences of the family caregivers. As this phase progressed, tensions and ambiguities regarding the inclusion of children's voices in asthma care decision-making became more evident. This was like a tug of war, where both sides are pulling to try to get their way, but ultimately, it's the stronger side who comes out victorious. This can be disheartening for the weaker side, as they feel powerless and have no control over the outcome. As children discussed their concerns, it was apparent that they felt helpless and powerless. Throughout their asthma journey, a cultural conflict was evident, and the child had to be the *piggy in the middle* as they *strived to gain control* over their condition. Several trial-and-error management strategies were identified under the subcategory of striving for control. This means that asthma management strategies did not remain consistent over time; they changed according to the power of various influences.

Thus, the three phases occurred in a cyclical manner. Participants in the study reflected on their asthma experiences and modified their approach based on personal experiences and support networks, which helped them manage various degrees of fear at different stages of their asthma battle.

The next section presents the final GT in the form of a published paper in the JCN. This journal has an impact factor of 4.423 (2021).



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STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the student and the student's main supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the student's contribution as indicated below in the Statement of Originality.

Student name:	Indu Sudarsan
Name and title of main supervisor:	Prof. Karen Hoare
In which chapter is the manuscript/published work?	Chapter 5
What percentage of the manuscript/published work was contributed by the student?	90%

Describe the contribution that the student has made to the manuscript/published work:

Indu Sudarsan prepared the primary draft of the manuscript. Prof. Karen Hoare made significant changes to the structure of the manuscript and advised modification of the content, including the addition of new headings and deletion of some existing headings. Prof. Nicolette Sheridan and Dr. Jennifer Roberts gave guidance on the modification of the content in selected areas of the manuscript after the changes advised by Prof. Karen Hoare were made by Indu Sudarsan.

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This form should be placed at the beginning of each relevant thesis chapter.

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Doctoral Research Committee
July 2022

Article 4: Navigating asthma—The immigrant child in a tug-of-war: A constructivist grounded theory

Abstract

Background: Avoidable hospitalisation rates for Indian immigrant children with asthma is high in New Zealand and other Western countries. Understanding how children and their carers manage asthma may lead to a reduction in hospitalisation rates. The topic of asthma and Indian immigrant children's perspectives has not been investigated. Most studies on the topic focus on the experiences of family carers and health professionals. Practice cannot be advanced in the child's best interests unless the child's asthma experiences are explored. The following research addressed this gap by upholding Article 12 of the UNCRC, thereby giving Indian immigrant children a voice in describing their asthma experiences.

Design: Constructivist grounded theory.

Methods: Intensive interviews were conducted with ten family carers and nine children (eight to 17 years old). Child-sensitive data collection techniques, such as drawing and photography, were used to facilitate interviewing children younger than 14 years. The COREQ guidelines guided the reporting of this study.

Results: The theory, "Navigating asthma—The immigrant child in a tug-of-war," is the resulting grounded theory, with the *tug-of-war* being the basic social process. This theory comprises three main categories: *being fearful*, *seeking support*, and *clashing cultures*. The data reflected two types of tug-of-war: one between two cultures, the native Indian and the host NZ culture, and another between family carers' and children's preferences.

Conclusion: Acculturation and sociocultural factors may significantly influence the asthma experiences of Indian immigrants.

Relevance to Clinical Practice: The theory may assist healthcare practitioners to better comprehend Indian immigrants' asthma experiences within their wider sociocultural context.

Our research indicates the need for healthcare practitioners to work in partnership with Indian immigrant families to implement culturally safe asthma management strategies.

Patient/Public Contribution: The developed theory is grounded in the data collected from the participants.

Keywords: Grounded theory, immigrant, child, asthma, India, culture, belief, practice, experience, respiratory

What Does this Paper Contribute to Wider Community?

- The theory explains the complex interplay of various influences, such as sociocultural factors and acculturation, in the development of shared values, preferences, and priorities among Indian immigrant children with asthma and their family caregivers.
- The study reveals several tensions and ambiguities regarding the inclusion of children's voices in asthma care decision making.
- The theory stresses the importance of providing culturally safe nursing care, which integrates patients' care experiences and cultural beliefs about various illnesses and treatments, allowing care to be defined by those who receive it.

Navigating asthma—the immigrant child in a tug-of-war: A constructivist grounded theory

Introduction

Asthma is one of the most common chronic respiratory diseases in children globally, adversely affecting the quality of life and placing considerable strain on the healthcare system (O’Connell et al., 2021; WHO, 2022). It is one of the top ten causes of DALYs in children aged 5–14 years and is the major cause of chronic disease-related school-absenteeism. (Ramdzan et al., 2019; Schlichting et al., 2021; WHO, 2022). Asthma is also a major health issue among Indian immigrant children, as evidenced by high avoidable hospitalisation rates in NZ, the USA, the UK, and Canada (Mehta, 2012; Mehrotra et al., 2014; Lakhanpaul et al., 2019; Scragg, 2016; Stanojevic et al., 2014; Sudarsan et al., 2022d). The increased morbidity and hospitalisation due to asthma among Indian immigrant children in NZ have been reported since 2006. No further research to date has focused on Indian immigrant children to explore their experience of living with asthma or has explained why this group presents with a high avoidable hospitalisation rate, or what nursing measures are taken or could be done to prevent future hospital visits (Mehta, 2012; Plunket, 2015; Scragg, 2016; Wong & Tsang, 2018; Yong, 2018).

Additionally, the inclusion of Indians under the category of SA raises serious concerns (Parackal et al., 2021; Sudarsan et al., 2022d). According to the NZ Ministry of Health coding, the SA group refers to people from India, Pakistan, Afghanistan, Bangladesh, Nepal, Sri Lanka, and Fiji. When used in health research, this broad ethnicity classification may not only fail to capture SA's rich cultural diversity, but may also obscure significant differences in disease prevalence, risk factors, and health indicators among different subgroups. While the Indian ethnic group itself is diverse in terms of their language, food habits, religion, culture, and other aspects, studying this group alone is essential to yielding more reliable findings (Ahmed et al., 2018; Parackal et al., 2021; Wong, 2015). Moreover, as more Indian immigrant children utilise the health care system, the number of HCPs who are exposed to these children will grow. This forecast calls for proactive approaches to developing health policies for Indian immigrant children in key areas of health concerns such as childhood asthma (Lakhanpaul et al., 2019; Scragg, 2016).

Furthermore, the extant literature on Indian immigrant children's asthma focuses on the experiences of family caregivers and HCPs (Lakhanpaul et al., 2019). Indian immigrant children's voices tend to be excluded in research because of various cultural and linguistic barriers associated with researching immigrant children. For example, a major cultural barrier to engaging Indian immigrant families in asthma research is the social stigma attached to childhood asthma in Indian communities. NZ healthcare providers have frequently stressed the need for extra support such as involvement of cultural mediators, interpreter services, and/or capacity building to provide effective healthcare to migrants (Kanengoni et al., 2018; Lakhanpaul et al., 2014). The current study upheld Article 12 of the UNCRC and gave Indian immigrant children a voice in describing their experiences of asthma (Sudarsan et al., 2022a; UNICEF, 2006).

Study Aim

The aim of the study was to explore the beliefs, practices, and experiences of asthma among Indian immigrant children and their family caregivers using a CGT approach.

Method

Design: The study was guided by the CGT methodology, with social constructionism as the underpinning theoretical framework. CGT focuses on the social construction of knowledge, which highlights the importance of multiple perspectives of reality in this extremely complex social world (Berger & Luckmann, 1991; Charmaz, 2014). CGT emphasises that researchers are co-constructors of knowledge in the research process. (Charmaz, 2014). IS (first author) is an Indian immigrant RN, a former paediatric RN, and a mother of three children. She considered her personal and professional experiences integral to effectively addressing the research aim (Sudarsan et al., 2022c). Being reflexive is important in CGT, and IS recorded her thoughts in the form of memos throughout the project (Singh & Estefan, 2018). Using an interview guide, IS employed semi-structured intensive, interviews with children (8 to 17 years old) and their family carers. Child-sensitive data collection techniques such as drawing and photography were used to facilitate interviewing children under 14 years of age. The recruitment and data collection of this study is described in detail elsewhere (Sudarsan et al., 2022a) (see Appendix D). The Massey University Human Ethics Committee granted ethical approval for the study (Reference number: NOR 19/62). Table 11 illustrates characteristics of the 10 children and nine family carers who participated in the study. The *consolidated criteria for reporting qualitative research* (COREQ) (Tong et al., 2007) guided the reporting of this study (see Appendix Q).

Table 11

Participant Demographics

Family Carer's Code/ Pseudonym	**Relationship with the Child**	**Child's Code/ Pseudonym**	**Child's Age (Years) /gender**	**Child's Birth Country /Years in NZ**	**Years in NZ (Family Carer)**	**Family Carer's Occupation**
P1/Simon	Mother	C1/Surya	8Y/M	India/3	4	Teacher
P2/Neha	Mother	C2/Hari	10Y/M	India/7	7	Self-employed (Owns a restaurant)
P3/Mandira	Mother	C3/Mandeep	16Y/F	NZ/16	17	Self-employed (Owns a restaurant)
P4/Philip	Father	C4/Nehan	8Y/M	NZ/8	14	Quality manager
P5/Nitty	Mother	C5/Krishna	9Y/M	India/3	6	RN
P6/Raghu	Father	C6/Nidhi	9Y/F	India/4	6	Engineer
P7/ Sandhya	Mother	C7/Shekar	15Y/M	India/2	2	Unemployed
P8/Rekha	Mother	C8/Ryan	8Y/M	India/1	2	RN
P9/Manju	Mother	C9/Shika	13Y/F	India/3	6	RN
P9/Manju	Mother	C10/Sruti	12Y/F	India/3	6	RN

Note: P9's two children took part in the study.

The table is slightly different from the published version as it is edited to include participant pseudonyms.

Data Analysis: Concurrent data collection and analysis took place, accompanied by memoing. Data analysis was conducted manually and involved phases of initial, focused, and theoretical coding. In the initial coding phase, IS conducted line-by-line coding of each transcript following each interview. Gerunds (verbs ending in “ing”) were mostly used to code transcripts. The use of gerunds facilitates the study of enacted processes, indicating that theoretical insights can be developed by focusing on actions and processes rather than individuals. Similar codes were grouped into categories, each defined by its own properties and dimensions (Charmaz, 2014). Concurrent data analysis provided leads for IS to follow in subsequent interviews and guided theoretical sampling. IS constantly engaged with the data by continually comparing all the data sources to facilitate progression to subsequent phases of analysis. To process large volumes of data and enhance the initial codes, a focused coding approach was applied. Finally, theoretical coding was employed to conceptualise the relationships between various codes. Data collection was stopped when theoretical saturation was attained by the 19th interview, when no more new codes were constructed. IS utilised NVivo 20 software for data organisation and storage. The grounded theory of navigating asthma—the immigrant child in a tug-of-war—comprises three categories: being fearful, seeking support, and clashing cultures, and is depicted in Figure 26.

Results

Explaining the Tug-of-War Metaphor: The tug-of-war occurs in asthma management because of the clash of cultures that participants experience as they transition between enculturation and acculturation. Several challenges arose as they tried to reconcile the Western approach to asthma with the Indian approach. The cultural clash was evident from the first interview, but the metaphor of tug-of-war was the BSP constructed following identification of three main categories.

The data reflected two types of tug-of-war: one between the Indian and NZ cultures, and another between carers and their children. The following conversation between a 12-year-old child participant and her mother demonstrates the tug-of-war that occurred between the family carer and child:

> Yes, I have many [friends]. They have those inhalers, and they carry that. But I don't, as my mum does not want me to. (C10, 12Y/F)
>
> I told her [to C10] why I said that. She wants it to be carried like them. If she carries, she will use it unnecessarily. (P9/Mother)
>
> No, I won't. (C10, 12Y/F)

Theory Summary: The theory of navigating asthma—the immigrant child in a tug-of-war, is presented using storyline. According to Birks and Mills (2020), a "storyline facilitates the development of a digestible, readable expression of a grounded theory" (p. 252). The following storyline illustrates the three categories of being fearful, seeking support, and clashing cultures and their sub-categories (see Figure 26).

Children and their family carers experienced a feeling of ongoing fear *(battling symptoms, fear of blame, shame, and discrimination,* and *fear of treatment side effects)* which became the first phase of *being fearful*. They sought support regularly to overcome their fears, which became the subsequent phase of *seeking support* with two subcategories of *being influenced* and *making sense*. In addition to their cultural beliefs and personal experiences, the participants were constantly influenced by several people in society; they were bombarded with information from a variety of sources (parents, extended family members, health experts, and peers) based on which they attempted to make sense of asthma. This led to the final phase of *clashing cultures*.

Clashing cultures, the core category, is comprised of three subcategories: *feeling conflicted*, *making negotiations*, and *striving for control*. The participants developed a feeling of being conflicted as they were often caught between contradictory interpretations of asthma arising from Indian cultural values on one hand and Western values on the other. Tensions arose as the family carers tried to incorporate their cultural expectations into the child's plan of care, which often differed from the children's choices. While children and their family carers made a range of decisions, depending upon the context and the uniqueness of each family, these decisions often ended up in making negotiations centred mostly around family carers' preferences. The tensions and ambiguities around including children's voices in asthma-care decision-making were apparent throughout the study. Feelings of helplessness and powerlessness were evident as children talked through their issues. A cultural clash was evident throughout their asthma journey, and the child tended to become the *piggy-in-the-middle* as they strived to gain control over the condition.

The progression through the three phases was not linear. The three phases proceeded in a cyclic pattern. Indian immigrant children and their family carers reflected on their asthma experiences. They modified their approach to the condition as they acquired new insights from their personal experiences and support networks, which helped them manage their varying degrees of fear at different times during their asthma battle. The participants went back and forth between these phases in their asthma battle based on changing internal and external influences.

Category 1–Being Fearful: The overarching emotion expressed by the participants as they discussed various elements of asthma was that of fear. There are three sub-categories under the category of being fearful, which include battling symptoms, fear of blame, shame, and discrimination, and fear of treatment side-effects.

Battling Symptoms: While younger children articulated their fears predominantly about triggers and symptoms, older children and family carers voiced their worries about uncertainty due to the unpredictability of the disease.

> I get stressed about it [asthma flare-ups] if there are some pending assignments. So, I try to take the precautions to prevent flare-ups during that time. I also get nervous around that time. Like… if I will get flare-ups or not. (C9, 13Y/F)

> Hoping and praying to God that he will be fine. I hope he does not use all this thing [inhaler] in the future. Now he is fine. But I don't know how he will be in his teenage age with inhalers. Hopefully, everything will go away, and he will be fine. (P5/Mother)

Family carers monitored their children closely and warned them of situations where they might be exposed to triggers. One of the common findings under this sub-category was the fear of the *cold*, considering it as trigger. Triggers listed by family carers included cold foods, weather, showers, and other factors that cool the body, including playing in the water. Cold foods not only included physically cold foods but also foods that had a cold base such as milk, bananas, or grapes were believed to trigger asthma flare-ups by increasing phlegm production. One of the family carers explains this idea in the following data segment:

> So, the ice cream mainly. Among the fruits, the grapes are the worst thing I feel because it makes the body cool and he suddenly… he gets fever, and it triggers him, and it later ends up in asthma. Whenever he gets sick, I also restrict him, not to shower. Yeah, I feel like it is getting his body again cold and sick…. sick again... so, I used to restrict him. So, I believe everything helped him one or the other way. (P7/Mother)

Family carers' guidance on the hot-cold theory was echoed in children's conversations.

> Don't eat ice creams. Don't play outside…only on sunny days. Yeah, and they say to drink hot water. (C8, 8Y/M)

Fear of sports or physical activities was another common theme that was identified during the interviews. Family carers who held this belief restricted children from it.

> We started swimming lessons for the elder one, but we didn't start for him [her son with asthma] because we were scared like how he will he cope. (P1/Mother)

Children who had a history of severe asthma attacks during sports or other physical activities expressed their fear of engaging in the activities, which further reinforced their carer’s advice of considering it as a trigger.

> I know my restrictions. Sometimes, I can’t play with my friends. My friends used to play rugby and all other kind of things. I like cricket a lot. But I can’t play because of the problem [asthma]. Because I know I might get an attack if I am over doing. Yes. I had it may be once or twice actually. I got scared of it and have never done it after that because once I was playing cricket, I had it and it was really bad. (C7, 15Y/M)

Fear of Blame, Shame, and Discrimination: Family carers and older children were conscious of the stigma existing in the Indian community, and their approach towards asthma was guided to an extent by their level of perceived stigma.

> If someone knows the stories out of our house, it might affect her [child’s] future life. (P9/Mother)

Although young children did not explicitly address stigma, their experiences indicated the indirect influence of family caregiver stigma. For example, some parents did not give inhalers to the school despite being the school policy as inhaler use made the disease visible. The following conversation between the researcher and the child illustrates the stigma associated with inhaler use.

> So, do you take it [reliever inhaler] with you always, like to the school? (Researcher)
>
> School? Oh…No. Mum and dad won’t let me. I get picked up if I am unwell. (C2, 10Y/M)

Family carers were blamed for their child’s asthma due to their family history. They were also blamed for adopting Westernised management strategies or were fearful of being blamed for the same.

> Oh…I didn't tell them [extended family members] about it [use of inhalers] because they will be like ‘aah’. They will be like stressful, and they will be thinking like…something serious for him. (P8/Mother)

Family carers were afraid of the possibility of their children getting discriminated against in the Indian community due to their condition. One of the family carers described her experience with asthma.

> Every time in the college and all, I still remember when they go for excursion, I was not at all allowed. When they go for…I mean… for my graduation, we had three days… sorry five days …excursion trip to Place X, Place Y and then my teacher called my parents and told that we won't take you. We don't want to take a risk because they saw, I had a couple of incidents in the college. (P1/Mother)

Children were underestimated for their skills in doing physical activities and were singled-out during social or cultural gatherings as others tried to overprotect them.

> Yeah. He [child with asthma] gets isolated. That kid can’t do anything like that. Kid can’t do anything like sports like that. (P4/Father)

Family carers did everything they could to safeguard their children from the negative connotations associated with asthma. Children received stigma coaching from parents and others in the family.

> Hm…I think when I was in India, some of my relatives used to scare me talking about it…that it is a serious disease, etc. I too was a bit scared. They told me not to tell others about it. (C9, 13Y/F)

One of the children believed that asthma was contagious and caused by microorganisms that he called "asthma bugs." He was brought up by his grandmother, who also believed that asthma was contagious.

> It [the asthma bug] may get out when they talk. Sometimes they can get out when they talk and can spread. (C8, 8Y/M)

Fear of Treatment Side Effects: Inhaler phobia and steroid phobia were the two most common fears, which were dominant amongst family carers. Some feared inhaler addiction in general, while others were more concerned about the specific side effects associated with preventer inhalers.

> At first, I was not willing to take the inhaler. The main thing is that I was thinking that she will be addicted to that. (P8/Mother)

Surprisingly, similar views were held even by family caregivers who were registered health professionals such as RNs.

> You know in olden ages, the diseases like this were still there. But you know, there were no inhalers and stuffs but still, people managed. People those days relied on natural remedies, lived long. So, I will prefer it [the inhaler] as a last resort. If we can manage it otherwise, that would be the best thing, I would say. And I also believe that inhalers can also destroy the lung function. (P9/Mother, an RN)

Children received specific instructions regarding the use of inhalers whose talk reflected the inhaler phobias that were passed on to them.

> Yes, it [inhalers] really helped. But mum does not like me using it. She keeps it with her. (C10, 12Y/F).

One of the family carers chose to substitute a reliever inhaler for a preventer inhaler for his child due to concerns about the possible side effects of steroids. The child was advised by his family carer to use Ventolin [the reliever inhaler] regularly in the morning.

> My dad is helping me with it [reliever inhaler] in the morning; I go in there with it and I do eye drops and stuffs, and then my dad gives me the inhaler every day in the morning. (C4, 8Y/M).

Despite their concerns about inhalers, most parents agreed that they were effective. Consequently, they were faced with the dilemma of adhering to an effective treatment while also risking having a negative impact on their children's future in terms of inhaler stigma and side effects on their children's future.

Category 2–Seeking Support: The participants sought support from trustworthy sources, both formal and informal, to overcome their fears. The category of seeking support included two sub-categories: being influenced and making sense.

Being Influenced: The participants’ attitudes and actions were affected by relatives, friends, community experts, their personal experiences, and the dominant culture in which they socialised. There were positive (for example: physical and emotional support) and negative (for instance: stigma coaching, conveying myths and misconceptions about asthma) influences from multiple support sources. Children were primarily influenced by their parents, mostly by their mothers. Mothers were usually the primary caretakers for their children's asthma issues, which continued well into adolescence.

Family carers passed on various cultural beliefs to children by sharing their perspectives on asthma.

> They [the child’s parents] tell us not to eat very cold things and no drinking cold things like ice and water that makes you very sick. (C6, 9Y/F)
>
> She [the child’s mother] does all sorts of things and tries to give me God’s things from the temple to get rid of it [asthma]. (C7, 15Y/M)

Children received support from HCPs and maintained a close relationship with them. However, the family carers’ influence was stronger than HCPs’ that children finally followed the family carers’ decision about asthma management strategies.

> My mom didn't prefer me to use it [the inhaler] as she was telling me that I might get addicted to it. So, I tried it twice—I think the blue one—and then I didn't use it afterwards. (C9, 13Y/F)

Children described the influence of their friends and the support they received from them. Friends became increasingly influential in the teenage years.

> My friends know that I have asthma and I have an inhaler and most of them do know that there are lots of allergies going on and those inhalers are a common thing out here. So, it is not a big deal using it here [in NZ]. (C7, 15Y/M)

Family carers were primarily influenced by their extended family members. They valued the physical, emotional, and informational support they received from them.

> I would say Yoga like that…the breathing exercise specifically helps. My aunt got the same similar problem. And she used to take that blue inhaler twice a day. She is a severe asthmatic patient, and once she started practising the Yoga… specially that ‘Sudarsanakriya’ [a type of Yoga practice] she would… my mum said she is only taking the inhaler hardly two or three times in a month. (P7/Mother)

Family carers were influenced by their traditional beliefs and practices.

> When she gets flare-ups, we try to manage mostly…what we call like… with the natural remedies like dried ginger powder, ginger coffee like that…and also like orange juice…like that. I always give her vitamin-C based fruits like oranges…all those sorts…I encourage them to take lemon juices. (P9/Mother)

Parents often sought a second opinion from extended family members or friends regarding the advice provided by HCPs.

> Some of my friends, they…. like I mean they told, not them, some of their friends had issues. That is how I realised about the orange inhaler as well…. I told you in the beginning like when the doctor suggested also, we were… like… bit scared…. like… how we will start the orange one… he is a child. Then, they all suggested that it is better to take this. (P1/Mother)

The power and sources of influence varied as Indian immigrant children and their family carers formed and modified judgements regarding them to achieve their goals. The influence from various support sources formed the basis of how participants made sense of asthma, took decisions, and sought further assistance.

Making Sense: Making sense refers to how participants accepted and understood asthma. Participants were overwhelmed by the amount of information they received on asthma from multiple formal and informal sources. The participants' reports reflected a feeling of being pulled, pushed, and dragged as they tried to make sense of the information from various sources. The strength of the push and pull varied depending on the power of various influences.

> Because three months back, we went to India. Then, everywhere, I was going with this inhaler and then, people saw this [inhalers], and all were asking: Why you are giving this? Why don't you try Homeo and all those things? Then my parents, they said, we never did that [Homeopathy–an alternate system of Indian medicine] with you, and we never gave you that. We went with the modern medicine. So, better you go with that. He [her son] will be fine after some years because that was what happened with me. (P1/Mother)

> They [the child's mother and grandmother] make me do all the non-sense stuffs. They tell me to do steam with Vicks when I have it [flare-ups], only warm food, and water.

> Mum gives me that yucky medicine [Ayurvedic cough syrup]. She won’t let me use this [puffer]. My doctor gave it to me when I was unwell. It is so cool. (C8, 8Y/M)

Children and family carers filtered the information they received, developed their own views about the condition, triggers, and symptoms, and made choices about management strategies. The following quote by one of the child participants reflected his perspectives on asthma, its impact on his life, and the fear of uncertainty.

> Asthma is really bad actually... And people get it… I think… so it is… it is one of those severe conditions where people struggle for breath … For God sake, people don’t want to get it... that is the best thing I can say…especially during teenage years….you can't play with your friends… you can’t enjoy your life… that is the worst part of asthma… but you are totally fit… it comes as an episode… so you are always waiting for it… you are waiting for that trigger that…so always it will be back in your mind. (C7, 15Y/M)

Older children’s perspectives towards asthma were mainly influenced by the attitudes of their friends who had asthma.

> We notice that most of the Japanese at my age at high school have asthma, and my friends…they mostly have asthma as well. Oh…they keep quite ok with that…like …come on…I don’t mind at all. (C3, 16Y/F)

As the children received multiple pieces of advice on the condition, some of the young children developed misunderstandings about asthma and its management. For example, one of the children’s talks revealed her confusion over the purpose of preventer inhalers.

> Yes, because we can't use the orange inhaler. Because that means you are feeling good. (C6, 9Y/F)

Children had diverse opinions about inhaler effectiveness. The way they made sense of inhaler effectiveness had a significant impact on the decisions they took for managing asthma.

> I feel my neck is not blocked anymore. I can breathe in. But I don’t like spacer. They tell me to use it. But I am good without it. The orange one helps me normally. But, sometimes, I need the blue one when I do some activities. (C2, 10Y/M)

One of the child participants, a 16-year-old girl, although aware about the role of a preventer inhaler, preferred to use the reliever inhaler alone as she found the regular use of preventer inhaler as inconvenient.

> Yeah…It [the reliever inhaler] is like a stimulator… I think the orange one [the preventer inhaler] as the primary one…and the other one as well…I didn’t use the orange one because I have to use it every day. I can’t bother taking it. Well, they said like it is useful in preventing asthma attacks. (C3, 16Y/F)

Family carers developed diverse views on asthma. Although they received advice from HCPs, they valued advice from their close family members and friends either as equally important or superior to that of health professionals.

> And I have seen my friends' kids got asthma and they are saying their kids having trouble doing certain activities like swimming and other activities where they cannot go and play. Taking those things into considerations, to be honest, we did not send our kid for any strenuous activities just as a precaution. Since we are in a phase like… we both are working and we don't want any struggle within ourselves, so we just don’t send her for any activities at this moment. But our doctors told that we can send her to any activities. (P6/Father).

The participants made sense of asthma based on the stigma existing in the Indian community.

> Yeah, he [her brother] is married. Yeah, now the girl knows that he has these breathing problems sometimes…before marriage, the family...they don’t know……we did not inform them. It is a part of our stigma. If we have informed them, he won’t get any proposal. (P9/Mother).

Category 3–Clashing Cultures: Cultural tension often occurred as the participants attempted to make sense of asthma between Indian and Western views, and the tug-of-war became further intensified as family carers tried to incorporate their beliefs and practices into their children's asthma control strategy. The category of clashing cultures included three sub-categories: feeling conflicted, making negotiations, and striving for control.

Feeling Conflicted: Family carers' beliefs shaped the context within which children received care. They expressed their shock and surprise as the advice given by the host country's HCPs did not match their traditional way of managing the disease. However, children had distinct goals and preferred different strategies to manage asthma compared with their family carers, especially in the case of older children. Children were also confused as they could see their peers adopting a different approach towards asthma while they were trained to approach it in an entirely different way by their parents. Many children were reported to challenge their family carers' views and actions, which were predominantly based on traditional cultural norms and beliefs. Tension arose when family carers disagreed with how their children wished to manage their asthma, resulting in a conflict of interests. Table 12 shows the data segments which refer to the participants' feelings of being conflicted.

Table 12

Quotes Illustrating the Sub-Category of Feeling Conflicted

Excerpts from Children's Interview	Excerpts from Family Carers' Interview
Sam [his friend with asthma] eats ice cream, but my mum won't let me. (C8, 8Y/M)	I had this fear that giving him cold foods like ice creams….so I was restricting him [her child with asthma] from all those…... don't give him ice cream. I always used to take out ice cream and keep it in a bowl out for some time to melt, then give him. And every time, he used to ask every time why Master Y [child's brother] gets it in the

	normal and why when I am getting in this way. (P1/Mother)
They [doctors] are funny. They say to use it [preventer inhaler]. But my mum say it is not good. (C4, 8Y/M)	I prefer them [her two children with asthma] not to have milk-based products and I tell them the reason that it will increase the phlegm production. But I think the doctors here [in NZ], they recommend giving everything unless they have got any allergy. They don't recommend restricting any type of food for asthma. But I think that [her way of diet modification] has worked for my girls and that is what I have learnt from my experience. (P9/Mother)
And you are severely ill in front of people, and you can't show it [inhaler], and you can't hide. In that scenario, basically, you have to use it in front of people, and there will be talks going on. (C7, 15Y/M)	Yeah. yeah… they [HCPs] did advise in between. But as we got social stigma that we…if we use the inhaler… it is not good for kids…we didn't. (P7/Mother)
Like a sort of instant relief. I did feel like using it [reliever inhaler] again to get that feel when I again had the same breathing difficulty. I did it again then. Then, my mum advised me to try to avoid it as much and to go with natural remedies first. (C9, 13Y/F)	There are different types of inhalers here, I think. Even for a short thing they [General Practitioners] are giving inhalers… First, I also thought like, they will be giving a nebulisation, like one dose of nebulisation. So, I was also thinking that in our country and also in Middle East, we will be giving at least one dose of nebulisation in that emergency department, and then the child will be getting the relief. (P8/Mother)

Making negotiations: The children and their family carers worked together on how to manage the disease. They made comparisons between Indian and Western approaches in each aspect of asthma care. Family carers developed a personalised management plan after filtering the advice they received from HCPs, friends, and extended family members and tried to implement it for their children. Their management plans were mostly shaped by the networks of relationships outside the formal health system. They made negotiations with children regarding the approach towards the condition and management strategies. These negotiated understandings determined the children's and family's approach to the condition. The tug-of-war got more intense in this phase.

Family carers in the study tried to retain their grasp on the tug-of-war rope as much as possible by imposing their beliefs and practices onto their children. They were conscious of the areas they were pulling against and relaxed their grasp on some aspects while maintaining a strong grip on others or tugging too hard on the rope. Most family carers, for instance, had rigid rules about inhaler use that they expected their children to follow, based on traditional beliefs. They performed a detailed assessment of the state of their children’s' asthma before deciding whether or not to administer inhalers.

> My teacher knows that I have an inhaler at home. I told her the day when I got unwell. Then she wanted me to carry it with me as others do. But mum said **NO**. So, I don’t carry it. (C10, 12Y/F)

The following statement from the child’s mother provides an explanation for her decision not to provide an inhaler for her child at school, and further demonstrates the stigma that exists in Indian society regarding inhaler use.

> No…I have not told them…because I think she is in the stage of outgrowing it…so why we should say them that...it is not that bad…I am not sure if it is asthma or…if we tell them they may treat her like that forever. (P9/Mother)

Some family carers personalised their children's use of preventer inhalers to minimise the medicine uptake. For example, some parents stopped using preventers when their children were symptom-free but intended to start using them when they were symptomatic or during winter.

> He is on that one then and whenever I see any change, you know, or my wife sees any change, then we or any trigger we use the stronger one. (P4/Father)

Although parents wished to do their best to manage their child's asthma, they had the challenge of meeting societal and cultural expectations regarding asthma, which often conflicted with biomedical explanations. The children's goal was to maintain the normalcy of childhood by gaining control over the disease and living a life like their peers. Meanwhile, they were obliged to fulfil parental expectations towards managing the disease. Carers relinquished the hold of the rope in certain elements of asthma care, such as dietary restrictions, based on the negotiations they made with the child. For example, children were allowed to have ice cream or were given melted ice cream when it was summer or when they desperately demanded it. However, the tension around family carer-child decision-making became apparent from family carers' interviews.

> I had this fear that giving him cold foods like ice creams….so I was restricting him from all those…... don't give him ice cream. I always used to take out ice cream and keep it in a bowl out for some time to melt, then give him. And every time, he used to ask every time why Master Y [his brother] gets it in the normal way and why I am getting in this way. (P1/Mother)

> We have stopped giving him dairy products. My son loves dairy products. It is sad that he is not taking dairy products. He is very sad for that. (P5/Mother)

However, family carers' strategy, on the other hand, was not consistent; it changed depending on the power of the influences at different points in time. Initially, the informal influences mostly pushed them towards a more traditional approach. As children and family carers became more acculturated, they tended to gradually release the rope in favour of Western methods. It was also noted that family carers started to accept Western management strategies either when their traditional management tactics failed or in the case of acute attacks.

> No, I have stopped it [Ayurveda] because I do not think it was helping initially. But right now, since I am taking both [the preventer and reliever inhalers] the medications, I am feeling much better. (C7, 15Y/M)
>
> And even the pool we had, we did not keep it outside just because of him. But this summer, we allowed him to play in the pool and all. Because so we had the fear that like if he plays in water more, he will have this asthma or if we have more cold food. So, all these things we were restricting him. But now, we don't do any such things. (P1/Mother)

The authoritarian parenting style did not allow the parents to let go of the rope completely, even with teenagers, while children generally let go of the rope after trying their best to negotiate with carers. One of the family carers explained her rules about restrictions on cold food, which she had asked her children to follow.

> I advised them not to have any cold foods especially when they are unwell. They can have cold foods when it is really hot or summer. But when it is winter, a complete no to cold foods. (P9/Mother).
>
> Her child revealed her attitude towards these restrictions and how she responded to it.
>
> I do feel sad sometimes when I go for a friend’s party, also when others are having it. But I am ok with that. (C9, 13Y/F).

Striving for Control: The family carer-child dyad continued working together to gain control over the condition based on the negotiations. The major process observed throughout this phase was a continuous effort to strike a balance between conventional and biomedical approaches to asthma. The following quote reflects one of the family carer’s strategies to control his child’s asthma, which are mainly centred around traditional beliefs.

> That is what I said triggers… keeping that in mind and thinking of that… and we try to avoid cold foods and everything. Yeah, we try to keep her and follow the same. During this period [time of asthma flare-ups], we normally keep her warm as much as possible, even warm food, nothing from the fridge straight. We try to avoid all those foods, and my parents used to say they offer prayers. Back in India, we offer prayers like if you have got some sort of a disease. They go to temple and offer prayers and they believe while doing these things, get the disease cured. As you could see, she has got a red string on her arm. (P6/Father)

Family carers adopted a trial-and-error approach to managing their child’s asthma, and the child became a victim of it. Most family carers tried experimenting with CAM until the child’s asthma became worse. One of the family carers, who was an RN, chose a traditional approach to asthma management for her two children. She preferred her children to use inhalers only as a last resort.

> She gets flare-ups, but it is not as worse as when we were in India. Yeah…she has used it twice or thrice just like C9 and she knows how to use it. But I told her…. I advised her… so they knew the pros and cons. So, I think…. maybe two months ago she had like mild cold and fever along with mild flare-ups...yeah, but we managed with all our natural remedies and stuffs. You know that I make sure that they are fine and well enough. In such a case, they do not have to go to a stage where they have to use the inhalers. (P9/Mother)

Children, regardless of their age, relied on their family carers to help them plan strategies to control their asthma. Children gradually learnt and acquired the confidence to autonomously self-manage asthma through their personal experiences and self-experimentation, while also mirroring their family carers' asthma management strategies. They explained their various strategies to gain control over the disease.

> Yeah, like when I am unwell. I stay away from activities. I carry my blue inhaler to the activities sometimes as a precaution. But I never had to use it. I try not to use it, but to be on the safe side, I carry it. But if I am unwell, I don’t go to the activities. Avoid the triggers. We have to look after ourselves. Try to avoid milk products and cold food. Whenever I get fever, we go to the doctors and try to sort it early and that it doesn't flare up my asthma. That's about it. Also, oranges help, steam inhalation. (C9, 13Y/F).
>
> The orange one [preventer inhaler] helps me normally. But, sometimes, I need the blue one [reliever inhaler] when I do some activities. (C2, 10/M)
>
> When I always wake up in the morning, I get my inhaler. The inhaler always stays at home, and when we go out, we take the inhaler. I take honey and avoid milk. (C5, 9Y/M)

Children and their family carers described how their immigrant status impacted their effort to acquire control over asthma. Issues related to acculturation, such as lack of extended family or wider community support, lack of confidence in the NZ healthcare system, language barriers, financial constraints, and changes in gender roles, were some of the primary challenges (see Table 13).

Table 13

Quotes Referring to Challenges Associated with Acculturation in Striving for Control towards Asthma

Excerpts from Children’s Interview	Excerpts from Family Carers’ Interview
If I was in India, my grandpa and grandma could help me. (C1, 8Y/M)	I had to come back because we only have one car and I have to bring the car, and he has trouble in communicating the issues. So, I took sick leave on that day. So, it affects our family as a whole when they are unwell. (P9/Mother)
In the case of hospitals here [in NZ], it is	You cannot cope with one person’s earning

really hard to get into the emergency, the waiting time is too much. I had to wait like hours and hours when I was having severe fever and chest infection along with my asthma flare-ups. (C9, 13Y/F)	here. That is another really struggling part. So, both have to go to work. We really struggled last couple of times when she was unwell. (P6/Father)
But sometimes like as my mom said they are just giving you like the same medication for everything… With GP you can go only for like minor things. For asthma and like allergies, I feel you need to go to a specialist. (C3, 16Y/F)	But in India, we got so many treatment…you got another one…another one…you can see lots of things in India…so we keep trying like this one not working…you can try other things like…Homeopathy, Allopathy, Ayurveda…but, in here [NZ], you can only go to GPs. (P3/Mother)
	Yeah…plenty of people would be there [in India] to look after. Yeah...yeah…definitely. So, that is the drawback we have here [NZ]. (P4/Father)

Discussion

Navigating asthma—the immigrant child in a tug-of-war, explains the challenges faced by Indian immigrant children and their family carers as they construct and negotiate their understanding of asthma influenced by their Indian heritage within the Western healthcare context. Our study results showed that the familial, cultural, and societal norms about asthma played a key role in determining how the participants viewed the condition, interpreted the causes and symptoms, planned the management strategies, and utilised healthcare. The findings extend and link to the existing literature which associates health disparities among Indian immigrants to beliefs and practices that contradict the evidence-based advice of HCPs (Heer et al., 2015; Lakhanpaul et al., 2017; Mehrotra et al., 2014; Mufti et al., 2015; Ravindran & Myers, 2012; Theara & Abbott, 2015). Findings supporting this notion are evident from Lakhanpaul et al.'s (2014) systematic review, which explored barriers to asthma management among SA immigrants which reported most of them to be culturally driven. This included denial of the disease, diverse beliefs regarding the cause and nature of asthma, under-use of preventer medications (due to fear of addiction and side effects), language barriers, use of complementary and alternative therapies, and the impact of prejudice and stigmatisation.

Although migration may affect the socialisation practices of immigrant Indian families, extant literature shows that their ties to Indian culture may remain strong in all aspects of their post-migration lives, including childrearing (Chadda & Deb, 2013; Nayar, 2011). The tug-of-war we observed is linked to Indian immigrants’ efforts to preserve their strong collectivistic cultural orientation, which emphasises collective needs and expectations of the family, community, and society over individual preferences (Raina et al., 2020; Nayar, 2011). Migration studies have shown that people's transitions from a primarily collectivistic society to an individualistic community are likely to be challenging, particularly if they continue to maintain collectivistic views (Joseph et al., 2020). For example, the stigma associated with asthma in the Indian community restricted children's inhaler use in public because they were afraid of being judged by people from their community. Similarly, many Indian immigrant families face challenges in inculcating traditional health practices and beliefs in their children to function effectively to meet the expectations of their local communities in the host country (Raina et al., 2020).

Indian immigrant children growing up in a Western health culture might not always understand some of these beliefs, causing confusion for them (Nayar, 2011; Raina et al., 2020). The current study also revealed similar tensions in the family carers' attempts to transmit their beliefs, practices, and societal expectations about asthma to their children while offering them a lens through which to interpret asthma care decisions. For instance, most parents strongly believed in the hot-cold theory of illness, which posits that asthma occurs when the body's equilibrium is disturbed by being excessively hot or cold (Ramdzan et al., 2019). This belief, based on Ayurveda, India's traditional medicine, was confusing to children because it differed from Western concepts that had no hot-cold restrictions in asthma management. The pressure to meet the expectations of their parents to manage the disease made the situation more complex, intensifying the tug-of-war. Studies have shown that parental influence over children appears to be greater in Indian immigrants than in the general population because of their authoritarian parenting style, even when teenage children are involved (Sondhi, 2017).

Parents who practise authoritarian parenting expect their children to obey them, depend on them, and work with them on all issues that affect them (Kuppens & Ceulemans, 2019; Sudarsan et al., 2022a). For example, Indian family carers in the study had rigid beliefs about inhaler use; they modified their child’s inhaler use to minimise medicine uptake or substituted it with various CAM therapies because they believed that the latter had fewer side effects than the former. Children who were forced to follow their parents’ beliefs expressed a sense ofbeing different as they received conflicting advice from HCPs and watched their peers do it differently. Berry (1980) states that individuals may suffer from acculturative stress when faced with problems arising from intercultural interactions. The study findings also revealed that the family caregivers struggled to cope with the competing demands of caregiving in the absence of extended family support, balancing daily life pressures in a foreign country, and adjusting to the NZ healthcare system.

To the best of our knowledge, the current study is the first to explore Indian immigrants’ childhood asthma experiences. Previous studies on childhood asthma in other immigrant groups were largely based on the experiences of family caregivers (Lakhanpaul et al., 2019). It is important to remember that children perceive and experience the world differently from adults. Any therapeutic intervention designed for children should account for these differences. Our GT study reflects both the experiences of the children and those of their family carers in their broader, complex sociocultural environment. Article 3 of the UNCRC states unequivocally that "all organisations concerned with children should work towards what is best for each child” (UNICEF, 2006, p. 1). Practice can be advanced in the best interests of the child only if the child’s experiences of asthma are explored (Lakhanpaul et al., 2019).

This GT study provides new insights into the challenges faced by Indian immigrant children during their asthma journey, as described by the children themselves. According to the theory, various tug-of-wars occur within various domains of asthma management. This theory raises concerns regarding children's exclusion from asthma care decisions by their family caregivers, close relatives, and HCPs. While children observed the adults around them collaborating and forming partnerships in terms of asthma care, they reported that they were unable to participate in their own care and were frequently passive observers. If children are not allowed to participate in their own healthcare, they may experience fear, anxiety, and prolonged emotional trauma as they try to navigate a complex system of healthcare (Barratt et al., 2022). While existing literature indicates the importance of letting family caregivers retain control over their children's asthma, our study emphasises the importance of giving children a sense of agency and power over their own healthcare. Further, the theory offers insights for HCPs not only in the context of Indian immigrants but also in other ethnic and cultural contexts for developing culturally appropriate interventions to improve asthma management among immigrant families.

Limitations

The study was a small qualitative study which included nine children and ten family carers and was restricted to the city of Wellington in NZ. All the family carers were the children’s parents, and most of them were mothers. The study excluded family carers and children who did not speak English. As Indians speak a variety of languages, it would have been necessary to hire multiple translators if non-English-speaking Indian immigrants had participated in the study. Furthermore, the translation process can be time-consuming and costly, and it may jeopardise the accuracy of the data due to the possibility of meaning loss during the translation process (Nurjannah et al., 2014). Considering the reasons above, and as a novice GT researcher, IS found it challenging to include non-English-speaking Indian immigrants in the current study.

As the study followed a CGT approach which included the reflexive engagement of the researcher, the resultant CGT is a constructed portrayal of the asthma experience of children and their family carers by the researchers. Therefore, different researchers would probably construct alternative codes and categories even under similar circumstances. Moreover, the theory is contextually positioned in time, place, culture, and situation and may not be transferable to other similar populations (Charmaz, 2014). Despite these limitations, the quality and amount of data enabled us to address the research aim credibly.

Conclusion

The findings of the study suggest that the experiences of Indian immigrant children and their family carers in NZ are distinct from those of the general population and may be influenced by several variables such as acculturation and sociocultural factors. To effectively plan and implement culturally congruent asthma management strategies, family carers and children must be involved in decision-making and recognised for their expertise. The theory provides a basis for service providers and practitioners to better understand Indian immigrant children’s and their family carers’ asthma experiences within their wider sociocultural context. The theory may have relevance and be applied in other similar contexts of healthcare.

Relevance to Clinical Practice

Culturally Safe Nursing Care: A key element in ensuring high quality transcultural nursing care is improving nurse’s skills to provide culturally safe care (Curtis et al., 2019; Westenra, 2019). The goal of culturally safe nursing care is to provide safe and effective care to all people while maintaining their personal, cultural, and social identities. Providing culturally safe care requires that nurses examine their attitudes towards each new individual they encounter while practising and approaching them in a non-judgemental and open manner. As nurses become more aware of their assumptions, stereotypes, biases, and prejudices, they will be able to communicate more effectively with the people they care for (Curtis et al., 2019).

Collectivistic Approach to Nursing Care: Nurses may consider adopting a collectivist approach when providing care to Indian immigrant families. Engaging with family members and other essential members of the community in asthma education, may change behaviours more effectively than an individualistic approach. If Indian immigrants can maintain cultural ties either through better social support or by maintaining cultural practices, then cultural bereavement may be minimised (Wojcik & Bhugra, 2010). We recommend that community members who are trustworthy, reliable, culturally competent, and able to identify with Indian immigrant families be hired by child healthcare services to help them meet the cultural needs of Indian immigrant families, explain local policies and services, and assist families understand the services their children receive (Karim et al., 2020).

Child Inclusive Nursing Practice: Nurses should collaborate with both family caregivers and children to develop effective asthma management strategies. This approach provides opportunities for both parties to participate in decision-making regarding the child's asthma care, thereby improving family outcomes. If, on the other hand, this partnership is adult-centric, children may lose their voice to the heavy voices of adults, thus resulting in an imbalance of power that may negatively affect them as they mature and seek more control and knowledge over their own health care (Barratt et al., 2022). Future research should therefore focus on developing policies that promote the active participation of children in their asthma care planning.

Postscript to the Paper

The study aimed to develop a substantive theory regarding the asthma experiences of Indian immigrant children, which is explained in the preceding manuscript. A second objective of the study was to identify various barriers and facilitators to effective asthma management among Indian immigrant children, which is discussed in the next section.

Barriers and Facilitators to Effective Asthma Management among Indian Immigrant Children

Barriers and facilitators to effective asthma management among Indian immigrant children are discussed under the three categories and their subcategories.

Being Fearful

Fear of the disease condition served both as a barrier and facilitator to effective asthma management.

Battling Symptoms: The degree of fear served as a key factor in determining participants’ approach towards managing symptoms. Older children expressed their severe fear, frustration, and sadness regarding the impact of asthma on their studies, sports, and socialisation. Their talk demonstrated how their fear of asthma symptoms resulted in heightened vigilance, which motivated them to follow appropriate asthma management plans.

> After studies or any sort of day, they [his friends] go for play or some other activities. But I can’t get involved in it. And also, if I have exams, I do get stressed a lot. And sometimes, if I get stressed, that is one of the triggers, and it can actually trigger. And

> for that reason, I try to calm myself down and use my inhaler well in advance if there are any symptoms. (C10, 12Y/F)

Family carers who had a history of asthma or who were fearful of the struggles associated with it were always attentive to their children's symptoms. One of the family carers who outgrew childhood asthma discussed the systematic approach he adopted to manage his son's condition.

> So, what happens is, like, if he is picking up any sort of running nose like that, obviously, that leads to inflammation in the lungs. So, we can pretty much pick it up straight away that he is getting a little bit of congestion. Either we give him some normal drugs and inhalers, or if we think that it is getting worse, we go to the doctor, and they give us some antibiotics, and if we can't contain that, then we definitely go to the stronger steroids. (P4/Father)

Low fear was associated with a disregard for asthma symptoms and neglect of asthma management. Mandeep preferred not to use the preventer inhaler despite being aware of its role in managing asthma, as she found it difficult to use the preventer inhaler daily. Hari’s parents did not give his inhaler to his school as they believed that Hari would not present with any symptoms at school. The following quote reflects Hari’s father’s reason for not giving his inhaler to the school.

> He is okay at school. He does not need it [the inhaler] at school. (P2/Father)

Despite the HCPs’ recommendations regarding the beneficial effect of physical activity on asthma control, family carers’ fear of activities as a trigger resulted in imposing restrictions on children’s physical activities and sports.

> And another thing was that, like, we always had a fear that if we made him run and do more activities, it would affect him. That was our fear…like… so we were restricting him from activities. In fact, we told him not to run so much in school and not to do

> much strenuous physical activities. But the doctor told me the other way that you need to make him do as much as he can and put him in for swimming classes and all that. We started swimming lessons for the elder one, but we didn't start for him because we were scared like how he will cope. (P1/Mother)

Children also treated physical activities as one of the triggers. See the following conversation between the researcher and the child:

> Do you think that anything specifically triggers your asthma? (Researcher)
>
> Like lack of sleep, I reckon, then activities, and that is about it (C3, 16Y/F)

Fear of Blame, Shame, and Discrimination: Participants feared, expected, and experienced discriminatory behaviour within the Indian community following the disclosure of an asthma diagnosis. Fear of blame, shame, and discrimination appeared to be one of the greatest barriers to health-seeking behaviour and adherence to standard management practices. The participants received stigma coaching in various forms from a variety of sources.

One of the family caregivers, who had been a victim of stigma herself, described her experience.

> All my other family members, even some distant ones, and my close friends, all told me not to reveal about my asthma, because they said that, then you won't get a good marriage proposal and all. (P1/Mother)

Parents were also concerned about the impact of disclosure of asthma diagnosis on a child's future such as marriage.

> Yeah…my mum said not to take the story out of my house, about my brother's asthma. So, no one tells others that you know… about their kids' asthma. They feel it as a shame to disclose… It affects the marriage alliance especially in case of girls. You

> know, it happens even in case of boys, I told you know what happened in our family. (P9/Mother)

Parents discussed how their relatives and friends responded when they learnt about their child's asthma diagnosis.

> When my parents came to know… like… she [C6] was having asthma they were… like too worried… They were asking why we are using this puffer. (P6/Father)

One of the parents said that she was blamed for her child’s asthma due to her asthma history.

> Our family members now realise that Simon [C1] has got this issue. Again, the same thing…. Oh…. because you had…. So, he is going to have… It is going to be a hereditary kind of thing. (P1/Mother).

P1 added that her child too blamed her for his condition.

> But he [C1] knows that I had this issue. Sometimes, he comes and blames me, ‘Mom, you had this thing, it is because of you I have this thing’. (P1/Mother)

P8 described the stigma coaching she received around inhaler use while in India and how her attitude towards using inhalers changed after migrating to NZ.

> But I had heard from others, here in NZ, that the doctors would begin inhalers for almost all the children. First, I was also really worried about that. But when I came to know that most of them were having these inhalers, so I was fine, and it is working well also. (P8/Mother)

Children were given specific advice around disclosure about inhaler use, when to use it, and considering the context before using it.

> Mum told me not to [disclose about inhaler use]. Yeah. So, I did not. They [child’s grandparents] may get worried about us. I don’t use it [inhalers] in front of them. (C10, 12Y/F)

Most children chose to follow their parents’ advice over that of health experts. The tug of war was evident in children’s conversations especially when they took decisions on inhaler use. Although many of the children realised the effectiveness of inhalers, parents modified its use in contrast to the advice received from health professionals. C9 and C10, two siblings, were forced to restrict inhaler use based on their mother’s advice. Their quotes related to inhaler use are described elsewhere (Sudarsan. et al., 2022b). Children who were conscious of their peers' expectations and societal norms on asthma in the host country attempted to normalise the condition. C7, one of the child participants, described his experience of stigma around inhaler use in India and compared it with NZ.

> It [inhaler use] is common here [in NZ] … so, for that reason… I think I can literally use it [inhaler] in the public or anywhere. But back in India, as I mentioned it is not common, people usually don't use it. My mum wanted me to hide it and use it when we were out somewhere (C7/15Y/M)

Participants described being socially rejected. While some participants surrendered to stigma passively, others eventually started to fight against it.

> I really struggle with that [stigma] even now. The other day someone came to my house, and they saw Simon. They came for dinner. While they were sitting here, he was going to bed. So, he had to take the inhaler. So, when they saw him taking this one, they were like, ‘Oh, has he got this?’ Then, I said, ‘It is just like any normal illness. If I have any diabetes or any other illness, I will take the medicine, just like that. It is just like any other disease.’ So, I just told them that very casually. Then, they were giving me something like a staring look. What are you talking about? like that. After coming here, I realised that people needed more awareness about this thing, that it was not a big thing, and to treat your child as normal. (P1/Mother)

Fear of Treatment Side Effects: Fear of treatment side effects adversely affected treatment adherence. A combination of CAM therapies and standard asthma treatments seemed to facilitate optimal management, while substituting standard asthma treatment with CAM appeared to impede it.

> I have got it [inhalers] here, but I am not using it. Instead, my mom tells me to use the steam inhaler. But you know, the inhaler works fast for me. She also gives me oranges every day, saying that it helps prevent infections naturally. (C9, 13/F)
>
> I use my inhalers. Also, we do Yoga every day whenever we [C7 and his mother] get time. Usually, I do it in the morning. It really helps. (C7, 15/M)

While some parents were aware of the treatment side effects, such as those caused by regular inhaled steroid therapy, they still chose to use it because of the benefits it would provide. The ability to make a clear distinction between the benefits and risks of asthma treatment contributed to improved adherence to inhaler therapy.

> The second thing is to take your medication properly. Don’t hesitate to give the preventers, it definitely helps you. The flixotide, some of them told me, is high-dose steroids and may cause problems. He might have obesity because these are all steroids and may have a lot of side effects that might have at this stage and was thinking of the advantages and the disadvantages. (P5/Mother)

Seeking Support

Participants were proactive, sought out more information, and actively learnt about the condition (about the potential triggers, various management strategies, etc.) in order to make sense of the condition. Some support sources offered participants the tools necessary to improve their asthma management, but others served as barriers. This is demonstrated under the following subcategories of being influenced and making sense.

Being Influenced: Parents were the primary source of practical and emotional support, even in children’s teenage years.

> My mom helps me when I am having those asthma attacks, takes me to the doctor, helps with my medications, and stays with me the whole night when I am unwell.” (C9, 13/F)
>
> It is sad. I feel sometimes low, but my parents support me a lot. (C7, 15/M).

Participants highlighted the spiritual support they relied on or were advised to rely on.

> I pray to God. The God is the correct one. (C5, 8/M)
>
> That is one of our beliefs. You know… It is like offering prayers, string tied upon the body prevents the disease or clears the body of the disease. (P6/Father)

The trust developed with the HCPs served as a facilitator for effective asthma management. Young children showed a positive attitude towards HCPs and described how they supported them.

> Doctors are very, very good. If we listen to them, we feel very well. (C6, 9Y/F)
>
> I like doctors because they make us better. (C8, 8Y/M)

Older children explained how they benefitted from HCPs. They developed trust in HCPs depending on how effectively they interacted with them and how comfortable they felt about the treatments they received. However, this did not always mean that they followed their advice as indicated before.

> They [GPs] actually try to help you a lot. My doctor tried to get me to the specialist. So, they take care a lot. (C3, 16Y/F)
>
> Here in NZ, they [the GPs] know what is happening with you, they know everything. There is an emotional connection between GP and me. So, he knows what I like and what I don't like. So, it is nice to meet him once in a while. In India, the doctor doesn't know who I am. Listens to the stories, gives the medicines, and that’s all. (C7, 15Y/M)

Family carers were generally satisfied with HCPs' communication and felt supported.

> The way that doctors communicate with the children is very good compared to the one in India. You know… and also the nurses. The way they treat them is so friendly. They are not scared of them. They just feel like they have a normal conversation like that. (P4/Father)
>
> He [the GP] understands and listens, which is good. Here [in NZ], the doctor gives you time. They explain to you what you need to do. Even though I am a health professional, he tries to explain how to use the inhaler, how many puffs you have to give, and he explains to me about asthma, and he says you can come if you have any problems. He is supportive. (P5/Mother)

The support children received from school played a key role in facilitating asthma management. Some children had specific asthma management plans at school, including leaving the reliever inhaler at school, while many did not have any asthma management plans in place. The lack of proper asthma action plans at school adversely affected children's asthma management. They explained the plans they have in place when they get flare-ups at school.

> I also carry my inhalers to the schools as the teachers there prefer us to keep them with us, and if I am unwell, I stay at home. (C9, 13Y/F)

Some family carers did not feel confident leaving inhalers at school as they felt that their children might not use them properly in their absence.

> No. I haven't given it [the inhaler] to the school. Because he does not know how to press the button. If he is unwell, I will give the inhaler to school or I will tell his teacher that day. Mostly, I won't send him to school if he gets flare-ups. (P8/Mother)

Family carers explained the support they received from the school and how they coordinated with the school staff in managing their child's asthma.

> Yeah, that is a prerequisite from the school that when you go and tell them [school staff] that he has this issue, they prefer us to have this one [reliever inhaler] in his bag. If something goes wrong, you know, just to be on the safe side. (P4/Father)
>
> So, when they take him [child with asthma] out of the school for some activities, games, or something they always take this [reliever inhaler]. I realise that even though he doesn't go and tell the teacher, if they see that he is having a struggle in breathing inside the class, then they go and ask him...are you OK? or do you need the inhaler? Then he says, YES. They are really doing an amazing job. (P1/Mother)

Some family carers were unaware of the asthma action plans offered by schools. The following conversation between the family carer and the researcher demonstrates this.

> I have informed the school that he has asthma, this year, but we have not given salbutamol at school. (P5/Mother)
>
> OK. I think some of the schools have plans, like, they want these children to have their inhalers at school. That is why I asked. (Researcher)
>
> Yeah, but this school 'NO' I think. I don't know, actually. (P5/Mother)

Participants valued the physical, emotional, and informational support they received from their close family members and friends.

> My mom told me to use Ayurvedic remedies for him. But now, we have stopped Ayurvedic medications for one year because he doesn't like to take them. He has been hesitant to take them. It did really help, honestly. We did not give him the inhaler till he was ten years old. She also suggested home remedies as well. We have tried, when he was five, she said that the pigeon eggs are good. (P7/Mother).

Sometimes, the informational support received from friends/family members served as a barrier to effective asthma management.

> She is too young because it is like steroids that could affect her growth and brain, so we were reluctant. When we discussed this issue, they [his parents] used to say the same thing. As you know, they follow the same beliefs. They try to pass on some information to us as well. Just like I said, the activities could trigger asthma. And they said not to send him to any sports at this point. (P6/Father)

The following comment by one of the family carers reveals her mother's misconception about asthma being contagious.

> So, they [grandparents] are thinking that if these children play with others, they will get something like that. (P8/Mother)

Making Sense: The age and developmental stage of the child served as important factors in determining how they understood asthma. For example, one child misinterpreted asthma as eczema.

> One of the people, a friend in the classroom, has asthma, but they don't take a puff. They take a cream. (C1, 8Y/M)

Participants tried to make sense of various aspects of asthma and its management. For example, they tried to make sense of various triggers.

> It triggers me, and basically, it gives me an attack—not every time, but once in a while, you get it. So, I completely stopped it. One of the things I noticed was putting shampoo on my head and also pets, especially cats. Cat fur can actually trigger my attack. So, I try not to go places where they have cats. (C7, 15Y/M)

Family caregivers had different perspectives on the condition that informed how they approached the disease.

> You have to reclassify or redefine the term 'asthma', to be frank. Some people are born with asthma, which is very rare. And place Z in specific, when you go to Google and search, you know, Place Y is one of the most asthmatic bases. But that is not

> actually asthma. It might be an allergic reaction or some other form of breathing difficulty. Asthma is a condition, you know, and some people never grow out of it. I would rather call that proper asthma. (P4/Father)

Initially, P7 was concerned about starting her child on inhaler therapy. Nevertheless, when she learnt that NZ offers greater support in terms of the condition and inhalers than India, her perspective changed.

> I think it [stigma] is not there in NZ. People here are not really bothered. (P7/Mother).

Family carers who were registered HCPs admitted their stigmatic views around asthma and inhaler use.

> Yeah. Still. Even the people are more educated, and you know…people are still on it…stigma is still there. Actually, for my brother, we hide it from other people, like outside, because of stigma. Maybe because of the stigma towards inhalers, even I have refused to use them for my kids when my doctor has suggested it. (P9/Mother).

Clashing Cultures

Participants and HCPs did not share the same understanding of asthma knowledge, which posed a significant barrier to effective asthma management. Moreover, as mentioned previously, the clash between the preferences of the children and their family caregivers contributed to gaps in asthma care.

Feeling Conflicted: Asthma knowledge among participants and HCPs differed significantly.

> I have never seen many people using inhalers in India. I think it is more like the elderly using inhalers. I think… yeah… in my opinion as well, I don't prefer my kids to use inhalers really. (P9/Mother)

Family carers felt conflicted about the services they received from HCPs. Their expectations about the host healthcare system were different. Furthermore, they made comparisons with the care they received from India.

> Here [in NZ] you go to doctors; they give you the same medicine…like…take this one [reliever inhaler] and come back…. every time we keep going and going…and sometimes it does not work. But in India, we got so many treatments, you got another one and another one. (P3/Mother)
>
> I prefer paediatricians for children. But here, it is hard to get hold of the specialists. Also, it is very difficult to get their appointments unless it is like really an emergency. (P8/Mother)

Older children who had healthcare experiences in India brought up their concerns about the host healthcare system by comparing it with the Indian health system.

> Here [in NZ], there is only the GP you can go to. And, sometimes, the GP won't be available to prescribe any sort of thing. And you have to wait until the GP comes back. Or in case, if I feel any sort of problems, then I have to go to the hospital emergency. That is the only difference I have felt. But the GP out here knows much more about my condition. That is much more friendly. It is like a family GP. He knows more about me and about my allergies. But in an emergency, I need to ask if my GP is not available. That will be the time I will be having problems. I have to go to the ED and tell them everything what has been happening, and then they have to prescribe the medicine. That is a long process. (C7, 15/M)

C3 was a NZ citizen born to Indian immigrant parents and brought up in NZ. The following quote reflects her concerns about the NZ healthcare system and her expectations.

> It [the NZ healthcare system] is pretty good. But sometimes, as my mom said, they just give you the same medication for everything. With GP you can go only for like

> minor things like allergies. For asthma, I feel you need to go to a specialist. Other thing, I think sometimes it is hard to get that inhaler. Like you need to get a prescription, and I have only just realised that you have to pay like 20-something dollars for the prescription as well. (C3, 16/F)

Family carers voiced their apprehension and frustration as they described the uncertainty involved with the waiting that frequently accompanied medical care.

> But you know it is where they are going to draw the line between OK or NOT OK. For parents where their line is not OK. Because you see your kids struggling to breathe. That is our borderline. But they will wait for another hour, and then it gets worse, and you have to nebulise. So, I think that they need to bring that standard down. They need to understand the feelings of the parents. (P4/Father)

> We have different options there [in India]. At least, we have multiple hospitals. We can go to emergency as well, which is far better than here [NZ]. They give the initial or preliminary treatments fast, and that is a good thing which is lacking here at the ED. There are no other options during the weekend, we can't go to the GP, and the only way is to go to the ED, and you can see everyone goes to the emergency at that time, and we need to wait there, and maybe a whole day. (P6/Father)

Making Negotiations: In some cases, family caregivers and children managed to devise effective management strategies through negotiations. P1 explained how she convinced her son about the importance of the use of a preventer inhaler.

> Because, after taking the orange inhaler [the preventer inhaler], he had mouth sores. I think the doctor had already told us that when he starts taking the orange one, there is a chance of getting mouth sores. So, he got mouth sores, and then he said, ‘I don’t want to take it anymore. It is really hurting… and why I have to take’ …... I said… ‘See, you take this, you will be fine one day…. instead of taking the medicine the

> whole life.' Now, with the orange inhaler, he reminds me even if I forget. So, he knows that morning and evening he has to take that. So, he reminds me. (P1/Mother)

C10 explained how her negotiation attempts to carry the reliever inhaler to school failed with her mother.

> She [her mother] does not know how good it [the inhaler] is. How many times have I asked, you know? Still, she won't let me. (C10, 12/F)

Striving for Control: Participants modified their strategies for gaining control over the condition based on various influences. P1, who used to manage her son's asthma based on traditional beliefs, discussed how her management practices evolved after migrating to NZ.

> Earlier, we were restricting him too much, and I think people need more awareness in this regard, like, you don't have to give any extra care. And even in school and back in kindy, where he was going, I told them, 'Please don't allow him to play in the water.' And you know, here, if we give them some suggestions like that, they take it very seriously, and they won't allow him. And every day, he comes home in the summer, he used to cry and tell that his friends played in the water, and he did not get a chance. And even with the pool we had, we did not keep it outside just because of him. But this summer, we allowed him to play in the pool and all. Because so we had the fear that like if he plays in the water more, he will have this asthma or if we have more cold food. So, with all these things, we were restricting him. But now, we don't do any such things. (P1/Mother)

Gaining control over the condition also depended on how well children could self-manage their asthma.

> I need to prompt him to take his inhaler morning and evening. I need to tell him: How to do it with the spacer, how many puffs he has to take, and how many breaths he has

> to take, and after taking it, washing it, rinsing his mouth, brushing his teeth. All things he knows. We need to push him. (P5/Mother)
>
> It is not always that I need to find him, but sometimes he comes and tells me, 'I need a puff. I have breathing difficulty.' And now, with the orange inhaler, he reminds me even if I forget. So, he knows that each morning and evening, I [the child] have to take that. So, he reminds me. (P1/Mother)

Young children developed their own coping strategies when they presented with flare-ups.

> Sometimes when I do some of the word things, when we try to do a lot of words, and if we don't get them right, we need to try again, sometimes I need to take a deep breath. (C1, 8Y/M)
>
> I will tell them [others with asthma] that, if you stop breathing, then cough. That is what I do. (C2, 10Y/M)

Parental confidence in their child's ability to independently self-manage varied and increased as the child got older.

> Now, he does understand. I think that as he is 15 years old now, he is managing a bit by himself. I used to help him a lot. So, I think that the trouble some days are gone. Because he is a bit older, I feel more relaxed. (P7/Mother)

Children gradually learnt and acquired the confidence to autonomously self-manage asthma through their personal experiences and self-experimentation, while also mirroring their parents' asthma management strategies. They explained their various strategies to gain control over the disease.

> Once I start getting any sort of feverish kind of thing, I start sneezing and a bit of coughing along with it, and I know it is going to get worse. When I feel that I am getting worse, I normally use the inhaler. (C7, 15Y/M)

> Well, I just use the inhaler and stick with it, and take it when going to activities like that. Just always carry it. (C3, 16Y/F)

Family carers discussed the role of extended family members in childcare and how their absence impacted the children's well-being.

> Children also get very depressed because they are not getting the proper care they want because the situation doesn't let us do that sometimes. They are old enough to remember how they were treated back in India when they were unwell. So, they tell me sometimes that if they were in India, they would have gotten better care. They call their grandparents and inform them of how they are feeling here. Yeah…I feel bad because we are not able to provide them with the care they wish. But that's OK, you know, they understand the situation. (P10/Mother)

Participants identified several acculturation-related challenges as barriers to effective asthma management (see Table 13).

Summary

This chapter presented the final GT of navigating asthma, the immigrant child in a tug-of-war using a storyline. The three main categories and related sub-categories were discussed. The barriers and facilitators to effective asthma management among Indian immigrant children with asthma have been described. The findings under each of the three categories and related sub-categories were supported with quotations from the participants, allowing their voices to be heard directly. The next chapter delves deeper into the theory's applicability, demonstrating how my findings are supported by extant literature and theories. Chapter six also illustrates the unique insights acquired from this study.

Chapter 6–Discussion

> Fitting is a luxury rarely given to immigrants, or children of immigrants. We are stuck in emotional purgatory
>
> —*Scaachi Koul*

In the previous chapter, I presented my CGT of navigating asthma—the Indian immigrant child in a tug of war, which includes three categories: being fearful, seeking support, and clashing cultures. This chapter situates my grounded theory within the existing theories—Berry's acculturation model (1992), Kleinman's explanatory model (EM) of illness (1978), and Kleinman's model of local healthcare systems (1980)—and utilises the extant literature to support and strengthen my findings.

Linking the Tug-of-War Theory to Extant Literature

Recently, there has been an increase in evidence suggesting that SA immigrants experience asthma in a unique sociocultural context that goes beyond its clinical manifestations (Ahmed et al., 2018; Hudson et al., 2016; Lakhanpaul et al., 2020; Mehrotra et al., 2014; Mehta, 2012). My research confirms this notion that a childhood asthma diagnosis in an Indian immigrant community is a complex issue involving, responsibility, treatment adherence, and stigma. In addition, it includes subjective experiences of health, illness, and treatment-seeking behaviour from an ideological or ethnic standpoint. The family carers in my study relied predominantly on their traditional cultural beliefs and social support mechanisms to manage their child's asthma, which frequently contradicted biomedical recommendations.

The core category of navigating asthma—the immigrant child in a tug-of-war—is about clashing cultures (between Indian and NZ cultures, as well as the preferences of children and family caregivers). An extensive body of literature on immigrant research highlights the concept of clashing cultures and cultural conflicts (Badanta et al., 2021; Choy et al., 2021; Habib et al., 2017; Heer et al., 2015; Renzaho et al., 2017; Rydström & Englund, 2015). Nevertheless, to the best of my knowledge, the tug-of-war metaphor is being used for the first time in immigrant health research in order to describe the cultural clash between the native and host cultures.

The findings of my study are in line with those of Heer et al. (2015), who noted a similar cultural clash among SA immigrants caring for children with developmental disabilities in the UK as they attempted to incorporate their traditional SA cultural values into the Western approach to care. In light of the current study findings and extant research, it is evident that Indian immigrant families may face a unique set of challenges in managing childhood asthma, which may be a consequence of their different levels of acculturation (Heer et al., 2015; Hudson et al., 2016; Lakhanpaul et al., 2020; Mehrotra et al., 2014).

Additionally, consistent with the current findings, family carer-child friction related to care aspects has been observed in other qualitative studies of SA immigrant children with chronic diseases. These studies describe the challenges of allowing their children to make their own care decisions, as well as the struggles of children to achieve independence in caring for themselves (Hudson et al., 2016; Lakhanpaul et al., 2017; Sondhi, 2017). The challenges of raising children cross-culturally increase when parents are influenced by their native culture's socialisation process and their children have a different perspective on cultural differences. Assisting children and parents to communicate their perspectives on a child's participation in asthma care may allow children and parents to act together more effectively while simultaneously promoting a child's autonomy (Kuppens & Ceulemans, 2019; Lakhanpaul et al., 2017; Nap-van der Vlist et al., 2021).

The current study confirms the findings of Lakhanpaul et al.’s (2019) study on SA immigrant children with asthma. Among the key findings are a lack of knowledge about asthma, the stigma attached to asthma, the notion that physical activity triggers asthma, hot and cold beliefs related to asthma causation and management, inhaler/steroid phobia, a dearth of holistic discussions with HCPs, a lack of trust and confidence in the host healthcare system, and the influence friends and family have on asthma care decision-making. Existing research indicates that immigrant parents come across numerous barriers while attempting to navigate a healthcare system for their children that bears little similarity to what they are accustomed to (Habib et al., 2017; Ravindran & Myers, 2012; Rydström & Englund, 2015). As reported in previous research, Indian immigrant parents in the study sought advice from family, friends, communities, and parents of children with similar conditions—that is, people they associated with and trusted—on topics which even included when to involve HCPs (Heer et al., 2015; Hudson et al., 2016; Karim et al., 2020; Lakhanpaul et al., 2020; Mehrotra et al., 2014).

HCPs have an integral role in recognising the cultural influences on how people discuss their health, illnesses, the body, the type of health care they choose, and how well they adhere to treatment (Jönsson et al., 2020; Rydström & Englund, 2015). However**,** as evidenced by the findings from the current study, there can be a cultural discordance between HCPs and participants regarding asthma management, which may be associated with poor treatment adherence and health outcomes. Study results indicated that participants required knowledge, resources, and education to assist them in successfully navigating this important cultural transition. The findings demonstrate that offering biomedical services alone is insufficient to ensure that Indian immigrant children attend and adhere to treatment. Current evidence suggests that there will be significant benefits if HCPs focus on the interface between service delivery and practice uptake and explore approaches to maximise factors that promote positive treatment-seeking behaviours among minority immigrant populations while minimising those that impede them (Ganann, 2013; Mehrotra et al., 2014).

Linking the Theory of the Tug-of-War to the Extant Theories

Throughout the construction of my GT, I did not use any extant theoretical codes in order to stay open to Glaser and Strauss's (1967) advice that GT researchers should refrain from using any preconceived theoretical frameworks as guides to their research. Charmaz (2014, 2017), on the other hand, argued that researchers should be reflexive to avoid forcing their preconceived beliefs on data, and emphasised memo writing as a key component of this process. For example, in the reflective memos included in chapter one, I have briefly discussed Berry's model of acculturation in light of my own experience as an immigrant (Berry, 1992; Sudarsan et al., 2022c). It should be noted, however, that this theoretical code was never employed at any point during data collection or analysis. This strategy ensured that data was not forced to fit into any of the preconceived frameworks. In CGT, theoretically sensitive or sensitising concepts can drive research, although they represent mere "points of departure" (Charmaz, 2014, p. 30) for the development of ideas. At this phase in the thesis, I use theoretical codes from extant theories to add explanatory power to my GT of navigating asthma—the immigrant child in a tug-of-war.

Three theoretical codes are presented in this chapter to enhance my theory: Berry's acculturation model (1992), Kleinman's explanatory model of illness (1978), and Kleinman's model of local healthcare systems (1980). I will elaborate on these theories and demonstrate how they strengthen my GT. First, I consider Berry's acculturation model to be of great relevance to my GT since the current study contributes significantly to the literature on acculturation by highlighting the acculturative stress faced by the participants and the various strategies adopted by them to accommodate their needs to manage childhood asthma (Berry, 1992, 1997, 2003). Kleinman's EM of illness (Kleinman et al., 1978) and the model of local healthcare systems (Kleinman, 1980) are two other pertinent theoretical codes. In the context of this study, it makes more sense to explain both models rather than just one of them.

Furthermore, these two models are often discussed together in the literature. Therefore, I believe that the discussion and correlation of Kleinman's two models strengthen the explanatory power of the tug-of-war GT. Kleinman's models provide a framework for comprehending how individuals respond to an illness and are comprised of three sectors that often overlap and operate concurrently: the popular sector, the professional sector, and the folk sector (Kleinman et al., 1978; Kleinman, 1980).

Berry's Acculturation Model (1992)

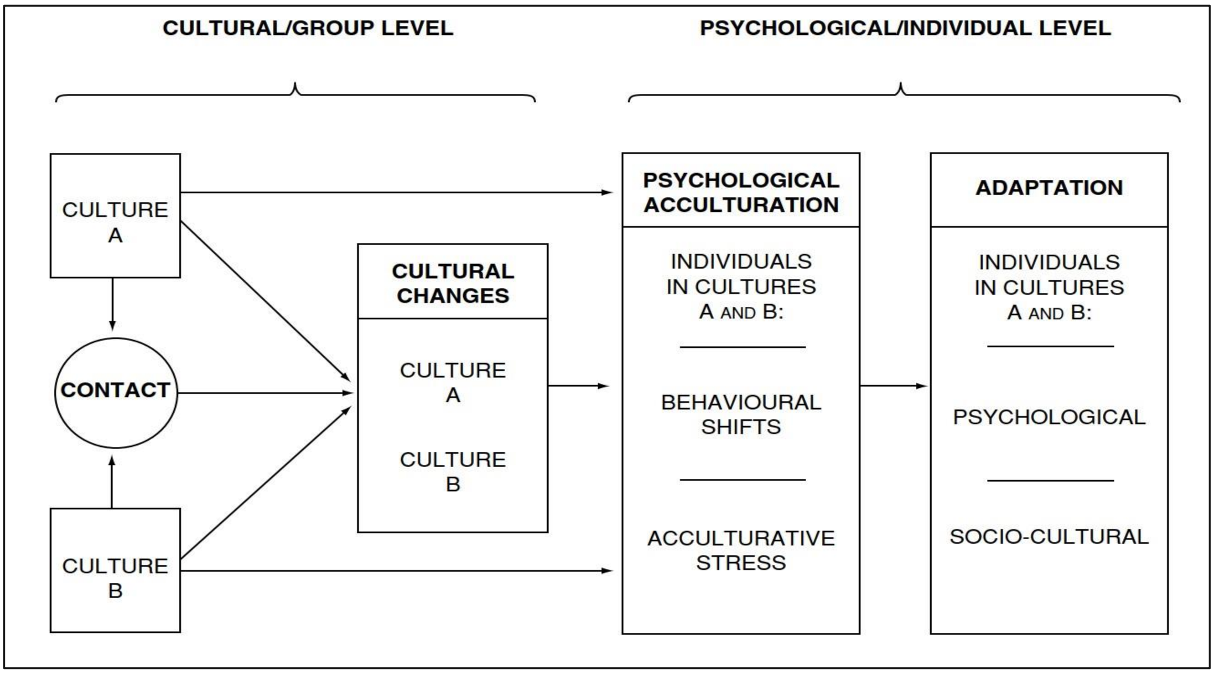
Acculturation is defined as "those phenomena which result when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original culture patterns of either or both groups" (Redfield et al., 1936, p. 146). Culture has long been regarded as a contested concept, with scholars suggesting that no single definition can satisfy all the demands placed on it in a coherent or theoretically useful manner. One of the popular definitions of culture is the one by Edward Tylor, the founding father of cultural anthropology, who defined culture as "that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capacities acquired by man as a member of society" (Tylor, 1871, p. 1). In the context of health and illness, culture is defined as the "unique shared values, beliefs, and practices that may be associated with the healthcare process and interactions" (Pasick & D'Onofrio, 1996, p. S142). In this study, the term culture refers to the changing environmental contexts, such as the new location, healthcare systems, settings, and social expectations.

During the acculturation process, immigrants may experience changes in their beliefs and practices about health care (Berry, 1992; Berry, 2018; Schmitz & Schmitz, 2022; Sudarsan et al., 2022c). It is crucial to understand how acculturation affects health behaviours in order to design interventions that can reduce the disease burden and improve the quality of life in these populations. In addition, while planning health interventions, it is essential to consider the dynamic character of these acculturative responses as well as the disparities that exist among members of the same ethnic group. It is noted that high levels of cultural acculturation may lead to positive health outcomes, while low levels of cultural acculturation may lead to negative health outcomes (Badanta, 2021; Berry, 2003; Chai et al., 2019). The use of acculturation theory may allow HCPs to identify factors that may contribute to the success of a person-centered transition programme beyond the medical condition itself (Nguyen & Baptiste, 2014; Schmitz & Schmitz, 2022).

In his studies of acculturation, the Canadian psychologist John Berry (1992, 2003) developed a comprehensive framework to assist people in gaining a better understanding of the acculturation process. In Berry's view, acculturation is characterised by two distinct processes: a cultural process and a psychological process. Figure 27 shows Berry's framework that outlines and relates cultural and psychological acculturation and identifies the two (or more) groups that interact (Berry, 1992, 1997, 2003).

Figure 27

A General Framework for Understanding Acculturation



Note: Reprinted from "Conceptual Approaches to Acculturation," by J. W. Berry, In K. M. Chun, P. B. Organista, and G. Marín (Eds.), *Acculturation: Advances in Theory, Measurement, and Applied Research* (p. 20), 2003, American Psychological Association. Copyright 2003 by American Psychological Association.

A cultural process (left) occurs at the group level, while a psychological process (right) occurs at the individual level, affecting the individual's attitudes and behaviours. The resulting changes may be minor or substantial, ranging from being relatively easy to being a cause of significant cultural disruption. At the cultural level, the practitioners need to have a comprehensive understanding of several factors: the characteristics of the two original cultures (A and B) before their major interaction, the nature of their relationships, and the effects of acculturation on both the groups and the emerging ethnocultural groups (Berry, 1992, 2003).

On the other hand, the changes experienced by individual members following immigration have been termed *psychological acculturation* (Graves, 1967). A characteristic feature of psychological acculturation is the possibility of individuals holding attitudes regarding how they wish to interact with other people and groups they encounter in their acculturation arena and how they desire to relate to them. Berry (1992, 2003) claims that individuals experience at least two types of changes when exposed to two or more cultures or as they try to adapt. At one level, there are behavioural changes that may affect how an individual behaves in diverse areas, such as dietary habits, clothing styles, speech patterns, and even self-identity. A second level addresses acculturative stress, which was proposed by Berry (1970) as an alternative term to cultural shock (Oberg, 1960). Acculturative stress is a term used to describe how individuals react to challenges brought on by cultural adaptation (Berry, 1980; Berry, 2003; Sam & Berry, 2006).

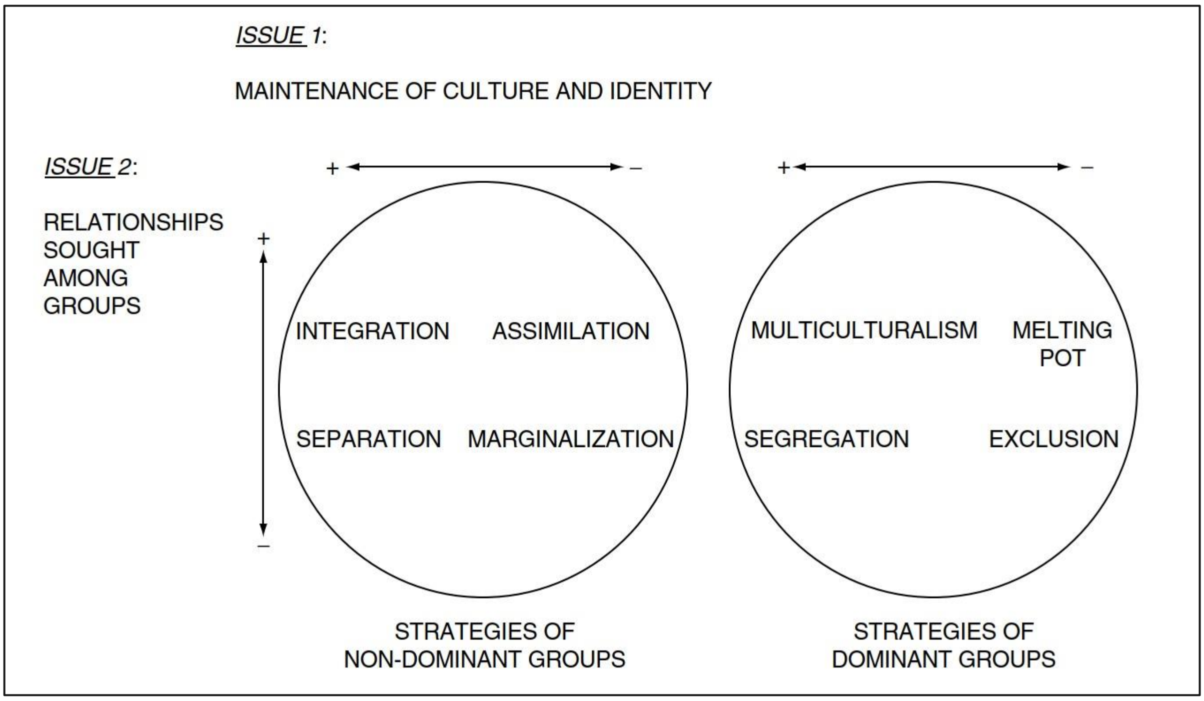
The notion of adaptation is viewed as a long-term result of the acculturation process. The adaptations to the aforementioned challenges can generally be divided into two categories: psychological (i.e., adaptations that affect the individual's self-esteem or well-being) and sociocultural (i.e., adaptations that connect an individual with other members of the host society, such as competence in local activities) (Berry, 1992, 2003). Despite individuals’ voluntary migration from one culture to another, they may struggle to adapt and are likely to face stress in the host society, such as social isolation and cultural shock. When the difference between the native culture and the new culture is greater, acculturative stress can be more prevalent and may restrict an individual's ability to function effectively. For a comprehensive understanding of acculturative stress and the adaptation process, personal and cultural factors from both the immigrants' birth countries and their adopted countries must be taken into account (Berry, 1992; Hamedani & Markus, 2019).

Initially, the acculturation process was considered unidimensional, where the retention of the original culture and the acquisition of the new host culture were placed on opposite ends of a continuum (Park, 1928; Wood, 1969). In this unidimensional model, migrants were expected to adopt the beliefs, values, and practices of their host country and abandon those from their own culture. An important criticism of the unidimensional model was that it did not account for the possibility that an individual might strongly identify with both the host and native cultures. Today, acculturation is often conceptualised as a multidimensional process in which both cultures evolve through mutual influence and are impacted by a number of contextual factors (Fathi et al., 2018).

One of Berry's most significant contributions to the study of acculturation has been his emphasis on the significance of considering the variety of responses a person may have to the acculturation process. Berry (1980) initially referred to these responses as *varieties of acculturation* or *acculturation modes*, but he later used the term *acculturation strategies* instead (Berry, 2003). As mentioned in chapter one, Berry’s bidimensional acculturation theory suggests that immigrants may adopt up to four possible adaptation strategies (see Figure 28) (Berry, 1992, 2003).

Figure 28

Four Acculturation Strategies Based on Two Dimensions, in Ethnocultural Groups and the Larger Society



Note: Reprinted from “Conceptual Approaches to Acculturation,” by J. W. Berry, In K. M. Chun, P. B. Organista, and G. Marín (Eds.), *Acculturation: Advances in Theory, Measurement, and Applied Research* (p. 23), 2003. American Psychological Association. Copyright 2003 by American Psychological Association.

It is necessary to consider two dimensions when considering this model. The first dimension reflects an individual's attitudes towards native culture and identity. The second dimension determines how an individual prefers to interact with the host culture. The intersection of these two dimensions leads to the creation of the four categories of acculturation in Berry's model. The concept of acculturation strategies can be illustrated by examining each of the components in Figure 28 (Berry, 1992, 1997, 2003).

The two dimensions are depicted by the bipolar arrows. To simplify the presentation, generally positive or negative responses (yes or no) to these topics intersect to identify four acculturation strategies. These strategies are referred to in different ways, depending on which ethnocultural group is being considered (the dominant or non-dominant). Assimilation is the appropriate strategy when the members of a non-dominant group (on the left of Figure 28) do not wish to maintain their cultural identity and prefer to interact with other cultures on a daily basis. Alternatively, when people wish to retain their own culture and avoid contact with the other culture, then separation is the most appropriate option (Berry, 1992, 1997, 2003). Whenever a person is interested in preserving their original culture while also interacting with other groups, integration is an option. A person, for example, may switch between languages based on the linguistic context, speaking either language in appropriate circumstances (Schmitz & Schmitz, 2022). Finally, marginalisation occurs when the possibility or interest in cultural preservation is diminished (often due to an enforced loss of culture), and little interest is shown in forming relationships with others (often due to experiencing exclusion or discrimination). Marginalisation may be characterised by uncertainty, confusion, and often signs of social and psychological difficulties (such as substance abuse, failure to complete school, or difficulty finding employment) (Berry, 2018; Kunst, 2021; Schmitz & Schmitz, 2022).

In the beginning, acculturation strategies were approached from the perspective of the non-dominant ethnic groups. Nevertheless, the original anthropological definition of acculturation supported the notion that both groups in contact would become acculturated (Kunst et al., 2021). Hence, a third dimension was introduced by Berry (1974, 1980) to demonstrate the influential role played by the dominant group in influencing the course of mutual acculturation. This third dimension is shown on the right side of Figure 28. Assimilation is called the *melting pot* when sought by non-dominant acculturating groups, but the *pressure cooker* when desired by dominant groups. When acculturating groups desire separation, it is called *withdrawal*, while when dominant groups impose it, it is called *segregation*. When marginalisation is sought by members of a non-dominant group, it is referred to as *marginality*; whereas, when it is imposed by the dominant group, it is considered *ethnocide*. Lastly, integration is termed *pluralism* when diversity is present throughout society, and *multiculturalism* when diversity is desired by various ethnic groups (Berry, 2003).

The acculturation strategy selected is determined by a variety of antecedent factors (both cultural and psychological), and there are a wide range of consequences (both cultural and psychological) associated with these different strategies (Berry et al., 2022; Kunst et al., 2021; Schmitz & Schmitz, 2022). Generally, these strategies consist of two components: attitudes and behaviours (i.e., preferences and actual outcomes) that are exhibited in day-to-day intercultural interactions. There are generally fewer attitudinal and behavioural changes among individuals who have chosen the separation strategy, and the greatest number among those who have selected the assimilation strategy (Berry, 1992, 1997, 2003).

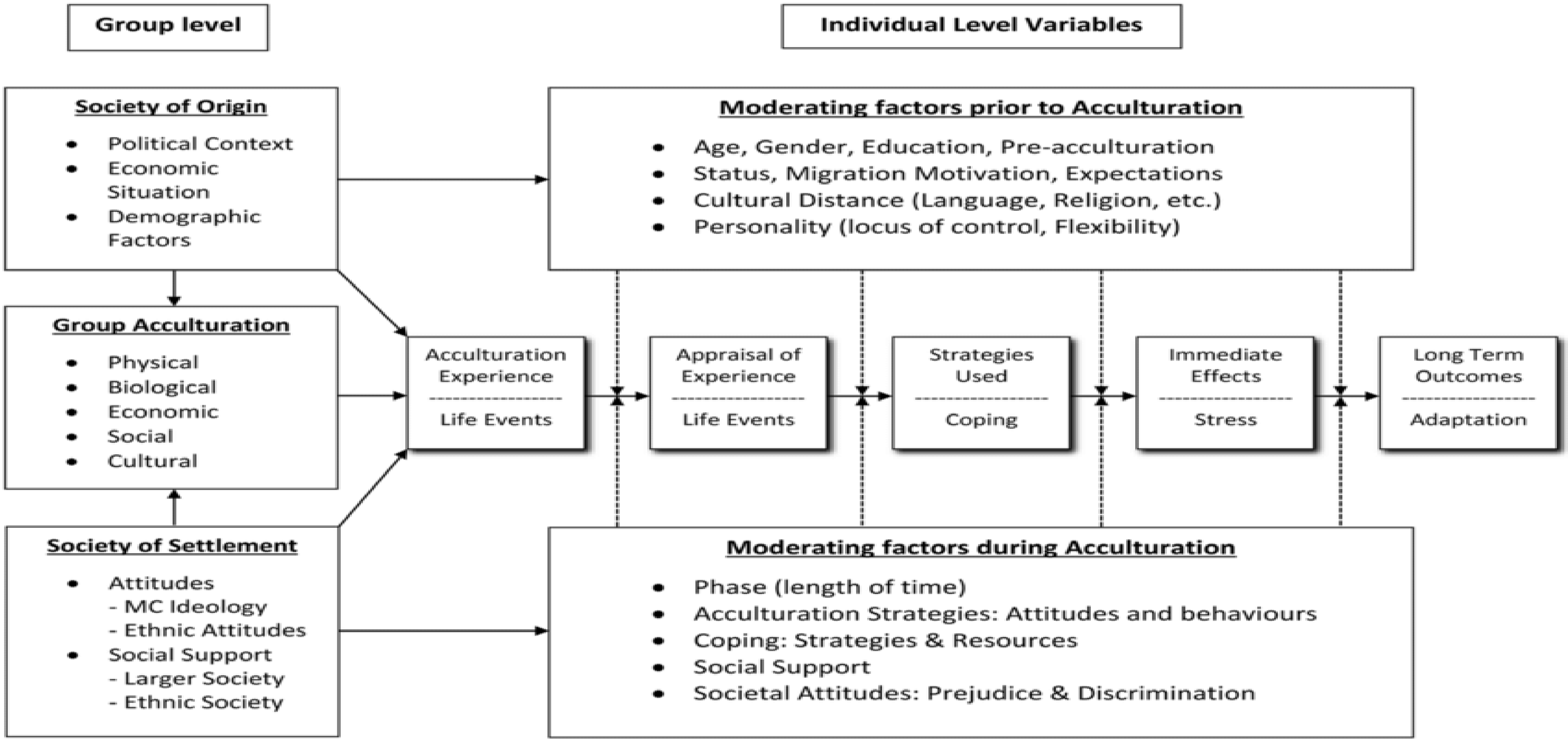
Integration and marginalisation are associated with selective maintenance and rejection processes involving moderate behavioural changes (Berry, 2003, 2022). According to Berry (2003), the lowest level of acculturative stress may be associated with integration, while the highest level of stress may be associated with marginalisation. It is projected that acculturating individuals who choose an integration strategy would be able to acquire the cultural characteristics of the new culture (as desired by the new cultural group members) while still maintaining the value of their heritage culture (as possibly expected by their parents, relatives, and friends) (Berry et al., 2022; Joseph et al., 2020; Kunst et al., 2021; Schmitz & Schmitz, 2022).

According to Berry (1992, 1997, 2003), three subprocesses may take place in people’s behaviour during the process of acculturation: culture shedding, culture learning, and culture conflict. The first two of these sub-processes involve the disappearance of certain behaviours, either deliberately or accidentally, and their replacement with other behaviours that allow the individual to better fit in with the larger social group. Acculturating individuals may also experience conflict, which may be gradually resolved by adapting to the behavioural norms of the dominant group. Arai (2006) describes the complex interaction between culture and conflict at the interpersonal and intergroup levels: "The potential for conflict may exist but remain unnoticed when differences between people do not hurt or trigger adverse feelings. Conflict emerges when people realise that their differences matter in the context of interdependence” (pp. 103–104). Conflict between people or groups occurs when fundamental differences in their perceptions of the world are recognised as problems that need to be addressed by all parties**.**

Furthermore, there may rarely be a perfect match between what an individual prefers (attitudes) and what one can accomplish (behaviour). Disparities such as these can usually be explained as the result of social constraints on behaviour (e.g., opportunities, norms, and discrimination). Berry (1992) has attempted to systematise the complex process of acculturation and exemplify the key factors that influence an individual’s adaptation through his acculturation framework (see Figure 29).

Figure 29

Berry's Framework for Acculturation Research



Note: Reprinted from "Immigration, acculturation, and adaptation," by J.W. Berry, 1997, *Applied Psychology: An International Review*, *46*(1), p. 15 (https://doi.org/10.1111/j.1464-0597.1997.tb01087.x). Copyright 1997 by International Association of Applied Psychology.

In Figure 29, both structural and process features can be observed: the central portion of the framework, which flows from group acculturation to adaptation through individual acculturation, clearly involves the development of a process over time, and the broad structure within which acculturation occurs is determined by factors at the upper and lower levels that influence this process. Thus, it is possible to argue that acculturation strategies are the result of contextual factors rather than a simple correlation, given that individuals have limited control over many of these group-level factors (Berry, 1997).

Berry's Acculturation Model and the Theory of Tug-of-War: The findings of the current study align well with Berry's acculturation model (1992, 1997, 2003). Historically, the acculturation theory has been utilised to examine cultural shifts within a specific ethnic group or country (Berry et al., 2022; Fathi et al., 2018; Ward & Szabó, 2019). The current study explored the relationship between participants' functioning and health, not only in relation to the medical diagnosis of asthma, but also with their personal, social, and cultural factors. As in other migration studies, the findings confirm that the environment in which people live plays a critical role in shaping their identity (Berry et al., 2022; Fathi et al., 2018). Consistent with previous literature, the participants in this study described their difficulty making sense of childhood asthma in light of two cultures, as described under the core category of clashing cultures (Ahmed et al., 2018; Hudson et al., 2016; Lakhanpaul et al., 2020; Mehrotra et al., 2014; Mehta, 2012).

As highlighted, it is common for Indians to attach great importance to their ethnic culture and traditions, which may influence their perspectives on paediatric disease and health (Banerjee et al., 2011; Joseph et al., 2020; Mehrotra et al., 2014; Sondhi, 2017; Sudarsan et al., 2022a, 2022b, 2022c). In this respect, Indian immigrants in NZ are likely to encounter opportunities for acculturation, and their strategies for responding to these opportunities may have implications for asthma management. In accordance with extant literature, participants carried with them culturally distinct ideas and values regarding concepts of asthma causation, symptom reporting, and treatments. It has been documented that cultural variations may affect individuals’ ability to comprehend, manage, and cope with the relevance of an asthma diagnosis, the progression of the disease, and the outcomes of therapy. Additionally, cultural norms may have an impact on the amount of knowledge sought by people about asthma and its treatment, their healthcare expectations, gender and family roles, and asthma care decision-making processes (Acorda et al., 2020; Ahmed et al., 2021). Participants in the current study had to construct and negotiate their understanding of asthma in relation to Western perspectives on asthma and a traditional Indian approach.

The category of seeking support explains the tug-of-war that occurs as participants attempt to make sense of various aspects of asthma while being influenced by multiple sources. Participants reported substantial losses associated with familial guidance, social support, and cultural continuity. These losses appeared to considerably impact their decisions regarding asthma care**.** However, consistent with Mehrotra’s (2014) findings, the participant family caregivers often sought advice regarding their child's asthma from their extended family members and friends overseas over the phone and the internet and valued this advice over that given by HCPs. These findings are not surprising, as Indian cultures place a greater emphasis on collective needs, interdependence, and cohesiveness than Western cultures. Indian immigrants may experience cultural shock as a result of the shift from a collectivistic to an individualistic society. When they fail to attain their collectivistic goals, acculturative stress may occur (Heer et al., 2015; Joseph et al., 2020).

It is important to highlight the findings by Koinis-Mitchell et al. (2011), who investigated the relationships among immigration, acculturation, and asthma morbidity in Latino children. She concluded that a range of immigration-related indicators and acculturation-related factors were essential to comprehend how immigrant children's experiences may affect asthma management. Immigration-related indicators include the country of origin of the caregiver and the child, the time spent in the host and native countries, and the timing of migration. Acculturation-related factors include acculturative stress levels, social support levels, language preference, and family resources (Koinis-Mitchell et al., 2011).

Family carers' attitudes and expectations about asthma and its management may, to a certain extent, be a reflection of Indian society's cultural characteristics and the healthcare system (Lakhanpaul et al., 2020; Mehrotra et al., 2014). These factors may have a marked influence in determining attitudes towards various aspects of the disease. For example, although fear is expected in children and their parents in the case of childhood asthma, being an immigrant made participants’ experiences of fear more daunting. As an example, some children felt that they were better taken care of by their extended family members when they were in India and felt lonely and less cared for after migration. In support of my findings, several studies demonstrate that immigrant status adversely affects the ability of SAs to manage various chronic health conditions (Habib et al., 2017; Heer et al., 2015; Lakhanpaul et al., 2020). For HCPs to communicate effectively with patients, it is imperative for them to acquire a detailed understanding of the context from which the patient originates and how this relates to the destination country.

In this study, the role of acculturation in asthma management is explored from the perspective of both parents and children, demonstrating the significance of family dynamics in acculturation. The findings reinforce the definition of acculturation as a collective as well as a psychological process. This definition acknowledges that not all individuals experience acculturation at the same level as their groups (Nguyen & Baptiste, 2014). In line with existing literature, participants in the study affirmed their original cultural beliefs within the new culture, attempting to reshape it according to their original cultural values (Lakhanpaul et al., 2019; Mehrotra et al., 2014).

As indicated in Berry's acculturation model, participants in the current study selectively adapted to the host culture (Berry, 2022). In adapting to the new culture, the selection of cultural values did not appear to be a simple matter of preference. The findings indicated that parents and children actively engaged in a negotiation process to settle cultural differences in various spheres of asthma management (Inman et al., 2007). The current study found that Indian immigrants primarily used two acculturation strategies in various domains related to asthma care: separation (characterised by a relatively high degree of preference for Indian culture over NZ culture) and integration (characterised by a similar degree of preference for both cultures) (Berry, 1992, 2003).

In my analysis, cultural separation was the most used strategy for social relationships among Indian immigrants in terms of asthma management (Berry 2003, 2022). The participants in the study were focused on meeting the expectations regarding asthma management within the Indian community. They responded favourably to maintaining strong ties with the group of origin, whereas contact with members of the new culture to seek advice on asthma management was limited. The Indian immigrant family carers in the study sought advice from other Indian immigrant families who had children with asthma in order to develop various strategies for managing the condition. Collectivism, one of the pillars of Indian culture, may again explain this behaviour (Joseph et al., 2020; Nayar, 2011; Raina et al., 2020; Sudarsan et al., 2022a, 2022b, 2022c, 2022d). Many of the studies included in the review in chapter two highlighted the importance of family and community in chronic illness management among SAs, where HCP's recommendations were often considered secondary to those of families and communities (Sudarsan et al., 2022b). Extant literature also shows that health beliefs among SAs are primarily developed as a result of exposure to a variety of social and cultural resources and that these resources can collectively affect SAs' health behaviour. It has been found that the cultural and social norms held by SA families and communities significantly affect how healthcare information from their healthcare providers is interpreted (Ahmed et al., 2021; Lakhanpaul et al., 2014).

My findings revealed that there was a clear food-cultural separation as participants attributed greater trust to beliefs about Indian diets when compared to Western diets in terms of asthma management. While some parents advocated the avoidance of junk food, most parents identified specific foods with a cold base to be avoided for children with asthma (bananas, milk, ice cream, etc.). Asthma is not the only respiratory illness that is explained by the hot-cold theory, it is also applicable to other respiratory illnesses such as common colds, bronchitis, bronchiolitis, sinusitis, etc (Ahmed et al., 2021; Lakhanpaul et al., 2014). As mentioned earlier, according to Indian Ayurvedic medicine, hot foods and drinks aid in opening the airways and easing breathing. It is believed that the warmth of the food or drink will loosen any mucus or phlegm that is blocking the airways. In contrast, cold foods and beverages may cause the airways to contract and cause asthma attacks.

The participants did not generally diverge from their dietary beliefs, regardless of how long they had lived in NZ. It should be noted that the NZ asthma management guidelines do not consider dietary restrictions, but Indian immigrant families have strongly held beliefs and practices about food and asthma. Participants were surprised as the doctors in NZ did not specify any dietary restrictions as a part of asthma management. The cultural belief related to the hot-cold theory is very common among many population groups, such as SAs, Southeast Asians, Chinese, and Puerto Rican populations (Ahmed et al., 2021; Ramdzan et al., 2019). The findings emphasise the importance of considering various dietary beliefs when planning asthma strategies among Indian immigrant children.

The Indian community contributes distinctive perspectives and values to the healthcare system (Mehrotra et al., 2014; Joseph et al., 2020). As a result, the participants met various challenges as they tried to integrate with the NZ healthcare system, such as insufficient access to services, inadequate support and resources, and contrasting healthcare beliefs. A significant barrier reported by participants, especially family caregivers and older children, was a lack of familiarity with Indian cultural beliefs regarding asthma among healthcare providers. Regarding cultural aspects of asthma care, family caregivers reported feeling ignored by their healthcare providers, which caused them to lose confidence in the system. Previous studies have found similar results, with SA immigrants reporting a greater level of discrimination and a poorer quality of healthcare than the host population (Lakhanpaul et al., 2017; Mehrotra et al., 2014).

The participants often compared their NZ healthcare experiences with their cultural background and home country's healthcare system regardless of the time they had lived in NZ. Many of the participants' beliefs and practices were in contradiction with the standard healthcare culture in NZ. The present study raises the possibility that HCPs may face challenges in providing culturally competent care and understanding the expectations and needs of Indian immigrant families. While HCPs may expect their patients to adhere to Western medicine, these expectations may result in barriers to effective care that are worsened by linguistic, cultural, and educational disparities between patients and HCPs from different backgrounds (Rydström & Englund, 2015).

The research conducted by Lakhanpaul et al. (2017) on parental perceptions of and barriers to asthma management within SA immigrant and native British families revealed that SA immigrant family carers faced many challenges regarding healthcare access and utilisation within their host country, as did Indian immigrants in the present study. As an example, one of the reasons for choosing ED as the first point of contact by SA immigrant family carers included the difficulty in obtaining an appointment at the GP's office. However, in contrast to the current findings, SA parents over-relied on EDs as they found them more convenient to access than primary care and if they had a previous positive experience in the ED (Lakhanpaul et al., 2017). Also, as opposed to our study findings, in which family carers identified language barriers as one of their concerns when interacting with HCPs, SA families in Lakhanpaul et al.'s (2017) study did not specifically refer to language barriers. Interestingly, SA families preferred to consult with a GP who spoke the same language as them. Furthermore, the participants went to the ED if their GP was absent or unavailable since interpreters were readily available there. These findings strongly imply that HCPs should work more closely with SA immigrant communities to understand their perceptions of barriers to optimal asthma care and to determine their perspectives regarding ways in which asthma services can be improved to better meet their expectations (Hudson et al., 2016; Lakhanpaul et al., 2017).

Family carers described feeling insecure and worrying that their children were not receiving the best treatment. They consulted HCPs, friends, and other trusted people from India to confirm the accuracy of the NZ HCP’s advice. As there are cultural disparities between healthcare systems in other nations, family caregivers may view the host country's healthcare system as foreign, resulting in confusion and uncertainty (Rydström & Englund, 2015). It is well established that education can contribute to the provision of high-quality transcultural care, but an additional strategy is to provide immigrant families with an opportunity to express their expectations and concerns (Rydström & Englund, 2015).

Indian immigrants may retain a strong sense of their native culture and customs even years after immigrating (Chadda & Deb, 2013; Inman et al., 2007). The *Ecological Acculturation Framework* model proposes that immigrants do not simply choose one acculturation strategy over another and that different life domains define how migrants navigate acculturation changes (Salo & Birman, 2015). This notion is in agreement with growing evidence showing that Indian immigrants are more likely to integrate into public domains such as occupations, language use, childrearing practices, economy, and clothing. However, they are less likely to integrate into private core domains such as cultural beliefs and practices, gender role expectations, and family relationships (Inman et al., 2007; Joseph et al., 2020; Nayar, 2011). This is commensurate with my study findings, which demonstrated that Indian immigrant family caregivers attempted to adhere to cultural practices on asthma management as long as they felt they were achieving the desired results. For instance, the family caregivers preferred to rely on Western medicine (e.g., inhaler use) as a last resort if their traditional care strategies had proven unsuccessful. The findings emphasise the significance of developing appropriate coping and cultural adaptation strategies in terms of asthma care to minimise the adverse health effects of migration (Choy et al., 2021).

It is important that children are able to cope with the two cultures in their lives when they are undergoing acculturation (Raina et al., 2020). The cultural clash discourse in the current study highlights the disparities between the first-generation (parents) and the second- generation (children). This dichotomy resulted in a variety of asthma-related conflicts between Indian immigrant children and their parents. Prior research suggests that Indian immigrant parents often perceive themselves as assuming the entire responsibility of transmitting cultural values to their children due to the culturally incongruent environment in which they live. This cultural clash may result in imposing restrictive behaviours on the part of the parents (Inman et al., 2007; Raina et al., 2020). The current study clearly illustrates the tug-of-war that occurs between children and their parents as they construct and negotiate meanings surrounding various aspects of asthma.

The first-generation immigrant family carers may have been exposed to their heritage Indian culture on a socio-structural level through schooling and language, as well as interpersonally through friends and family (Renzaho et al., 2017). Consequently, their sense of self may be strongly rooted in traditional culture. Second-generation immigrant children, in contrast, inherit their heritage culture primarily from their families. In most cases, their friends and social structure are influenced by the host culture. Therefore, second-generation immigrants may experience internal conflicts as a result of cultural disparities, in which they perceive themselves as misfits within both cultures. Specifically, unrelated to health, a number of studies have also highlighted the experiences of cultural and intergenerational conflicts, with a particular focus on Indians of the second-generation (Inman et al., 2007; Juang & Syed, 2019; Renzaho et al., 2017).

Furthermore, in Indian families, there is a strong cultural expectation about parent-child relationships. Internalisation of collectivistic culture norms in parenting often prevents children from expressing their own needs in favour of focusing on their parents' interests (Raina et al., 2020; Sudarsan et al., 2022a). As discussed in chapter three, authoritarian parenting, which is the common parenting style in Indian families and is characterised by a larger expectancy of dependence, obedience, and sociability from their children, restricts children's autonomy in many aspects of their lives, including asthma management (Chadda & Deb, 2013; Lakhanpaul et al., 2019; Sudarsan et al., 2022a, 2022b, 2022c).

In the current study, family carers were not only able to recognise their children's bicultural struggles, but they were also able to identify specific challenges they faced as a result of them. After recognising these challenges, parents were confused at times about whether they had done the correct thing in transmitting their values or whether they should have encouraged values that would assist their children in adapting to their new environment. This was particularly evident in their descriptions of stigma coaching given to children and various cultural practices, such as religious beliefs, dietary preferences, and physical activity restrictions. It should be noted that minority-ethnic children are underrepresented in all aspects of asthma research in NZ; as a result, ethnicity-specific factors are rarely incorporated into health services. Since CYP do not form a homogeneous group and may have different health needs depending on their capabilities, backgrounds, and interests, it is crucial that their voices are heard (Lakhanpaul et al., 2019; Schlichting et al., 2021).

Kleinman's Explanatory Model of Illness (1978) and the Model of Local Healthcare Systems (1980)

Among the models relevant to the study are Arthur Kleinman's EM of illness (Kleinman et al., 1978) and the model of local healthcare systems (1980).

Kleinman's Explanatory Model of Illness (1978): Psychiatrist and anthropologist Arthur Kleinman’s theory of EMs proposes that individuals and groups can have vastly different notions of health and disease. Kleinman et al. (1978) define EMs as “the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process” (p. 105) and serve as “the main vehicle for the clinical construction of reality” (p. 110). In contrast to an organisational model of how society provides healthcare, Kleinman’s model provides a framework for understanding how individuals respond to illness in their daily lives (Kleinman et al., 1978).

In Kleinman's work on EMs, patients and HCPs have different interpretations of sickness—the illness version for the patient and the disease aspect for the HCPs (Kleinman et al., 1978; Kleinman & Benson, 2006). In the case of patients, illness problems comprise the entire disorder, including the difficulties associated with living with the illness. HCPs, on the other hand, may ignore illness-related concerns and focus solely on the disease as a medical condition (Habte et al., 2016). Based on Kleinman’s theoretical model of asthma, disparities between biomedical recommendations and child/caregiver practices may be attributed to inconsistencies between provider and child/caregiver EMs (Spray et al., 2022).

According to Kleinman et al. (1978), illness has been culturally shaped in that how people perceive, experience, and cope with any disease has been shaped by their explanations of sickness, which are influenced by the positions they occupy in society and the meaning systems they employ. Patients' explanatory frameworks have a significant impact on how receptive they are to medical recommendations and interventions. Patients' EMs influence not only who they choose as physicians or healers but also how they proceed with their treatment, which involves following up with their HCPs, adhering to medication, changing their health behaviour, and participating in cultural, social, or spiritual activities that may be considered to promote recovery (Tirodkar et al., 2011). Additionally, the perception of illness symptoms varies widely between individuals (even when they have the same illness) because of their diverse illness perceptions, which are influenced by a variety of factors, such as individual knowledge, beliefs, and experiences (Conrad & Barker, 2010; Petrie & Weinman, 2012). Kleinman’s ideas agree with the social constructionist views that people's perceptions of various illnesses are influenced by their interactions with their social environment, rather than by chance or accident (Conrad & Barker, 2010).

Despite a shift towards training HCPs in the biopsychosocial model, which recognises the physical, psychological, and behavioural aspects of illness, HCPs’ EMs of illnesses have largely remained biomedical, emphasising physical and biological factors that contribute to disease (Kleinman & Benson, 2006; Rydström & Englund, 2015). The current study findings provide evidence to support Kleinman’s claim that individuals experiencing illness may have different explanations for their condition from that of their healthcare providers. It is common for HCPs to be frustrated by patients who fail to adhere to treatment regimens such as prescribed diets, drug regimens, and exercise schedules (Tirodkar et al., 2011).

Adherence refers to the idea that an individual's behaviour is in line with medical advice (Rafi et al., 2022). Non-adherence is the act of disobeying medical advice or failing to follow instructions, which is typically perceived as deviant behaviour with negative connotations. The causes of non-adherence are complex. There is a greater likelihood of non-adherence if HCPs are unaware of the cultural frameworks which patients use to conceptualise and communicate their illnesses (Rafi et al., 2022; Winkelman, 2008).

The process of eliciting the patient's explanation of illness is pivotal as it provides critical insight into what is most important to the patient, what they believe about health and illness, and what they think will help them achieve recovery (Acorda et al., 2020; Rydström & Englund, 2015). This approach not only ensures adherence, but also effective clinical care and patient satisfaction. Moreover, identifying and explaining the points of difference between a provider and patient perspective, especially those affecting appropriate care, can help facilitate clear explanations, education of the patient, and frank negotiations between the two (Habib et al., 2016). Kleinman et al. (1978) proposed the following targeted questions (Table 14) to assist HCPs in identifying the *patient's EM of illness* in order to facilitate cross-cultural communication, ensure patient comprehension, and identify areas of conflict that might need to be resolved. HCPs may alter the wording and number of questions as appropriate based on the characteristics of each patient, the nature of the problem, and the setting.

Table 14

Kleinman's Set of Targeted Questions to Elicit the Patient's EM of Illness

Sl No.	Questions
1	What do you think has caused your problem?
2	Why do you think it started when it did?
3	What do you think your sickness does to you? How does it work?
4	How severe is your sickness? Will it have a short or long course?
5	What kind of treatment do you think you should receive?

6	What are the most important results you hope to receive from this treatment?
7	What are the chief problems your sickness has caused for you?
8	What do you fear most about your sickness?

Note: Reprinted from "Culture, Illness, and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research," by A. Kleinman, L. Eisenberg, and B. J. Good, 1978, *Annals of Internal Medicine, 88*(2), p. 256. Copyright 1978 by the American College of Physicians.

Kleinman's Model of Local Healthcare Systems (1980): Healthcare, according to Kleinman (1980), is a cultural system that consists of three overlapping sectors that are frequently engaged simultaneously: the popular sector, the folk sector, and the professional sector. These sectors produce distinct clinical realities, which constitute a particular type of social reality that is characterised by a transactional world—a world in which institutions and relationships are jointly constructed based on symbolic meaning systems—which provides the context for illness and recovery. The use of these sectors varies by immediate circumstances and as a hierarchy of resorts or priorities. They are described in the following sections (Kleinman, 1980; Winkelman, 2008).

In the popular sector, most illness experiences originate from and are influenced by individual beliefs, familial and sociocultural contexts. Consultations with folk experts (folk sector) or, if necessary, with biomedical or other professional services (professional sector) may follow. The folk sector includes healers, rituals, and the use of CAM therapies (non-legal and unregistered therapies), while the professional sector includes biomedical treatments, HCPs, and other legally recognised CAM treatments (Kleinman, 1980). In the popular sector, individuals evaluate self-management techniques and medical treatments that they have learnt from both the professional and folk sectors. Biomedical resources are likely to be the first option, but they are often accessed through the family's (popular) decision-making process.

Because these sectors frequently complement or replace biomedicine, they have implications for biomedicine (Winkelman, 2008).

Popular Sector (Lay Sector/Personal Sector): The popular sector, also known as family care in nursing, serves as the foundation for most healthcare decisions and is composed of lay, non-specialist, and non-professional healthcare (Kleinman, 1980; Winkelman, 2008). In Western and non-Western societies, healthcare is largely practised in the popular domain. In most cases, illnesses are never discussed initially in the professional or folk domains. Clinical manifestations of the disease are also generally first observed in the personal sector. Family members, friends, social networks, and those who have experience with various illnesses provide assistance in assessing illnesses and determining treatment options, including seeking medical attention. This sector usually involves actions based on various cultural beliefs, practices, previous knowledge, and experiences (Acorda et al., 2020; Kleinman, 1980; Winkelman, 2008).

It has been established that cultural, social, and interpersonal factors are the primary determinants of patients' inclination to seek medical care (Ahmed et al., 2018). According to Kleinman et al. (1978), cultural conceptions of illness determine the patients’ interactions with HCPs rather than biomedical beliefs. For instance, the way in which symptoms are recognised as significant and requiring care is influenced by culture. Some populations may ignore symptoms due to their prevalence and relationship to their culture's values. People are less likely to seek medical treatment if they perceive symptoms to be of little danger (Winkelman, 2008). Additionally, the decision to seek medical assistance in response to a symptom may or may not include consulting with a specialist; however, that decision will to some extent be determined by the institutions and settings available for consultation. For instance, stigma existing around a disease in the community may restrict people from seeking healthcare assistance (Buser et al., 2021; Croot et al., 2012; Daudji et al., 2011; Habib et al., 2017; Heer et al., 2015; Lakhanpaul et al., 2019).

The popular sector, thus, pertains to what people believe and do regarding healthcare with no recourse to specialists, including ignoring symptoms and deciding whether to seek biomedical treatment or to utilise the folk sector instead (Acorda et al., 2020; Kleinman, 1980). The popular sector plays an important role in public health education since self-care practices have a direct impact on maintaining good health, preventing disease, and making informed medical decisions. This sector decides whether to participate in one of the other two sectors. Consulting an HCP implies that the individual engages in one of the other two sectors (Belqaid et al., 2018).

Professional Sector: The professional sector consists of organised HCPs who provide legalised medical care, which includes both scientific (Western) and traditional (Chinese, Ayurvedic, Unani, and chiropractic) healing practices (Kleinman, 1980; Winkelman, 2008). The professional sector is dominated by HCPs with a bio-medical background in most societies but includes other types of professionals as well. For example, in some societies, other healthcare systems have professional status, such as Chinese medicine in many parts of Asia and Ayurvedic medicine traditions in India. When patients transition from the personal to the professional sector, they are expected to adhere to treatment recommendations made by the respective healthcare systems. Having the authority to diagnose and propose treatment alternatives enables these HCPs to possess social power (Belqaid et al., 2018; Winkelman, 2008).

Folk Sector: The folk sector includes a variety of traditional cultural healing practices that are not generally affiliated with any formal or professional healthcare systems (Kleinman, 1980). This sector includes non-professional healers such as spiritual, religious, and natural healers (such as unregistered midwives, herbalists, and masseuses) and psychological healers (fortune tellers). While the folk sector does not generally comprise part of the society's dominant sector politically or economically, it may nonetheless be one of the most used health resources. It should be noted that what is regarded as folk practice in one society may be considered professional practice in another because of the differences in power structures of that society (Chinese medicine in mainland China as opposed to American medicine) (Kleinman, 1980; Winkelman, 2008). The use of folk therapies may also be sought to alleviate symptoms related to ancestral curses or bewitching, which are generally believed to be incurable by biomedicine. There is also a strong connection between folk medicine and local religious and ethnic identities. It is not uncommon for people to seek folk healing if their symptoms persist or worsen despite continued treatment (Acorda et al., 2020).

Kleinman’s Models and the Theory of Tug-of-War: The present study found that the Indian immigrants' EMs for asthma were largely conceptualised within a biopsychosocial framework. Despite the diversity of this group of Indian immigrants, the findings revealed various common themes, which largely framed asthma within the context of individual behaviours (such as diet, physical activity, medication adherence, etc.) and psychosocial factors (such as cultural expectations, social support, stigma, etc.). For example, a recent study found that SA family caregivers who discussed asthma exacerbations as a result of a hot-cold dietary imbalance were less likely to perceive their children as being at high risk of exacerbations if they maintained this diet plan (Ahmed et al., 2021; Lakhanpaul et al., 2017). Considering the importance of dietary principles in treating illnesses in traditional health systems such as Ayurveda and Unani, it is not surprising that the concept of a healthy diet was frequently mentioned as a concept of a good asthma management strategy in the participants’ EMs of asthma (Ramdzan et al., 2019; Sudarsan et al., 2022c).

An alarming finding of the present study that recurred repeatedly in the participants’ EM of asthma was the unsafe practices reported around medication use, particularly with inhalers. A number of reasons contributed to non-adherence with medications: medication phobias, the inconvenience of regular medication use, the trust in CAM treatments over western medicine, the stigma associated with medication/inhaler use, cultural differences, language barriers, and the discontinuation of medications during the asymptomatic period as the participants treated asthma as an acute condition. As mentioned earlier, family caregivers in the study were primarily concerned about the long-term effects of medications such as steroids. This links with the reports of others who have described in their studies the concerns expressed by family carers about the long-term effects of inhaled steroids, including the possibility of addiction, as well as how they might affect the growth and development of their children (Hudson et al., 2016; Lakhanpaul et al., 2017; Mehrotra et al., 2014).

Furthermore, medication adherence in paediatric patients is strongly influenced by family dynamics (Lakhanpaul et al., 2014; Sondhi, 2017; Sudarsan et al., 2022b, 2022c, 2022d**).** Family caregivers play a key role in ensuring that their children are compliant with their medications. The level of adherence with inhalers was related to various beliefs regarding treatment and, in particular, how family carers evaluated their child's need for the inhaler in comparison to concerns about potential adverse consequences of using the device regularly. A systematic review of barriers and facilitators to effective asthma management among SA immigrant children revealed that the family carers had difficulties complying with the medication regimen, which adversely impacted asthma control (Lakhanpaul et al., 2014). Consistent with the current findings, the SA family carers reported that they provided medications to their children after experimenting with them for a period of time to verify the risks versus benefits. The pivotal role of HCPs in increasing parental knowledge of asthma medication regimens to ensure adherence has been well documented (Lakhanpaul et al., 2014; Pars et al., 2020).

Several research studies have demonstrated that beliefs and concerns about medicines can impact adherence in chronic conditions such as asthma **(**Hudson et al., 2016; Lakhanpaul et al., 2017; Mehrotra et al., 2014; Ramdzan et al., 2019). Identifying non-adherence as a problem within a biomedical framework leads to interventions and research that focus on the medical aspects of the patient rather than the patient's holistic situation. For instance, in a biomedical approach, a child with asthma would be considered noncompliant if they did not use the prescribed inhalers as directed by their HCPs. This positions the implementation of interventions and patient education as a medical-centered model of care rather than a patient-centered model. If HCPs do not understand how patients with asthma interpret their condition and how they believe their asthma should be treated, they will not be able to effectively educate these patients. Growing evidence repeatedly shows that integration of the expertise of HCPs with the needs of patients is essential for improving the quality and outcomes of asthma care among Indian immigrants (Acorda et al., 2020; Kleinman & Benson, 2006).

It is important to note that the majority of participants' asthma care decisions were made in the popular sector, i.e., in the context of their daily lives, both individually and in interaction with their families, friends, and community members. As highlighted, the participants' approach to asthma was significantly influenced by traditional Indian cultural beliefs. In existing studies, it has been shown that traditional health beliefs may have varying influences depending on an individual's level of acculturation to the host culture (Acorda et al., 2020; Warmoth et al., 2020).

Family caregivers in my study developed their own approaches for interpreting the subtleties of their children's asthma, learnt how to intervene with medications when necessary, and established family routines in order to reduce the risk of asthma flare-ups and gain a better understanding of what normal life involves for children. The caregivers experimented with medications and methods that were best suited to their family contexts. Family caregivers obtained a profound grasp of the social and cultural factors surrounding asthma as they developed their expertise in providing asthma care. The current study found that Indian immigrants treated their children's asthma using both traditional and Western methods. Most of the time, biomedical management strategies were used when traditional treatments for asthma were ineffective. These results reflect those of Mehrotra et al. (2014), who report that experience-based familial regimes often supersede asthma action plans, asthma guidelines, or doctors' recommendations among Indian immigrant families.

The role of extended family support appears to be relatively unique to Indian immigrant parents, which has also been echoed by parents from the Indian diaspora in other studies (Raina et al., 2020; Nayar, 2011)**.** It was common for participants in the current study to use advice passed down from their mothers or grandmothers as their first option when their child experienced asthma attacks. Rekha, who arrived in NZ one year ago, provided me with an elaborate list of homemade remedies she used for her child's asthma. It was her mother-in-law who had passed down these recipes to her. A resident of NZ for the last seven years, Raghu, reported that he made his child follow his mother's advice to manage and prevent asthma attacks. A constant comparison was also made between the healthcare system in NZ and that in which the parents received care. As an alternative to understanding this phenomenon, one can consider the ideas of Altheide and Johnson (1997), who believe that human expectations are manifested through the meaning that people give to their experiences. People tend to construct an explanation for their illness experiences based on past experiences, education, and cultural traditions, which may lead to expectations concerning healthcare encounters when they become ill (Kleinman, 1980).

In the current study also, participants' existing knowledge, prior experiences, and beliefs about asthma influenced how they interpreted the disease and their approach to managing it. Family carers with experience managing their own asthma or the asthma of another member of their family were more comfortable in managing the condition or had a systematic plan for managing it. For example, some family caregivers expressed the need to remain vigilant and on guard at all times in order to administer treatment in a timely manner. Their daily life was carefully planned so that their child remained safe. They were also alert to situations where their child might be exposed to various triggers. However, on the other hand, some family carers overlooked or underestimated the severity of their child's asthma, and this constituted a major barrier to effective asthma management. Desai et al. (2016) found that the inability to understand the nature of the disease caused asthma management to be driven by the beliefs of family carers.

To treat their child's asthma, Indian immigrant family caregivers in the study used multiple systems of care—both the folk and professional sectors—simultaneously in order to care for their children. Medical pluralism refers to the use of multiple therapeutic modalities, including biomedical and CAM treatments (Acorda et al., 2020). Each participant expressed varying degrees of support for Indigenous remedies passed down from their ancestors. The most common practice was the use of herbal remedies (honey, turmeric, ginger tea, spice tea, etc.) and dietary modifications/restrictions (hot-based foods, dairy restrictions, avoidance of junk food, and cold food) as supportive therapy. The prevalence of these beliefs and rituals suggests that they are deeply ingrained in Indian culture and should be considered when developing care recommendations. The majority of the folk remedies uncovered by this study are generally safe and can be used to complement or support other treatments. Similar practices have been observed in other studies of Indian immigrants, both in the context of adults and children (Felicilda-Reynaldo et al., 2020; Lorensia et al., 2018; Sarvesh et al., 2018**)**. There is also research to support the fact that Indian immigrant parents turn to folk remedies and healers after being dissatisfied with providers because of unmet expectations, language barriers, and a perceived lack of knowledge about the condition (Sundararajan et al., 2020).

Despite the tension between traditional healing knowledge and the dominant medical paradigm in NZ, our findings confirm that biomedical treatment was not rejected by participants, but rather they tried to integrate it into a practical pluralistic attitude. Literature frequently describes this integrated approach to health practices among SA immigrants (Ahmed et al., 2020; Felicilda-Reynaldo et al., 2020; Lorensia et al., 2018; Sarvesh et al., 2018). The results of my study complement those of Mehrotra et al. (2014), who conducted a case study on the impact of cultural factors on asthma management in Indian immigrant children in the USA, which illustrates the overlap between Kleinman's three sectors. It was revealed in the case study that several cultural factors played an important role in the asthma management of Indian immigrant children. Parents in Indian communities relied on horoscopes and spiritual healers to treat their children's asthma. They used stone therapies, special amulets, and prayers to control asthma symptoms and prevent exacerbations. These articles were regarded as sacred by the parents, and their removal was considered inauspicious since it could worsen the asthma symptoms. Moreover, they followed alternative medicine such as Homeopathy and Ayurveda for the treatment of asthma, as they believed that these were less likely to cause side effects in the long run than Western medicine. They consumed a special diet based on the hot-cold theory since it was also prescribed in these systems of medicine for the treatment of asthma (Mehrotra et al., 2014).

Biomedicine and traditional healing therapies offer distinct forms of healthcare to patients. Extant studies reveal several reasons why patients choose one healthcare resource over another (Lakhanpaul et al., 2014; Mehrotra et al., 2014; Sundararajan et al., 2020). A consumer's dissatisfaction with a healthcare system may prompt them to switch to a different system. Some participants in the current study reported that their child's asthma was initially mismanaged by biomedical treatment and that it was subsequently cured by traditional means. Additionally, positive experiences with a particular healing therapy may contribute to the continued use of that healthcare modality, and an individual may become reluctant to engage with the alternative as a consequence of continuing to experience positive outcomes (Acorda et al., 2020; Sundararajan et al., 2020).

One of the common themes that emerged in the participants' EMs in the popular sector was the stigma associated with asthma in the Indian community. Stigmatising beliefs about asthma persist in some cultures despite advances in treatment. There is a stigma associated with asthma as well as a sense of personal responsibility and guilt associated with it, which are particularly prevalent in Indian culture. (Mehrotra et al., 2014).

In this study, as in previous studies, family caregivers reported a tendency to conceal their child's asthma (Lakhanpaul et al., 2017; Mehrotra et al., 2014). They expressed their fear of stigmatisation of their child being treated as imperfect by society because of the asthma diagnosis; similar attitudes from Indian immigrants were reported in previous studies. Some family carers reported being ostracised by their local communities due to their children's asthma and being blamed by their families. Findings of prior studies suggest that SA family carers are often reluctant to divulge the nature of their child's chronic illness for a variety of reasons, including the fear that it will negatively reflect on the child and their family (Croot et al., 2012; Kelly & Kelly, 2013; Lakhanpaul et al., 2017; Mehrotra et al., 2014). SA immigrant family caregivers of children with asthma and other chronic illnesses feared, experienced, and anticipated stigma, which created significant barriers to the adoption of effective management practices. The existing evidence indicates the general need to assess children's and family caregivers' attitudes towards stigma associated with various childhood chronic conditions, in order to effectively address the concerns associated with them (Lakhanpaul et al., 2017; Mehrotra et al., 2014).

Children in the study expressed dilemmas over whether to keep their asthma secret or reveal it as they received stigma coaching from their family carers. It was difficult for them to disclose their asthma to others, such as their friends, classmates, and teachers, for fear of not being accepted and being labelled as different by them and consequently being ostracised. Trollvik et al. (2011) report that stigma may adversely affect children's access to healthcare resources, social interactions, and asthma management behaviours. Members of a marginalised group may experience self-stigma when they become aware of the prejudice, stereotypes, and discrimination targeted against them. Furthermore, stigma may be internalised by children, which is known as self-stigma, adversely affecting their health and well-being. The internalisation of stigma may lead to feelings of shame, guilt, and diminished self-worth among people with stigmatised identities (Trollvik et al., 2011; Warmoth et al., 2020).

Some family carers in the study restricted their children's inhaler use in public settings due to a fear of being treated differently. Consequently, these child participants may have described external influences in a minimal manner. It is also possible, however, that minimal external stigma may have appeared in this study due to the increased recognition of asthma in NZ. There has been an increase in the visibility of asthmatic profiles in recent years, which may help reduce people's vulnerability to external stigma and isolation (Schlichting et al., 2021). Moreover, these assumptions are consistent with the findings of the current study, in which participants reported experiencing less stigmatisation following immigration to NZ than in India, highlighting the commonality of asthma in NZ as it gave them a sense of normality.

As mentioned in the literature review in chapter two, stigma is a common stressor experienced and reported by SA immigrants, which may influence their health behaviours and health-seeking behaviours (Croot et al., 2012; Kelly & Kelly, 2013; Lakhanpaul et al., 2017;

Mehrotra et al., 2014). Additionally, there is evidence that internalised stigma may negatively affect the quality of life of Indian immigrant children with asthma through maladaptive cognitive processes. This study hypothesised, consistent with prior research, that there would be a correlation between self-stigma and the development of self-management behaviours among Indian immigrant children with asthma. Moreover, imposed stigma may lead to greater perceived suffering and greater social isolation (Croot et al., 2012; Kelly & Kelly, 2013; Lakhanpaul et al., 2014).

There are also significant differences between Western cultures and many non-Western cultures regarding whether the concept of the individual is considered to be the primary social unit or not. Collective cultures, such as Indian culture, emphasise the interdependence of individuals and groups (Chadda & Sinha, 2013). Consequently, stigma may pose a greater threat to an individual's well-being and functioning in Indian culture than in Western culture, as those with the stigmatised identity may be more concerned about how it might affect their social relationships (Buser et al., 2020; Laakhanpaul et al., 2017). The belief that asthma is contagious, for example, adversely affected the socialisation habits of children and their parents in the current study. Similarly, as the use of inhalers made the disease more visible, children were prohibited from using them in public places. It is well documented that social support from family and community plays a powerful role in self-worth and coping with the disease among Indian communities. Therefore, self-stigmatisation may have an acute adverse effect on the mental health of Indian immigrant children with asthma and their families as it may restrict them from seeking the necessary social and healthcare support they need (Lakhanpaul et al., 2014; Mehrotra et al., 2014).

In their EMs, many participants raised concerns regarding asthma's detrimental effects on their sporting skills, since they often regarded physical activity as a trigger for asthma. The feeling of embarrassment may be associated with asthma-related stigmatisation which is prevalent in the wider Indian community. This finding aligns with Lakhanpaul et al.’s (2019) study, which revealed that SA immigrant children were more likely to experience disease-related embarrassment than British children. This may be more associated with day-to-day activities such as sports or taking asthma medications prior to them when others see them as visibly different, rather than just the fact of having asthma. Feeling embarrassed may make children hesitant to use inhalers, which may negatively impact their ability to self-manage their asthma. Many researchers have pointed to the need for a tailored approach to change SA children's perceptions concerning physical activity (Ahmed et al., 2018; Englund & Rydstrom, 2012).

The current study challenges the *one size fits all* approach to healthcare and the monocultural presentation of asthma management by highlighting the significance of the experiences, concerns, and efforts of each service user. For instance, some participants reported that, due to the stigma associated with asthma, they presented to clinicians only when their symptoms became severe. Having found the right clinician, who acknowledged their cultural dilemmas and connected the participants to resources in their community, participants experienced satisfaction with the care they received.

Summary

The purpose of this chapter was to discuss the constructed GT in light of other theories and extant literature in order to increase the level of abstraction of the theory. This chapter highlights the value of undertaking a comprehensive review of relevant theories and literature to strengthen the explanatory power of the produced theory. I have based my discussion on three relevant theoretical codes, namely Berry's acculturation model, Kleinman’s EM of illness, and Kleinman’s model of local healthcare systems, all of which support my theory of tug-of-war. The following chapter concludes my thesis.

Chapter 7–Conclusion

The feeling is less like an ending than just another starting point

—*Chuck Palahniuk*

This final chapter presents a summary of my thesis by revisiting my research aim, methodology, methods, and findings. I will explain the contributions I have made to new knowledge and reflect on my learning over the course of my PhD journey. In this chapter, the research process and product are also evaluated in terms of their quality and rigour. The subsequent sections highlight both the strengths and limitations of the study. Finally, the chapter concludes by discussing the implications for practice, research, policy, and education.

Re-visiting the Study Aim

There is a dearth of research on childhood asthma among Indian immigrants at the national and international levels. To my knowledge, this will be the first study of its kind to explore the beliefs, practices, and experiences of Indian immigrant children regarding their asthma, along with their family carers' perspectives.

The study aimed to develop a theory explaining the beliefs, practices, and experiences of asthma among Indian immigrant children and their family caregivers using a CGT approach. Using child-friendly, culturally sensitive, and participatory data collection methods, I was able to gain an in-depth understanding of the views and experiences of the participants, which allowed me to identify their asthma care priorities. I have achieved my aim by constructing the theory of navigating asthma—the immigrant child in a tug-of-war, with the categories: being fearful, seeking support, and clashing cultures, to partly explain how Indian immigrant children and their family carers in NZ manage asthma.

A Constructivist Grounded Theory Methodology

Social constructionism informed the study's design, CGT, as well as all phases of data collection, theory production, and the formulation of study recommendations (Berger &

Luckmann, 1991; Charmaz, 2014). Ideally, conventional research endeavours to provide an unbiased and objective explanation of the investigated topic. According to Birks et al. (2019), in a CGT study, “it is theoretical sensitivity rather than bias that informs analysis” (p. 4). Therefore, the CGT approach I employed in this project required me to acknowledge my own interest in the topic while confirming my role as an advocate for my research participants' values and concerns (Birks et al., 2019; Charmaz, 2014). Acknowledgment of my own experiences and the ongoing memoing during the study allowed me to acquire theoretical sensitivity (Sudarsan et al., 2022c).

To ensure the quality of the study, I have made the entire research process transparent throughout the thesis: I have explained how I conducted the study, why and how I used GT and specific data collection methods, how I obtained the sample, and acquired theoretical sensitivity (Birks et al., 2019; Charmaz, 2021). The codes, categories, and theoretical outlines were initially treated as provisional and subject to revision or rejection in response to new data and further analysis. The final storyline presented in chapter five explained how the theory of navigating asthma—the immigrant child in a tug-of-war was constructed. The next section provides a summary of the study's contribution to new knowledge (Birks & Mills, 2015).

Thesis Overview: The Generation of New Knowledge

The preliminary literature review revealed a dearth of research on Indian immigrant children's asthma experiences. The next step involved undertaking a rigorous research design such as CGT incorporating participant-driven research methods to explore the asthma experiences of Indian immigrant children and their family carers. According to Sheridan and Storch (2009), GT facilitates “[the] exploration of interrelatedness of the process of cross-cultural adaptation, which is individual for each migrant,” as it is an “open and flexible approach that is focused on the migrant’s actual experiences” (p. 4). HCPs may employ the substantive theory in developing culturally sensitive care plans for Indian immigrant children with asthma. Moreover, the findings may offer insight into the political and sociocultural impacts of immigration and acculturation for other minority groups.

In chapter one, I describe my background, personal and professional experience with the topic under investigation, and my ontological stance. Chapter two establishes the context for the study by presenting the evidence that justifies its necessity. It includes an integrative review of the studies that explore SA immigrants' beliefs, practices, and experiences of childhood LTCs. Charmaz's (2008) integration of CGT with social constructionism and the influence of social constructionism on my research approach are discussed in chapter three. This chapter also contains an in-depth discussion of the history of GT, including its three versions. The fourth chapter elaborates on the GT methods utilised in my research design. The constructed GT of navigating asthma and its three categories—being fearful, seeking support, and clashing cultures—are presented in chapter five. Chapter six discusses my findings and applies three extant theoretical codes—Berry's theory of acculturation (1992), Kleinman's EM of illness (1978), and Kleinman's model of local health care systems (1980)—to enhance the explanatory power of my theory. Finally, this chapter gives an overview of my thesis and illuminates the new knowledge it contains.

As the principal objective of a PhD is to generate new knowledge, I believe I have accomplished this objective through the published journal articles generated from this thesis. The following section provides an overview of the journal articles presented throughout this thesis that have been published in international peer-reviewed journals with high impact factors. The impact factors of these journals are JCN: 4.423; JAN: 3.187; RINAH: 2.238; QRJ: 0.87. In the following sections, a summary of the contribution of each journal article is provided, along with some feedback received during the publication process.

The first journal article in chapter one, "Positioning the researcher for studying Indian immigrant children's asthma in New Zealand: A reflective account" (published in the QRJ) (Sudarsan et al., 2022c), explores the meanings of researcher positionality and illustrates how reflective memos can be used to demonstrate positionality in CGT studies. The article reveals how my position influenced the way I chose the study design and framed the research question. Literature regarding how to write reflective pieces is scant, and only a few researchers reveal raw, unedited memos that they have made (Davis, 2020; Engward & Davis, 2015; McGrath, 2021). The lack of popularity of reflective articles in the publication arena may be ascribed to a lack of awareness of the significance of these articles in enhancing the credibility of the research. The following comment from one of the peer reviewers exemplifies this point: "This study presents the researcher's personal experiences without reference to a model, theory, or symbolic interaction.” This article addresses the existing gap in the literature by demonstrating how to write unedited reflective memos. It provides practical advice on how to outline positionality before conducting a CGT study as well as assistance to novice CGT researchers in developing effective reflexive writing techniques.

The second journal article in chapter two, titled “South Asian immigrants’ and their family carers’ beliefs, practices, and experiences of childhood long-term conditions: An integrative review” (published in the JAN), explores SA immigrants’ and their family carers' beliefs, practices, and experiences of childhood LTCs (Sudarsan et al., 2022d). According to my knowledge, this integrative review is the first of its kind to explore SA children's and their family carers' experience of LTCs in their host country. As there has been little research exploring Indian immigrants' LTC experiences, this review aimed to include either all SA immigrants or any SA subethnic group as the sample population. The following comment provided by one of the peer reviewers reinforces the importance of studying the Indian immigrant population alone rather than the SA population as a whole: "I would also make the point that lumping together all SAs into one group because they share this ethnic label is misleading.” This comment from the peer reviewer sheds light on the importance of the current study and points to the generation of new knowledge that could result from it. Highlighting the findings of this review to HCPs is a top priority, as the growth of SA immigrants worldwide, along with the increasing burden of LTCs among SA immigrant children, has implications for healthcare delivery.

I found it difficult to locate articles discussing and critiquing the use of CGT in children’s research while preparing my research proposal. This prompted me to write the paper presented in chapter three, entitled "Giving voice to children in research: The power of child-centered constructivist grounded theory methodology," published in the RINAH. I deem the title of the paper to be the most appropriate for the content, as it emphasises the efficacy of the CGT methodology in the field of child-centered research. In publishing this article, I hoped to leave a legacy for future researchers conducting CGT with children. The process of reading related resources, analysing the information, and writing the paper took a significant amount of time. It was very gratifying to hear the following comment from one of the peer reviewers: “I have really enjoyed reading this interesting paper, which is really well written. The methods used to engage and hear the experiences of children are really interesting, and the methodological approach aligns well with involving children in a meaningful way.”

The publication on findings in the JCN, “Navigating asthma— the immigrant child in a tug-of-war: A constructivist grounded theory,” was a delight to write. It makes sense and fits into Glaser's concept of "grab and fit" (1978, p. 4). This article has also been presented in a number of settings, including the Massey University doctoral school, the 3MT thesis competition, and numerous regional and international conferences. I felt very gratified by the following comment from my supervisor, Prof. Karen Hoare: “This is an excellent piece of work, Indu. Your grounded theory is plausible and very well explained in the storyline. The way you have weaved the child and carers' data is amazing." Prior to this study, I was unaware of the tug-of-war process in terms of clashing cultures, even though I had unknowingly experienced this myself as an immigrant. Following the development of the tug-of-war theory, I have been observing Indian immigrant families engaging in tug-of-war processes in various spheres of their lives.

Generic transferability has been proposed as a key indicator of a GT's utility and quality. There is considerable consensus regarding this among the developers of the method (Charmaz, 2014; Corbin & Strauss, 2008; Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1998). Some GT scholars use the term *flexibility* instead of generic transferability (Birks & Mills, 2015). This article posits that the central process that participants engaged in, in this study, the tug-of-war, may be applicable to other immigrant healthcare consumers (children, adults, and their family caregivers) who may find it challenging to navigate the healthcare system in the host country. The theory focuses on the processes that healthcare consumers encounter as they navigate healthcare systems, which may not always provide adequate or comprehensive support for them or fail to link them to therapies that are best suited to their needs.

Reflections on My Learning

The primary goal of the PhD programme is the development of researchers who are well-prepared to take on the research challenges of the future, for society's benefit. As an added benefit, a PhD with publications ensures that the candidate is equipped with the skills necessary for a successful academic career: the ability to write a clear, concise, and impactful research article, as well as the ability to successfully submit a paper for peer review (Jowsey et al., 2019).

As highlighted in chapter one, prior to undertaking this study, my experience as a qualitative researcher was limited. Aside from this, I did not have any publications to my credit. At first, I was unsure of my ability to publish. Now, my perspective has changed, and I no longer take anything for granted. My doctoral journey has not only allowed me to learn how to conduct a GT study but has also given me the confidence to write articles as a lead author. Having been new to GT methodology and facing challenges in data collection associated with COVID-19, I focused on completing the fieldwork and analysis in the initial years of my PhD programme. Therefore, I did not engage in any publication endeavours during the first three years of my study. Having published all four of my articles during my final year of study makes me feel proud as a first-time author. Also, I gained a greater understanding of how to be flexible without jeopardising the credibility of the study during major crises, such as the COVID-19 pandemic (discussed in chapters 3 and 4).

Various GT-related terminologies confused me at the beginning of the study. Glaser's (1967) seminal work, *The Discovery of Grounded Theory*, initially proved difficult for me to comprehend. Birks and Mills' (2015) book provided me with a solid understanding of GT’s fundamentals. My further engagement with the works of key GT developers enabled me to gain a deeper understanding of the methodology; as soon as I felt comfortable with the methodology, I gained confidence in carrying out the study, making the entire research process easier.

CGT research taught me how to think critically and be reflective. I was profoundly impacted by John Dewey's (1933a) fundamental work, *How to think*. I have developed the ability to be more open-minded and less biased in my research. For example, I have learnt to approach a concept with the mindset that there may be multiple perspectives and to objectively analyse the evidence rather than relying solely on my initial conclusions. In addition, I have become more accustomed to questioning my own assumptions and seeking alternative explanations. Through this process, I have been able to think outside the box and come up with innovative ideas and solutions. Memoing enhanced my understanding of theoretical sensitivity at the beginning of the study. In the beginning, I had difficulty deciding what to include in the memos, but as time progressed, I became increasingly confident in memoing, and I could not stop writing.

Prior to the study, I had no preconceived notions regarding the lives of Indian immigrant families with a child suffering from asthma. The discovery of clashing cultures, reflected through the basic social process of a tug-of-war, was a revelatory experience, and I felt the joy of being a grounded theorist at that time.

This PhD study has provided me with valuable insights into a number of factors that should be considered when interviewing children. There are a number of important areas that should be considered: power dynamics between parents/researchers and children; consent/assent procedures; scheduling convenient interview times and locations; ensuring that children are actively engaged throughout the interview process; tailoring child-friendly data collection methods according to their interests; addressing cultural differences; and the use of proper ethical procedures and guidelines. Also, I realised that conducting research remotely through online platforms raises a number of uncertainties, including whether a child has sufficient privacy to talk freely, how to actively engage children online, or how to build a successful relationship with a child wearing a mask or on a video conference call. When a researcher wears a mask, even when engaging with a child in person, it may be difficult to effectively connect with them. Although the challenges are real, I understand that it is possible to overcome them. Researchers may use creative strategies such as storytelling, or leveraging technology to create interactive activities that can help build emotional connections with the child. These are some areas that require further investigation. Therefore, it is important for research teams to consider the potential impacts of remote research on the quality of the data being gathered and consider ethical approaches to ensure the best possible outcomes.

Quality Considerations

In the following section, the final GT will be evaluated based on Charmaz’s four criteria for evaluating a GT.

Evaluating the Research Product or the Final Grounded Theory

Table 15 specifies a set of questions based on Charmaz’s evaluation criteria that assist readers in critiquing how the theory was produced in relation to implicit meanings and actions associated with the researched phenomenon.

Table 15

Evaluating the GT of Navigating Asthma—The Immigrant Child in a Tug-of-War

Sl No.	Evaluation Criteria	Questions
1	Credibility	Do you have enough data to support your claims? The number, range, and depth of observations should be considered. Is there sufficient evidence in your research to enable the reader to form an independent assessment of your claims and agree with them? Do the collected data, and your argument and analysis have strong logical connections?
2	Originality	Do the categories provide new insights and are they fresh? In what ways does this research challenge or refine existing ideas, concepts, and practices? Are your findings theoretically and socially significant?
3	Resonance	Would your GT make sense to your participants and

		others who may be experiencing similar circumstances? How does your analysis contribute to a deeper understanding of their lives and worlds? How accurately do the categories reflect the full range of experiences examined? Are both liminal and unstable, taken-for-granted meanings explicitly disclosed?
4	Usefulness	Does your analysis provide people with interpretations that they can apply to their everyday lives? Does the analysis have the potential to inspire further research in other substantive areas? In what ways does your work contribute to the advancement of knowledge?

Note: Adapted from *Constructing Grounded Theory* (2nd ed., pp. 337–338), by K. Charmaz, 2014, Sage Publications. Copyright 2015 by Kathy Charmaz.

Credibility: Credibility was ensured in this study by gathering data from multiple sources (interviews, photography, drawings, and literature) and by maintaining accurate audit trails, such as memos and field notes so that other researchers could evaluate the research process independently. In addition, the diversity of participants, constant engagement with the data, and rich, detailed descriptions of the findings increased credibility (Charmaz, 2006; Corbin & Strauss, 2015). Charmaz and Thornberg (2021) state, "[t]he more controversial the topic and/or analysis is, the more data the researcher needs to persuade skeptical audiences" (para. 35).

Moreover, the credibility of a research finding is determined by the fact that participants and audiences who have had relevant experiences are able to recognise the researcher's descriptions as their own (Charmaz, 2014). As a first step towards disseminating the findings, I considered conducting focus groups with participants to discuss the findings in a more open manner and gain feedback from them. Most participants, however, indicated that time constraints were a barrier to attending the focus group and that they would rather provide their feedback individually. Thus, in order to communicate the results, a pamphlet containing the diagram (Figure 24) as well as the published article on the results was sent to each participant. The diagrammatic representation of theory and its explanation is an effective means of communicating findings to a critical audience (Charmaz, 2014; Oktay, 2012).

Additionally, an audio podcast was sent out to all child participants in order to communicate research findings to them effectively. Translating research findings into a format that can be interpreted, understood, and used is an important step in acknowledging the right of children to know the findings of research conducted on them or with them (Egli et al., 2019). I asked the participants whether they found the findings to be understandable and whether their experiences were consistent with the GT of the tug-of-war. The participants, including older children, subsequently agreed with the findings, and confirmed they were credible. Participants widely accepted the theory of tug-of-war. In general, participants felt that the findings should be shared with NZ HCPs in order to help them develop effective asthma care strategies.

The following were some of the comments from participants:

> That is very well written, Indu. I can see myself there. The theory really makes sense to me. I still don't understand all these hot and cold beliefs. I will give a copy of your findings to my GP. Then he will know what we are going through. All these things are hard to explain in a consultation, and I also doubt that they will understand. I mean, I feel that they will laugh at us if we tell them everything we believe and do. Your

> findings article says everything we are worried about, so it is a lot easier for them to read our minds. (Participant family carer)
>
> I think that is exactly what is going on. Tug-of-war is the right word. I don’t know what is right and what is wrong. Whether we should listen to our GP or our parents. And you know, my other friends–they don't care at all about the inhaler and stuff. Still using it and doing well. (Participant child)

Additionally, a copy of the published article on the study findings was sent to the participant gatekeepers.

> I can see them [Indian immigrants] not using the preventer inhalers regularly. They treat it as more of an acute condition. But I was unaware of the stigma around the use of inhalers among them. I think we should work more on it. (General practice clinical nurse manager)

A member of the Indian community association suggested that I present my findings to the group members to raise awareness about asthma at some point. I discussed my theory with my colleagues, friends, and family members throughout its development. In addition, I presented the theory of tug-of-war at several platforms, such as the Massey University Doctoral School, the Health Workforce Academy conference, the first international GT conference, the 3MT thesis competition, and various Indian community associations, where I received positive feedback. Feedback received on these presentations confirmed the theory's resonance as well as what Glaser (1978, p. 4) described as “grab and fit.” Audience comments included:

> Indu, I am going to watch your presentation again. I have a PhD student who is exploring the experiences of Caribbean populations who have diabetes. I can see exactly the same tug-of-war happening there. The theory you developed is fascinating, and I suggest you write a paper on how it can be used to bring about a significant

> change in practice and policy.(One of the organisers of the IGTA conference and a GT expert)
>
> You know, the script for preventer inhalers will be sent from the practice. But they [Indian immigrants] only buy the relievers. I have been seeing this practice a lot. Now I can relate to why this has been going on. (Indian immigrant pharmacist)

HCPs articulated the need for better organisational support for them to provide resources, education, and training in providing support to the immigrant population. Furthermore, the GT of the tug-of-war was presented informally to several small groups of Indian immigrants who either had children with asthma or expressed an interest in the subject at various community gatherings. These talks were incidental and occurred when community members who were familiar with my research topic and who knew me as a researcher expressed an interest in learning more about my findings. Hence, the findings were disseminated in an informal manner, which allowed the audience to provide feedback freely, whereas a more formal atmosphere would not have permitted this interactive session. Active interaction and the use of regional languages made it possible for the members to freely exchange their opinions, experiences, and concerns. For those interested, I sent them the article on my findings. A few comments made during these informal discussions are listed below.

> What you are talking about in this article is indeed true. I was first surprised by the medical care here. See, in the case of fever, they [HCPs] ask kids to have ice blocks. But we don't give it in cases of fever back in India. We give them hot drinks instead. Just the opposite. Kids too ask the same. Why are they being told to have ice blocks when they are having a fever while we ask them to have hot drinks at home? I don't have an answer to that. His grandmother gives him all the hot stuff when he is sick. He asks them the same questions. (Indian immigrant parent)

> I don't think the people at the health centre get how we do things in India with Ayurveda and everything. We only get inhalers from them. I don't give my kids those inhalers every day, either. I don't like it at all, to be honest. They will have to use it for the rest of their lives once they start. Ayurveda is a better choice. It is great. My sister is an example. (Indian immigrant parent of a child with asthma)

While the theory resonated with most of the participants, one of the NZ-born nurses expressed her surprise that she was unaware of the stigma surrounding the use of inhalers among Indian immigrants despite caring for them over a long period of time.

> Oh, I see a lot of them [Indian immigrant children]. But I didn't realise there was a stigma around the condition and inhaler use in the Indian community. There are several of them who do not use their inhalers properly. With kids, you can expect that. I took it that way. Now I understand what causes non-adherence in this group. Your article is really helpful. (Native NZ RN)

By disseminating the findings to the participants, gatekeepers, and other interested parties, I was able to receive feedback and confirm an independent evaluation of the GT of the tug-of-war.

Originality: The GT of tug-of-war offers an original conceptualisation of the data and a relevant theory that addresses the study question. Chapter six provides a detailed explanation of the theoretical significance of this study. Various national and international conferences accepted abstracts of my study findings, demonstrating an interest in the research results presented. Having been accepted for publication in a Q1 peer-reviewed nursing journal (JCN) further demonstrates the originality of the GT tug-of-war theory.

Resonance: As previously discussed, all the participants agreed that the concept of tug-of-war made sense to them, and they confirmed that the findings reflected their own experiences. The incorporation of participants' quotations, photographs, and pictures in chapters four and five confirms that the developed GT represented their individual and collective experiences. The supervisory team members, Indian immigrant HCPs, and other Indian immigrants with asthma or having children with asthma supported my findings. They also compared the tug-of-war metaphor with other life domains such as children's schooling, the workplace, grooming, etc.

Usefulness: An indication of GT's usefulness is the practical application of its results in addition to the generation of new knowledge (Birks & Mills, 2015). The GT provided participants, gatekeepers, conference attendees, and other audiences with an explanation of the data that was readily understandable and that they could observe in their daily lives. The theory has demonstrated its usefulness not only in paediatric healthcare settings or in the context of Indian immigrants, but it is also flexible enough to be applied in other healthcare settings, including adult care and with other ethnic minority immigrants.

As a result, I have discussed my findings with people working in the healthcare, education, and health research sectors throughout NZ. They have also been able to relate to the theory, and many have suggested ways to improve healthcare services for Indian immigrants. By presenting a comprehensive picture of Indian immigrant children's asthma that incorporates numerous complex sociocultural factors, the GT of the tug-of-war fills a significant gap in the existing literature. Moreover, the recommendations that result from this study contribute to its usefulness.

Comprehensive Evaluation of the Research Process

In addition to the classic evaluation criteria proposed by the three GT developers, Birks and Mills (2015) recommend that GT researchers perform a comprehensive evaluation of their GTs. Researchers' expertise, methodological congruence with the research question, and the precision with which GT methods are applied are the three major domains that contribute significantly to the quality of GT research. As shown in Table 16, the theory has been evaluated in terms of the three main domains.

Table 16

Evaluating the GT of the Tug-of-War

Sl No	Domain	Evaluation Criteria	Evidence
1	Researcher expertise	Demonstrates skills in scholarly writing.	Chapters 1–7 Publications that arose from this study are presented in chapters one, two, three, and five.
		Evidence researcher is familiar with GT methods.	Chapters 3 and 4
		Citations of relevant methodological resources are presented.	Chapters 1–7
		Limitations in the study design and research process are acknowledged.	Chapters 5 and 7
2	Methodological congruence	Researcher has articulated their philosophical position.	Chapters 1, 3 and 7
		GT has been determined to be an appropriate research strategy for the stated aim of the study.	Chapters 1, 3, 4, 5 and 7
		Outcomes of the research met the stated aims.	Chapters 1, 3, 4, 5, and 7
		GT is presented as the product of the research.	Chapters 1, 3, 4,5, and 7

		Identified and addressed philosophical and methodological inconsistencies.	Chapters 3, 4, 5 and 7
3	Procedural precision	Evidence that memoing has been conducted throughout the study. Audit trail maintained. Procedures for the management of data and resources are described. Evidence that the researcher has applied the essential GT methods appropriately in the context of the study. Evidence that the theory is grounded in the data. The final GT is credible.	Chapters 1, 3, 4, 5 and 7 Memoing, field notes, and supervisory meeting minutes. Chapters 3 and 4. Chapters 1–4 Chapters 3–5 and chapter 7 Adhered meticulously to the main tenets of GT to generate the final GT, the tug-of-war. Chapter 7 Final GT evaluated and published in a leading international peer-reviewed journal. Presented at various platforms: national and international conferences, doctoral

		Are potential applications examined and explored?	school, 3 MT competition, and community associations. Chapters 5 and 7

Note: Adapted from *Grounded Theory* (2nd ed., pp. 147–148), by M. Birks and J. Mills, 2015, Sage Publications. Copyright 2015 by Melanie Birks and Jane Mills.

In Table 16, I outline the procedures that were used to demonstrate my expertise in research, methodological consistency, and procedural precision in conducting this study. I have demonstrated my research expertise as a presenter by sharing the study's findings through a variety of platforms, including local, national, and international nursing and research conferences. The four peer-reviewed articles with me as the lead author, which were published from this research, also reflect my research expertise. Methodological congruence was established in this study because the methodology, my philosophical stance, and the research design were appropriate for answering the research question and achieving the study objectives. The precision with which the GT methods are rigorously applied is evident in the quality of the final product, which was discussed in the previous section.

Strengths

This study has several strengths, including the incorporation of the child's voice within the study findings, the use of child-sensitive participatory techniques, such as drawing and photography, which recognise children as active social agents, and addressing the research gap on Indian immigrant children and their family caregivers' asthma experiences (Kyritsi, 2019; Poku et al., 2019). Although NZ is a signatory to the UNCRC, the voices of immigrant children remain underrepresented in healthcare and research despite various government initiatives that acknowledge and promote their participation (Kanengoni et al., 2018; The

Children’s Convention Monitoring Group, 2018). This gap is filled by the current study, which upholds Article 12 of the UNCRC and fulfils New Zealand's obligation as a signatory.

Having transcribed the data verbatim manually myself, the analysis remained close to and true to the participants' own words, thus enhancing the credibility of the research results (Birks & Mills, 2015; Charmaz, 2014). The variety of quotes presented in chapter five reflects the diversity of participants' perspectives. In addition, one of the strengths of the reflective approach used in CGT is that it promotes transparency between the participants' perspectives and the researchers' interpretations, thereby enhancing the credibility of the research findings (Charmaz & Thornberg, 2021).

There are many advantages to a researcher having a similar cultural background to the participants. Cultural insiders contribute to the overall design of the study while exercising caution, being honest, and identifying areas of bias (Carter et al., 2014; Hoare et al., 2012b; Savvides et al., 2014). As an insider researcher, I brought both strengths and limitations to the study. Being an insider provided me with insight into the everyday realities of participants' lives, allowing me to identify how most effectively to engage and work with them. However, throughout the interview process, I drew upon my ethical need to distinguish between my own bias and that of the participants. Before beginning the interviews, I became aware that some of my personal and clinical assumptions were influencing the research topic; thus, I conducted a self-interview to determine how these assumptions would affect data collection, analysis, and interpretation. As pointed out earlier, writing memos enabled me to remain aware of my assumptions and be open to other interpretations (Sudarsan et al., 2022c).

As an insider researcher, I found it easier to establish rapport with the participants, gain their trust, and address their ethical concerns. There were many things that the participants revealed to me that they would not have revealed to an outsider researcher (explained in detail in chapter four). Having been an outsider culturally, such as a researcher from another ethnic group, I would have expended additional time and energy in order to gain a better understanding of what was taking place (Carter et al., 2014; Savvides et al., 2014).

My outsider status was highlighted in chapters one, three, and four; I did not have the opportunity to work professionally with children with asthma in NZ since I have been an aged care nurse. It was a distinct advantage for me to know very little about children's asthma experiences in NZ. Compared to an insider researcher, I felt an intuitive ability to observe subtle differences in happenings with openness and objectivity. As a result, I was able to clarify all understated actions and those that are perceived as routine. This involved recognising patterns of activity that may be overlooked by a researcher who is familiar with the situation (Savvides et al., 2014).

As previously mentioned, the study population was drawn from one of NZ's major cities. There is a possibility that people's experiences may vary throughout the country, which may have a significant impact on how Indian immigrant children and their family caregivers interpret and manage their asthma symptoms. This study, however, is significant because it is the first in NZ, perhaps even the world, that specifically examines the impact of sociocultural factors on the asthma experiences of Indian immigrant children and their caregivers, as well as the interpretation and management of asthma symptoms as a result of these factors.

It is also significant that this study supports improved recognition and understanding of a historically understudied and difficult-to-reach population. Optimistically, this study will act as a guide to future research that will facilitate an improvement in Indian immigrants' asthma awareness, health literacy, medication competence, and symptom management strategies. It is hoped that healthcare providers, educators, and sports coaches will use the information gathered through this study when supporting Indian immigrants with asthma.

Limitations

The published journal article in chapter five highlights some of the limitations of the study. The following are a few additional limitations that were observed:

- Some limitations include the difficulties associated with participant recruitment (discussed in chapter four), the under-representation of ethnically diverse populations, and the absence of representation of family caregivers other than children’s parents.
- Many schools and general practices were unable to serve as gatekeepers due to the increased workload caused by the COVID-19 pandemic. Due to this, most recruitment was restricted to Indian community associations.
- The use of an interpreter would have greatly enhanced inclusivity within this population. Compared to a novice GT researcher, an experienced GT researcher could have used interpreters effectively for the same study.
- A child's contribution to the study may have been influenced by the presence of family caregivers during the interview.
- It is likely that being an insider researcher would have adversely affected recruitment since potential participants may be concerned about confidentiality issues within the Indian community.

Despite these limitations, the findings provide a detailed insight into how Indian immigrant children and their family carers manage asthma.

Recommendations of the Thesis

Indian immigrants' asthma experiences and their actions in the context of clashing cultures have significant implications for improving paediatric health services for this group. Furthermore, due to the multicultural nature of NZ society, the findings of the research are relevant for the healthcare system in providing appropriate, accessible, and engaging services to culturally diverse populations. Thus, there are important implications for nursing practice, future research, policy, and education arising from this study.

Nursing Practice

The journal article in chapter five discusses a few implications (culturally safe nursing practice, a collectivistic approach to nursing care, and child-inclusive nursing practice) for nursing practice that are derived from this study. Some further key implications are outlined below:

Incorporating Approaches from Epidemiology and Transcultural Theories into Nursing Care: As HCPs work with culturally and linguistically diverse (CALD) populations such as Indian immigrants, cultural safety alone may not be sufficient to provide quality care given the changing ways in which healthcare is provided, including increased community-based care, telephonic, and electronic consultations. This is supported by the latest studies that challenge the notion that “a nurse who can understand his or her own culture and the theory of power relations can be culturally safe in any context” (NCNZ, 2011, p. 7). In line with recent studies, the current study indicates that the lack of cultural knowledge and skills on the part of HCPs is a major barrier to delivering safe and equitable healthcare. Additionally, NZ studies identify that nurses feel inadequately prepared and unsafe when caring for clients from ethnically diverse communities (Mortensen, 2010).

The use of a combination of the approaches of cultural safety, epidemiology, and transcultural nursing theories may assist healthcare providers in developing culturally responsive policies and services that recognise other cultures' ways of doing things, as well as gain a better understanding of the populations they serve (Mortensen, 2010; Nelson, 2017). While HCPs may find epidemiological techniques useful for examining patterns of daily life that contribute to an individual's health and illness behaviour, transcultural theories may assist them in understanding and addressing people's values, beliefs, and practices regarding health in the best possible way.

Advancing Health Literacy–A Call to Action: The concept of health literacy is an area nurses should consider since it focuses on the ways in which people gather, process, and comprehend health information in order to make informed health decisions (Abreu et al., 2018; Johnson, 2015). Studies have shown that nurses tend to overestimate consumers' health literacy. Limited health literacy in the context of asthma has been linked to decreased knowledge and self-efficacy, low medication adherence, increased emergency room visits, and ultimately a decrease in quality of life. For nurses, it is imperative that they gain an understanding of what children with asthma and their families know regarding the condition and how they prefer to obtain information. Asthma education should be tailored to the level of asthma health literacy of Indian immigrant children and their families in order to be effective. It is always advisable to verify that the main points have been understood correctly (Abreu et al., 2018; Acorda et al., 2020; Ahmed et al., 2021; Mehrotra et al., 2014).

A Pluralistic Approach to Healthcare Practice: The guiding principle of pluralistic practice in healthcare is respecting differences between individuals and cross-cultural traditions, as well as combining the knowledge and experiences of HCPs and clients to make shared decisions (Acorda et al., 2020; Kleinman, 1980). It may be advantageous to acknowledge Indian immigrant families' beliefs in home remedies and folk medicine, discuss their pros and cons openly, and perhaps combine the use of these remedies if beneficial with the treatment plan in order to increase their child's adherence to biomedical therapies (Desai et al., 2016). The MOH should ensure the proper allocation of resources, funding, and assets towards popular CAM therapies such as Ayurveda and Homeopathy to effectively manage the current and future healthcare needs of Indian immigrant populations.

Strategies to Tackle the Stigma of Asthma: It may be difficult to change socially constructed attitudes towards illnesses, such as stigma. However, the social stigma associated with asthma continues to be underestimated among HCPs and is often overlooked during healthcare consultations (Lakhanpaul et al., 2014). Most participants described the commonality of asthma diagnoses in NZ as they discussed the stigma associated with the disease. The commonality offered some participants a sense of normalcy. Those who provide healthcare to children and adolescents must be acutely aware of the significance of their desire for a sense of normalcy. In order to facilitate social acceptance of people with asthma in the Indian community, HCPs may consider emphasising the commonality of asthma in NZ (Hamer, 2014).

The establishment of different types of support groups would potentially be a possible intervention for stigma reduction. For example, school-based asthma support groups may be an option. The findings of this study reveal that most participants place a high value on support from peers who also have asthma. Schools should therefore consider encouraging teachers with adequate asthma knowledge to implement asthmatic support groups as a means of providing informational and emotional support to students in order to reduce isolation (Hamer, 2014) and promote a sense of normality. Additionally, face-to-face or online support groups for families with Indian immigrant children with asthma may allow caregivers to connect with other caregivers experiencing the same stressors and frustrations. Being able to connect with others who are having similar experiences may reduce feelings of loneliness and foster a sense of belonging.

Research

- Future research should promote Indian immigrant children's agency by recruiting them without family carers’ restrictions, but within ethical frameworks, and by exploring research methods that these children perceive as facilitative of their active engagement in research.

- It is evident from the present study that grandparents play a significant role in supporting Indian children with asthma, which is consistent with other studies (Raina et al., 2020; Nayar, 2011). Including grandparents in future studies would provide a more comprehensive understanding of their role in the lives of Indian immigrant families and may provide valuable insights into the development of culturally appropriate asthma management interventions and better support systems for these families.
- Further research is imperative in identifying and addressing system-level barriers to Indian immigrant children’s participation in asthma management decision-making processes in order to develop effective management strategies that will balance children's preferences with the preferences of their family carers.
- A mixed methods design, which combines quantitative and qualitative data, will enhance the current study findings by offering a comprehensive research framework.
- Researchers may use large sample sizes involving diverse Indian subgroups in future studies on the current study topic.
- The MOH should provide adequate funding for Asian immigrants' health to fill research gaps in the current New Zealand Health Research Strategy (MBIE, 2017).
- The need for more longitudinal research on the asthma of Indian immigrant children is imperative in order to determine how the variables associated with coping are linked to the process of acculturation over time.
- The extent to which stigma impacts asthma medication adherence and healthcare-seeking behaviour among Indian immigrants should be further researched.

- As part of the MOH's Strategic Intentions 2021–2025, one of the government's priorities is to ensure access to planned care and reduce the number of days spent in hospitals for unplanned care (MBIE, 2021). Future studies should build on the current study by exploring factors responsible for high PAH in Indian immigrant children with asthma, in order to tailor interventions to address these factors.
- The use of interpreters in future research on the current study topic should be considered to promote inclusivity.
- The gap between HCPs' ability to provide culturally competent care and the expectations of Indian immigrant families should be the subject of future research.
- Further research in this area is warranted in order to examine the transferability of the theory to other immigrant groups from collectivist cultural backgrounds.
- There is a need for additional research to determine whether Indian immigrants with other LTCs also experience the same processes as identified in this study.

Policy

- In NZ, the recent *Tamariki Tū, Tamariki Ora: Child and Youth Well-being Strategy* seeks to promote child participation and empowerment through the representation of their voice. The strategy aims to provide them with happiness and good health through healthy and sustainable communities (Department of the Prime Minister and Cabinet 2019). This national strategy was based on priorities, perspectives, and needs to be reported by children, setting a strong precedent and standard for future policy initiatives. However, children from immigrant backgrounds experience persistent health inequities. There is a need to review and revise current national health policies so that immigrant children receive health care from a culturally competent workforce that can respond to and accommodate their healthcare needs. It will be only then NZ be able to implement social justice strategies that are in line with the *2030 Sustainable Development Agenda* that emphasises *leaving no one behind* (Fukuda-Parr & Hegstad, 2018).

- Organisational policies should be modified to provide HCPs with support and organisational conditions that facilitate working with immigrant families having children with chronic conditions such as asthma.
- A key factor in preventing PAH is the provision of quality primary healthcare (Mehta, 2012). Primary healthcare policies should be reviewed to identify the pitfalls contributing to high PAH rates among Indian immigrant children with asthma.
- HCPs should advocate for children by challenging and influencing asthma management policies in schools. As indicated in the current study, school policies regarding the management of childhood asthma were inadequately operationalised. Having clear policies based on Indian immigrant children’s needs, along with improved training for teachers, could ensure a greater level of collaboration between HCPs, school nurses, and family caregivers.

Education

- Cultural competency training for HCPs should be further developed to identify and address cultural diversity in mainstream healthcare in NZ.
- The theory of tug-of-war has already been disseminated through a variety of platforms, including in-service trainings, healthcare unions/associations, professional journals, conferences, schools, early childhood centres as well as community organisations and publications.
- Health care inequities may be attributed to disparities in the distribution of social determinants of health, power imbalances, biases, marginalisation, institutional racism, and unexamined privileges (Curtis et al., 2019). In addition to reviewing

and revising organisational policies and practices related to immigrant health, health professional education should address these factors in their curriculum.

- Culture brokers should be consulted when designing continuing nursing education programs aimed at improving culturally competent nursing practice for different CALD groups.

Summary

The purpose of this chapter was to revisit the research aim and summarise the new knowledge gained from this study. I have discussed the contents of each chapter in a systematic manner. The four publications in leading international journals reflect the new knowledge generated by my thesis. A list of limitations is included, along with recommendations for policy, practice, education, and research. Based on these recommendations, it is evident that significant work needs to be done to ensure high-quality asthma care for Indian immigrant children. My thesis also demonstrates how culture has a significant impact on people's health and illnesses. The study revealed significant challenges that Indian immigrants face in the management of childhood asthma, which appear at the individual, societal, provider, and system levels. A comprehensive intervention programme that incorporates both general strategies and cultural considerations is essential for effectively managing asthma in Indian immigrant children.

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Appendix A

Letter of Invitation to Organisations

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

LETTER OF INVITATION

Indu Sudarsan
PhD Candidate
School of Nursing
Massey University
Email id: Indu.Sudarsan.1@uni.massey.ac.nz

Date: dd/mm/yyyy

Subject: Research project about Indian immigrant children's and their families' beliefs, practices and experiences of living with asthma.

Hi,

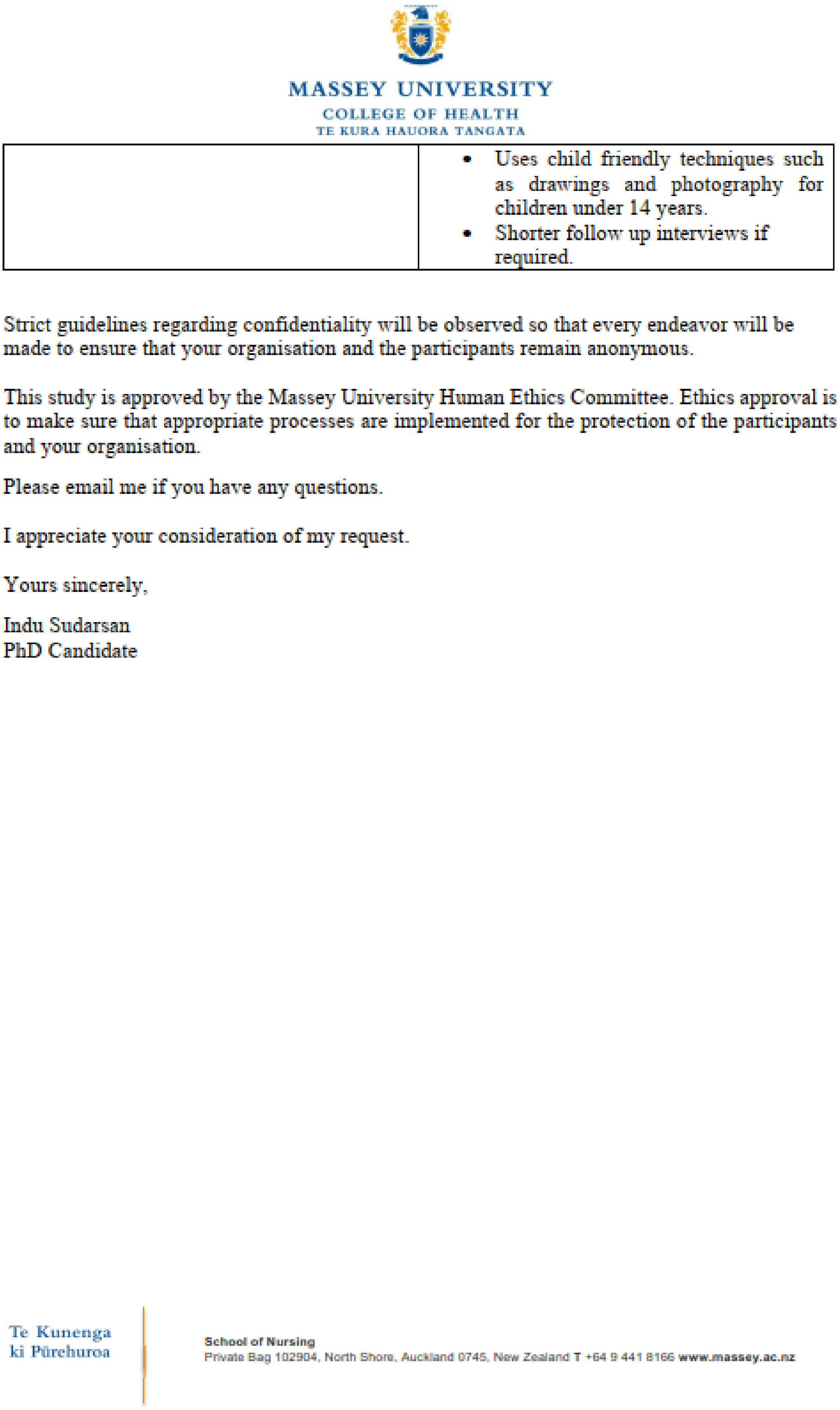
I am doing this research as a partial fulfilment for my PhD studies at Massey University under the supervision of Associate Professor Karen Hoare and Professor Nicolette Sheridan.

The study I am undertaking is around Indian immigrant children's asthma. Asthma is one of the most common diseases among Indian immigrant children living in New Zealand. Anecdotal reports say that Indian people approach asthma in a unique way and have several beliefs and practices towards asthma. There is no published research that portrays viewpoints of Indian immigrant children on their thoughts, feelings and experiences of asthma. Also, not much is known about carers' perspectives around their children's asthma. Understanding the views of Indian children and their carers is important to guide information about asthma management. The purpose of this study is to gain understanding of the beliefs, practices and experiences of asthma for Indian immigrant children and their carers. This will help health professionals in their care of Indian immigrant children with asthma.

As a part of this study, I intend to interview a wide range of Indian immigrant children (8-17 years old) with asthma and their family carers. I am planning to recruit children through multiple channels such as general practices and schools from selected suburbs of Wellington and through various Indian cultural associations. I know that your practice center may have participants who may be eligible for the study. I have enclosed the flyers, participant information sheets, assent and consent forms for your kind reference. If you are interested, please let me know so that I can give you more details about the study. I would be much grateful to you if you can contact potential participants or their family carers to see if they want to be a part of the study. If they are keen to take part, I can contact them to explain more about the study.

What is involved?

A face to face interview with the family carer	*A face to face interview with the child*
• May take up to 1 hour • Shorter follow up telephone interviews if required.	• Half an hour and maximum up to one hour if the child is talkative.



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

	• Uses child friendly techniques such as drawings and photography for children under 14 years. • Shorter follow up interviews if required.

Strict guidelines regarding confidentiality will be observed so that every endeavor will be made to ensure that your organisation and the participants remain anonymous.

This study is approved by the Massey University Human Ethics Committee. Ethics approval is to make sure that appropriate processes are implemented for the protection of the participants and your organisation.

Please email me if you have any questions.

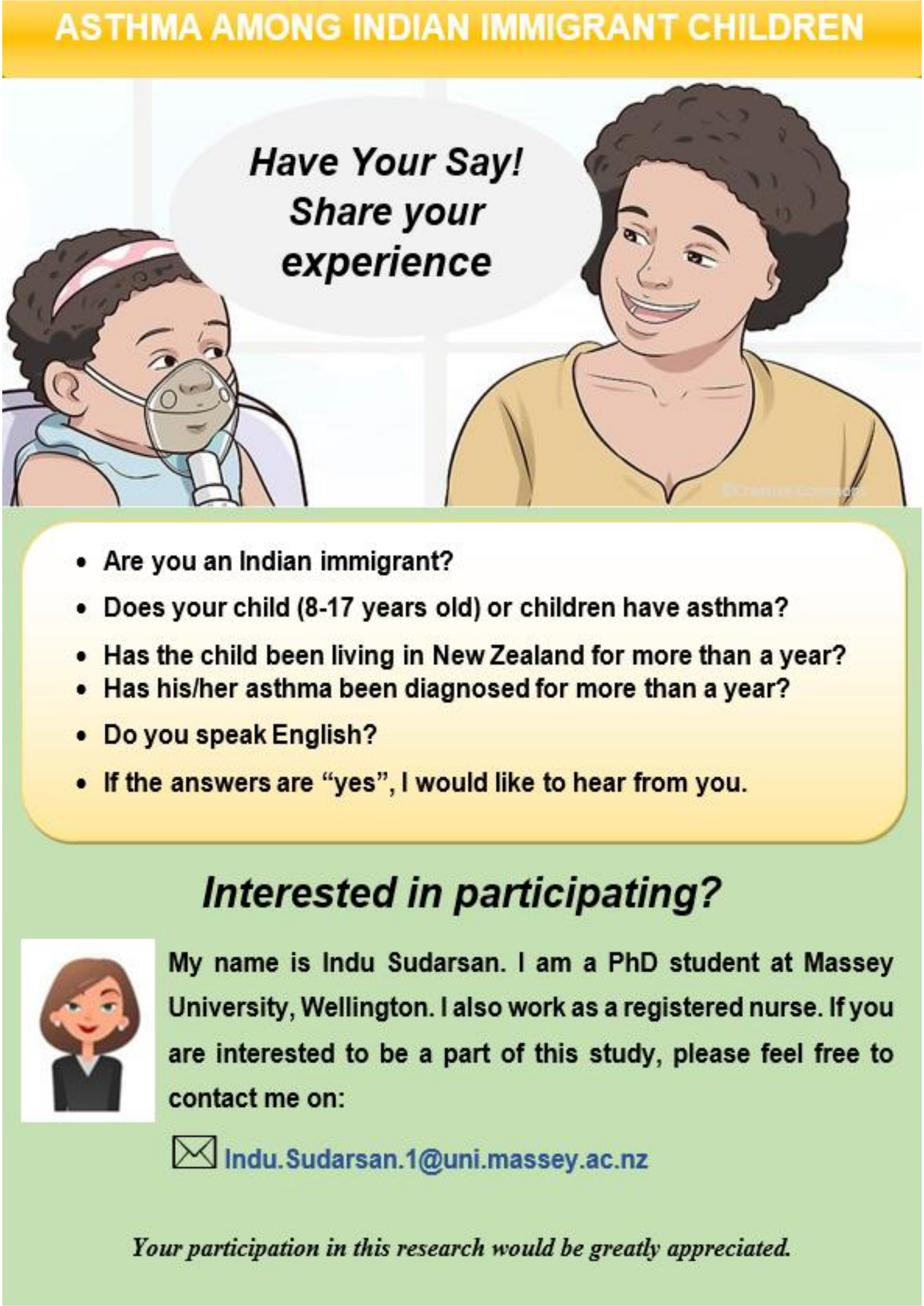
I appreciate your consideration of my request.

Yours sincerely,

Indu Sudarsan
PhD Candidate

Appendix B

Research Recruitment Flyer



ASTHMA AMONG INDIAN IMMIGRANT CHILDREN

Have Your Say!
Share your
experience

- Are you an Indian immigrant?
- Does your child (8-17 years old) or children have asthma?
- Has the child been living in New Zealand for more than a year?
- Has his/her asthma been diagnosed for more than a year?
- Do you speak English?
- If the answers are "yes", I would like to hear from you.

Interested in participating?

My name is Indu Sudarsan. I am a PhD student at Massey University, Wellington. I also work as a registered nurse. If you are interested to be a part of this study, please feel free to contact me on:

✉ Indu.Sudarsan.1@uni.massey.ac.nz

Your participation in this research would be greatly appreciated.

Appendix C

Ethics Approval

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Date: 11 December 2019

Dear Indu Sudarsan

Re: Ethics Notification - **NOR 19/62 - Indian immigrant children's and their families' beliefs, practices and experiences of living with asthma in New Zealand: A grounded theory study.**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Northern Committee** at their meeting held on **Wednesday, 11 December,**

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

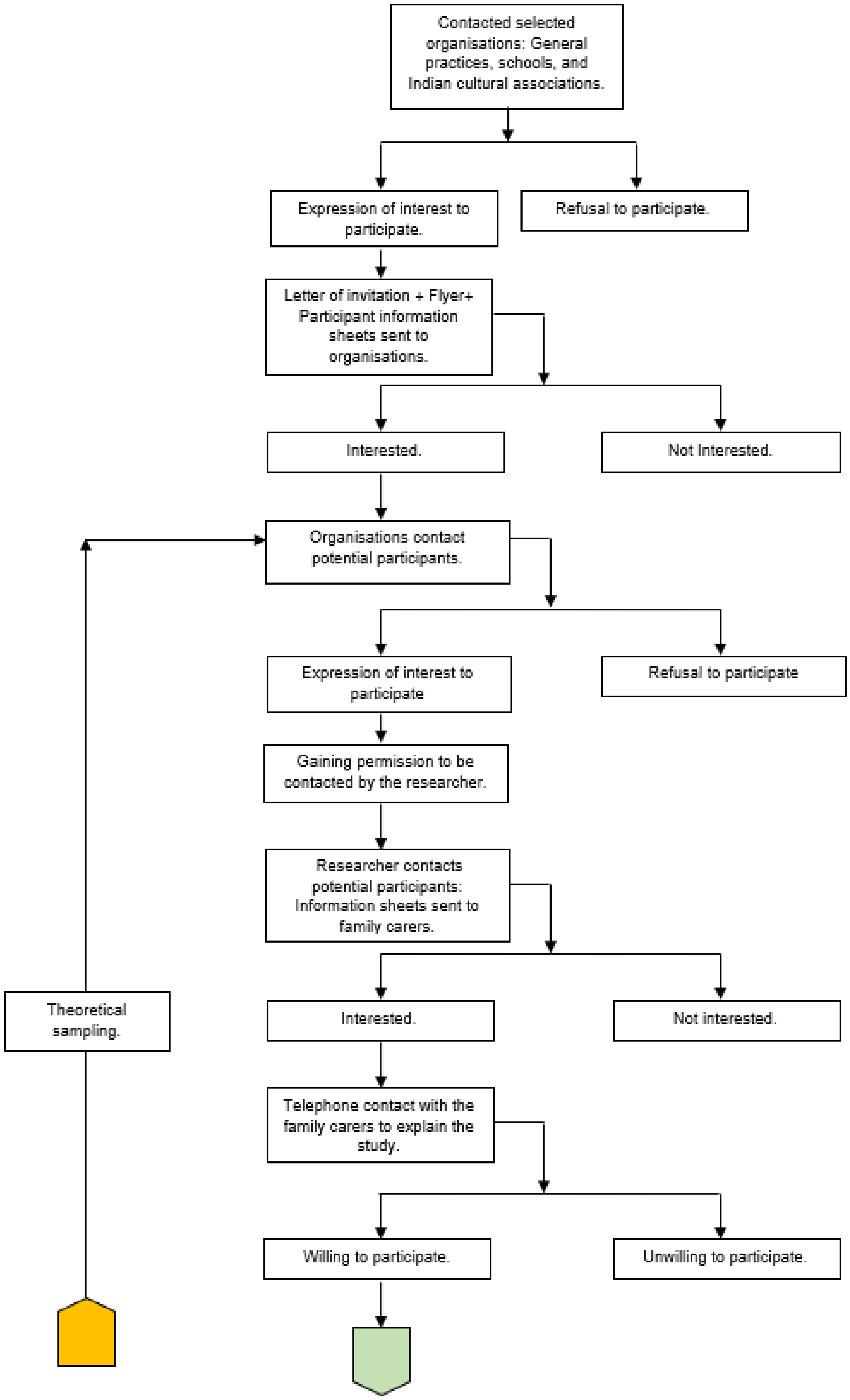
Yours sincerely

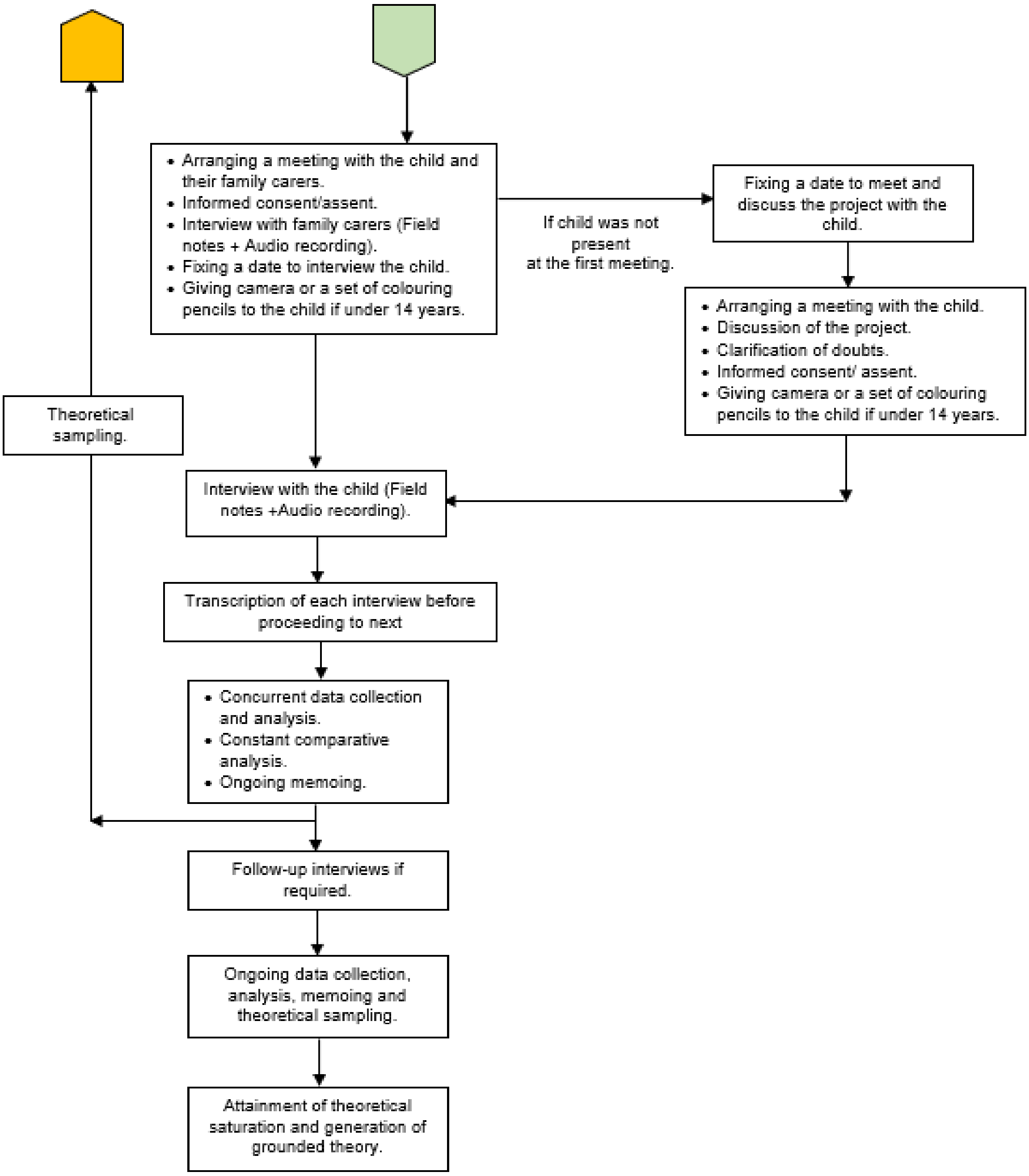
Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand **T** 06 350 5573; 06 350 5575 **F** 06 355 7973
E humanethics@massey.ac.nz **W** http://humanethics.massey.ac.nz

Appendix D

Recruitment, Data Collection and Data Analysis Flow Chart




• Arranging a meeting with the child and their family carers.
• Informed consent/assent.
• Interview with family carers (Field notes + Audio recording).
• Fixing a date to interview the child.
• Giving camera or a set of colouring pencils to the child if under 14 years.
If child was not present at the first meeting.
Fixing a date to meet and discuss the project with the child.
• Arranging a meeting with the child.
• Discussion of the project.
• Clarification of doubts.
• Informed consent/ assent.
• Giving camera or a set of colouring pencils to the child if under 14 years.
Theoretical sampling.
Interview with the child (Field notes +Audio recording).
Transcription of each interview before proceeding to next
• Concurrent data collection and analysis.
• Constant comparative analysis.
• Ongoing memoing.
Follow-up interviews if required.
Ongoing data collection, analysis, memoing and theoretical sampling.
Attainment of theoretical saturation and generation of grounded theory.

Appendix E

Child Assent Form

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

CHILD ASSENT FORM

RESEARCH TITLE: Indian immigrant children's and their families' beliefs, practices, and experiences of living with asthma in New Zealand

Student researcher:	Supervisors	
Indu Sudarsan	A/Prof Karen Hoare	Prof Nicolette Sheridan
Indu.Sudarsan.1@uni.massey.ac.nz	K.J.Hoare@massey.ac.nz	N.Sheridan@massey.ac.nz

I have read the Participant Information Sheet, have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I agree to take part in this research.
- I understand that I am free to withdraw participation at any time
- I agree / do not agree to be audiotaped.
- I wish / do not wish to receive the summary of findings.
- I understand that data will be kept for 6 years, after which they will be destroyed.

Name ________________________________

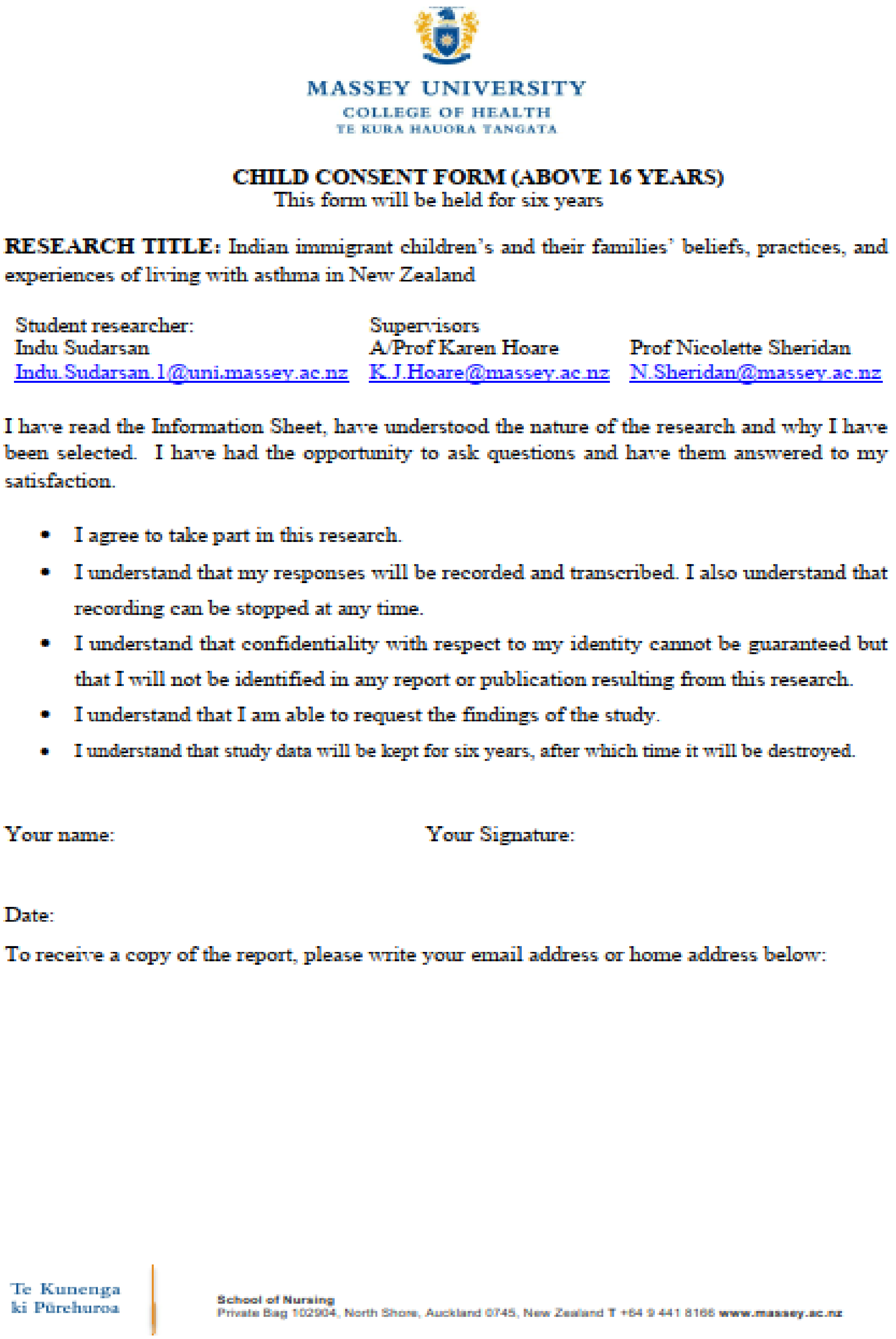
Signature ________________________________ Date ____________________

Te Kunenga
ki Pūrehuroa

School of Nursing
Private Bag 102904, North Shore, Auckland 0745, New Zealand T +64 9 441 8166 www.massey.ac.nz

Appendix F

Child Consent Form for Children Above 16 Years



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

CHILD CONSENT FORM (ABOVE 16 YEARS)
This form will be held for six years

RESEARCH TITLE: Indian immigrant children's and their families' beliefs, practices, and experiences of living with asthma in New Zealand

Student researcher:	Supervisors	
Indu Sudarsan	A/Prof Karen Hoare	Prof Nicolette Sheridan
Indu.Sudarsan.1@uni.massey.ac.nz	K.J.Hoare@massey.ac.nz	N.Sheridan@massey.ac.nz

I have read the Information Sheet, have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I agree to take part in this research.
- I understand that my responses will be recorded and transcribed. I also understand that recording can be stopped at any time.
- I understand that confidentiality with respect to my identity cannot be guaranteed but that I will not be identified in any report or publication resulting from this research.
- I understand that I am able to request the findings of the study.
- I understand that study data will be kept for six years, after which time it will be destroyed.

Your name: Your Signature:

Date:

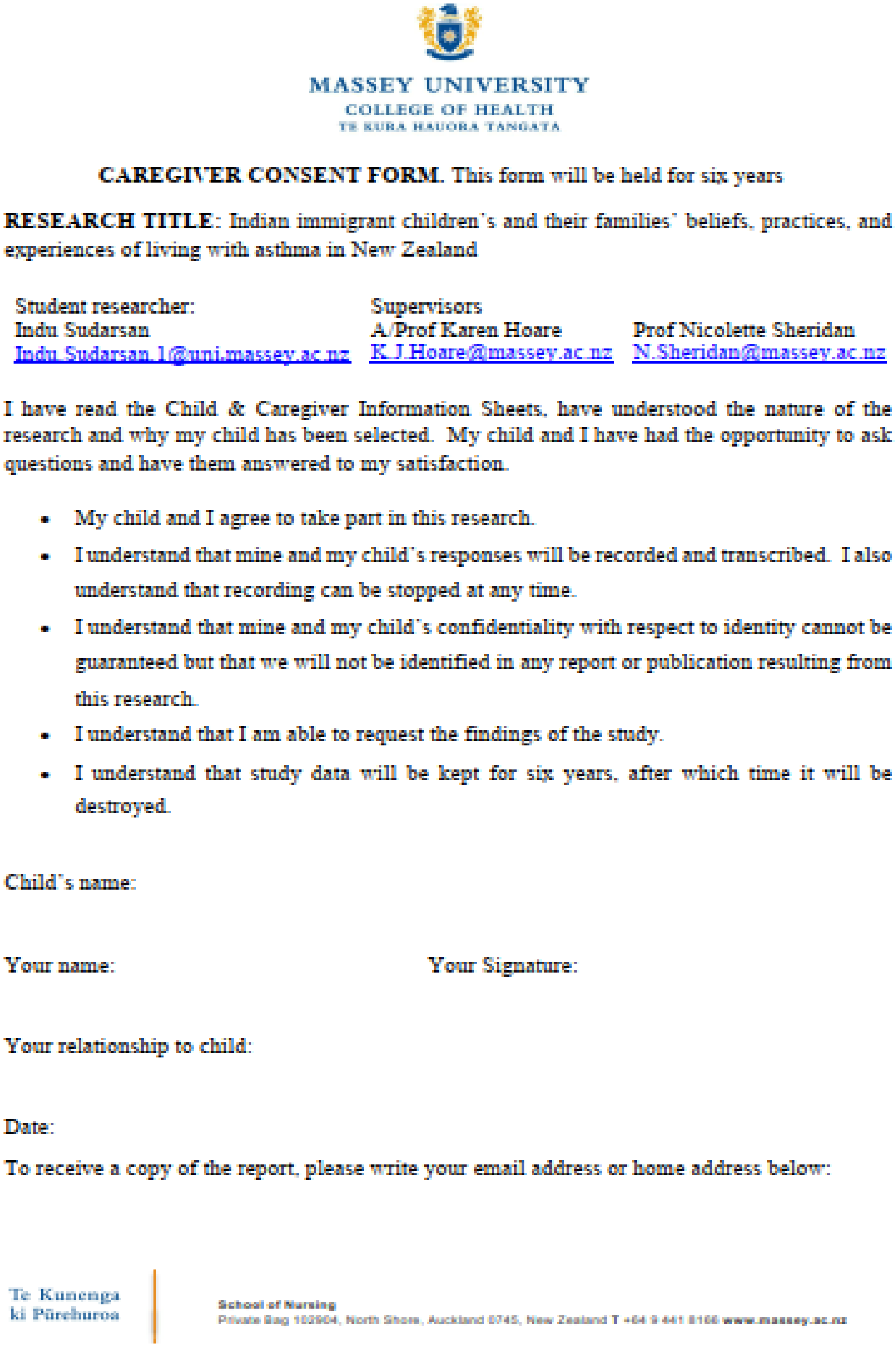
To receive a copy of the report, please write your email address or home address below:

Te Kunenga
ki Pūrehuroa

School of Nursing
Private Bag 102904, North Shore, Auckland 0745, New Zealand T +64 9 441 8166 www.massey.ac.nz

Appendix G

Care Giver Consent Form



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

CAREGIVER CONSENT FORM. This form will be held for six years

RESEARCH TITLE: Indian immigrant children's and their families' beliefs, practices, and experiences of living with asthma in New Zealand

Student researcher:	Supervisors	
Indu Sudarsan	A/Prof Karen Hoare	Prof Nicolette Sheridan
Indu.Sudarsan.1@uni.massey.ac.nz	K.J.Hoare@massey.ac.nz	N.Sheridan@massey.ac.nz

I have read the Child & Caregiver Information Sheets, have understood the nature of the research and why my child has been selected. My child and I have had the opportunity to ask questions and have them answered to my satisfaction.

- My child and I agree to take part in this research.
- I understand that mine and my child's responses will be recorded and transcribed. I also understand that recording can be stopped at any time.
- I understand that mine and my child's confidentiality with respect to identity cannot be guaranteed but that we will not be identified in any report or publication resulting from this research.
- I understand that I am able to request the findings of the study.
- I understand that study data will be kept for six years, after which time it will be destroyed.

Child's name:

Your name: Your Signature:

Your relationship to child:

Date:

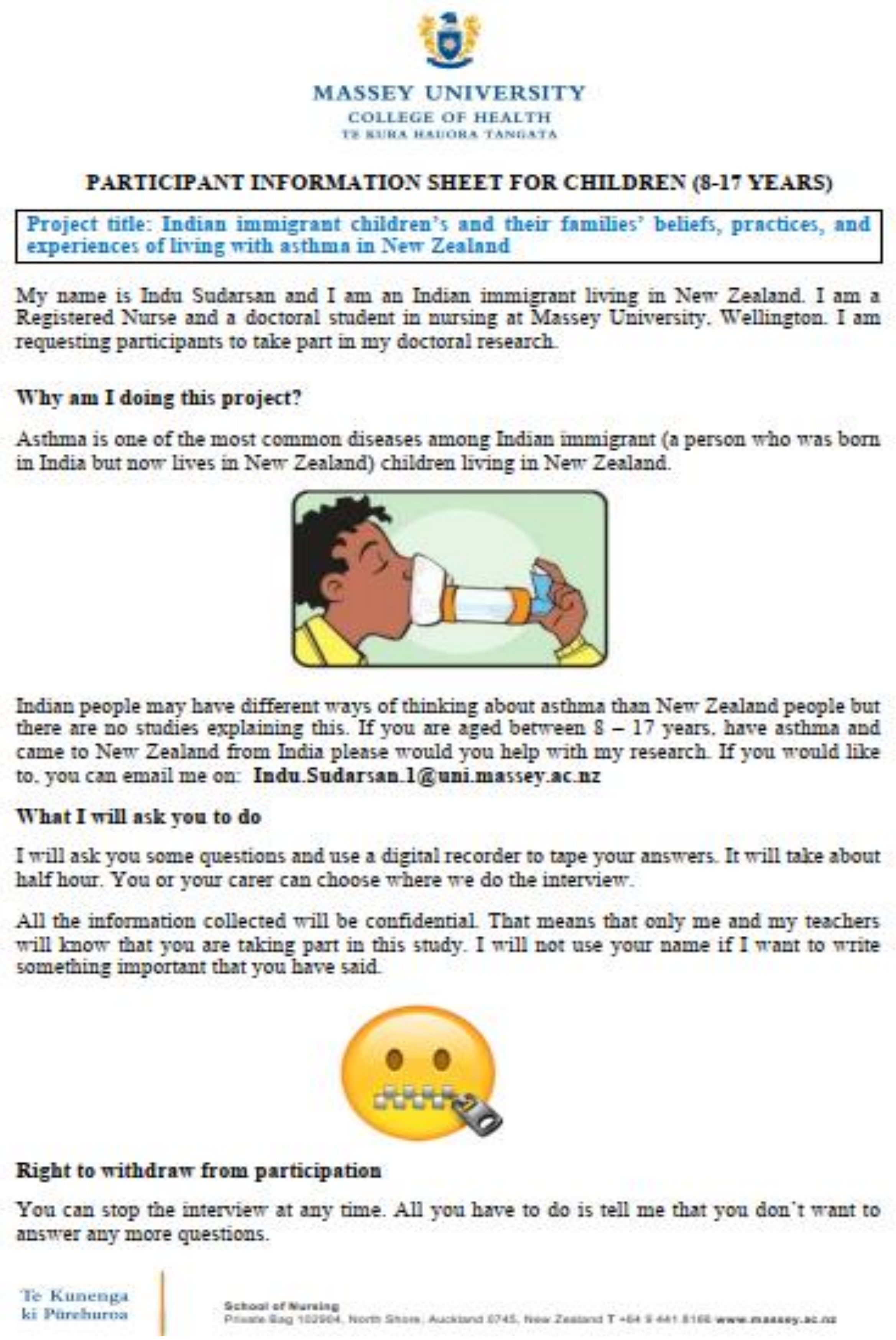
To receive a copy of the report, please write your email address or home address below:

Te Kunenga ki Pūrehuroa

School of Nursing
Private Bag 102904, North Shore, Auckland 0745, New Zealand T +64 9 441 8166 www.massey.ac.nz

Appendix H

Participant Information Sheet for Children



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

PARTICIPANT INFORMATION SHEET FOR CHILDREN (8-17 YEARS)

Project title: Indian immigrant children's and their families' beliefs, practices, and experiences of living with asthma in New Zealand

My name is Indu Sudarsan and I am an Indian immigrant living in New Zealand. I am a Registered Nurse and a doctoral student in nursing at Massey University, Wellington. I am requesting participants to take part in my doctoral research.

Why am I doing this project?

Asthma is one of the most common diseases among Indian immigrant (a person who was born in India but now lives in New Zealand) children living in New Zealand.

Indian people may have different ways of thinking about asthma than New Zealand people but there are no studies explaining this. If you are aged between 8 – 17 years, have asthma and came to New Zealand from India please would you help with my research. If you would like to, you can email me on: **Indu.Sudarsan.1@uni.massey.ac.nz**

What I will ask you to do

I will ask you some questions and use a digital recorder to tape your answers. It will take about half hour. You or your carer can choose where we do the interview.

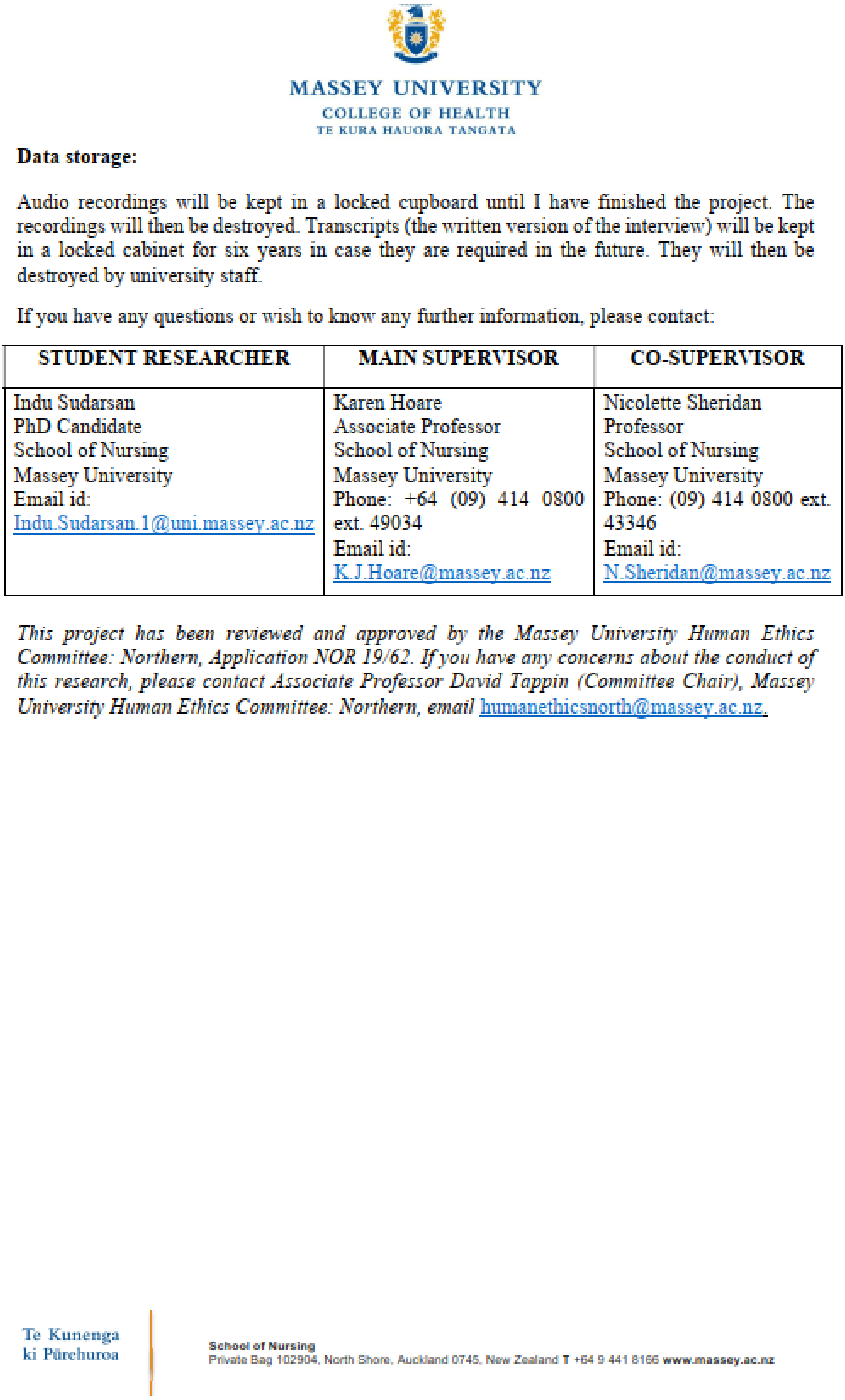
All the information collected will be confidential. That means that only me and my teachers will know that you are taking part in this study. I will not use your name if I want to write something important that you have said.

Right to withdraw from participation

You can stop the interview at any time. All you have to do is tell me that you don't want to answer any more questions.

Te Kunenga
ki Pūrehuroa

School of Nursing
Private Bag 102904, North Shore, Auckland 0745, New Zealand T +64 9 441 8166 www.massey.ac.nz



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Data storage:

Audio recordings will be kept in a locked cupboard until I have finished the project. The recordings will then be destroyed. Transcripts (the written version of the interview) will be kept in a locked cabinet for six years in case they are required in the future. They will then be destroyed by university staff.

If you have any questions or wish to know any further information, please contact:

STUDENT RESEARCHER	MAIN SUPERVISOR	CO-SUPERVISOR
Indu Sudarsan PhD Candidate School of Nursing Massey University Email id: Indu.Sudarsan.1@uni.massey.ac.nz	Karen Hoare Associate Professor School of Nursing Massey University Phone: +64 (09) 414 0800 ext. 49034 Email id: K.J.Hoare@massey.ac.nz	Nicolette Sheridan Professor School of Nursing Massey University Phone: (09) 414 0800 ext. 43346 Email id: N.Sheridan@massey.ac.nz

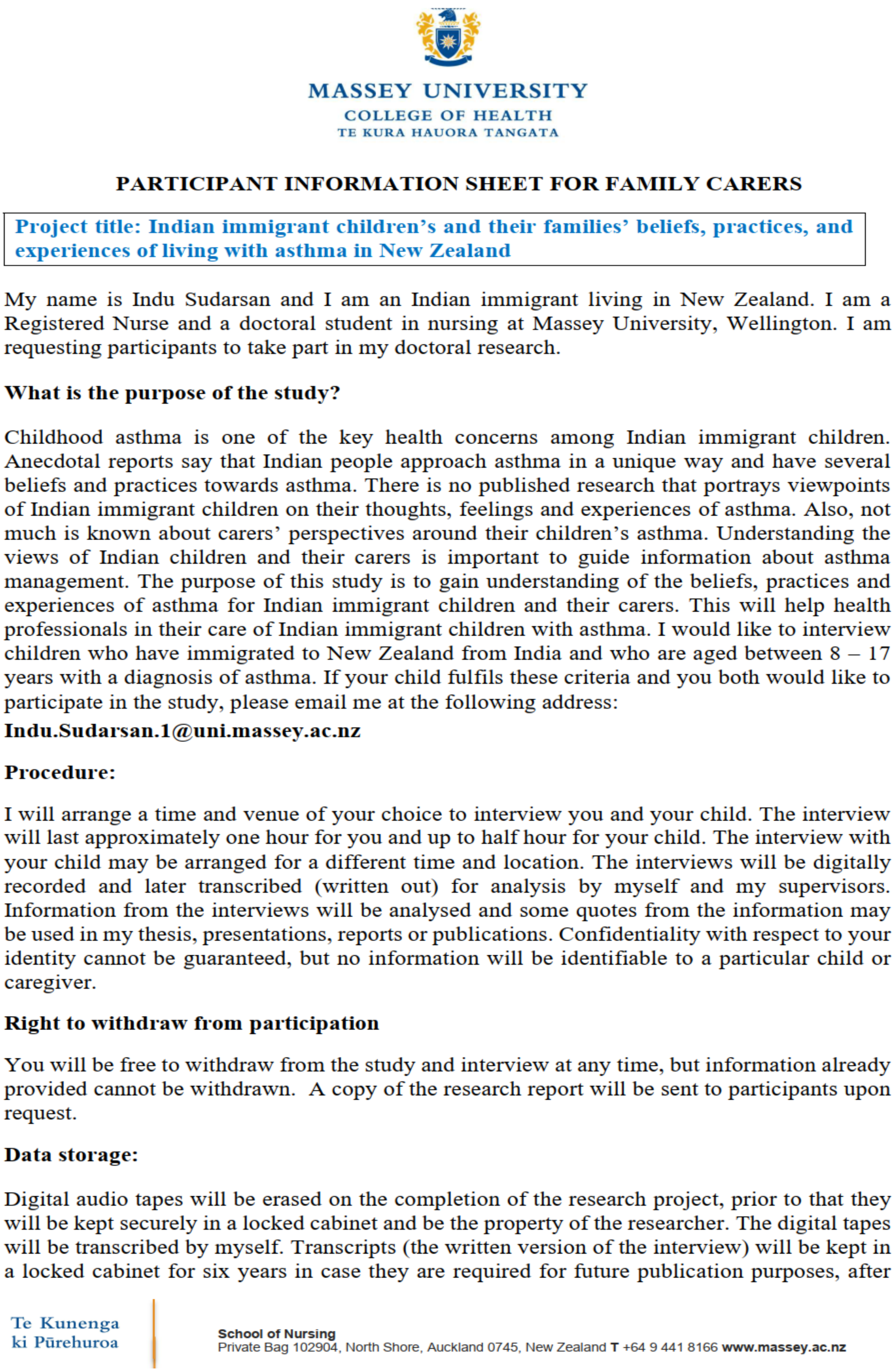
This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 19/62. If you have any concerns about the conduct of this research, please contact Associate Professor David Tappin (Committee Chair), Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz.

Te Kunenga
ki Pūrehuroa

School of Nursing
Private Bag 102904, North Shore, Auckland 0745, New Zealand **T** +64 9 441 8166 **www.massey.ac.nz**

Appendix I

Participant Information Sheet for Family Carers



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

PARTICIPANT INFORMATION SHEET FOR FAMILY CARERS

Project title: Indian immigrant children's and their families' beliefs, practices, and experiences of living with asthma in New Zealand

My name is Indu Sudarsan and I am an Indian immigrant living in New Zealand. I am a Registered Nurse and a doctoral student in nursing at Massey University, Wellington. I am requesting participants to take part in my doctoral research.

What is the purpose of the study?

Childhood asthma is one of the key health concerns among Indian immigrant children. Anecdotal reports say that Indian people approach asthma in a unique way and have several beliefs and practices towards asthma. There is no published research that portrays viewpoints of Indian immigrant children on their thoughts, feelings and experiences of asthma. Also, not much is known about carers' perspectives around their children's asthma. Understanding the views of Indian children and their carers is important to guide information about asthma management. The purpose of this study is to gain understanding of the beliefs, practices and experiences of asthma for Indian immigrant children and their carers. This will help health professionals in their care of Indian immigrant children with asthma. I would like to interview children who have immigrated to New Zealand from India and who are aged between 8 – 17 years with a diagnosis of asthma. If your child fulfils these criteria and you both would like to participate in the study, please email me at the following address:
Indu.Sudarsan.1@uni.massey.ac.nz

Procedure:

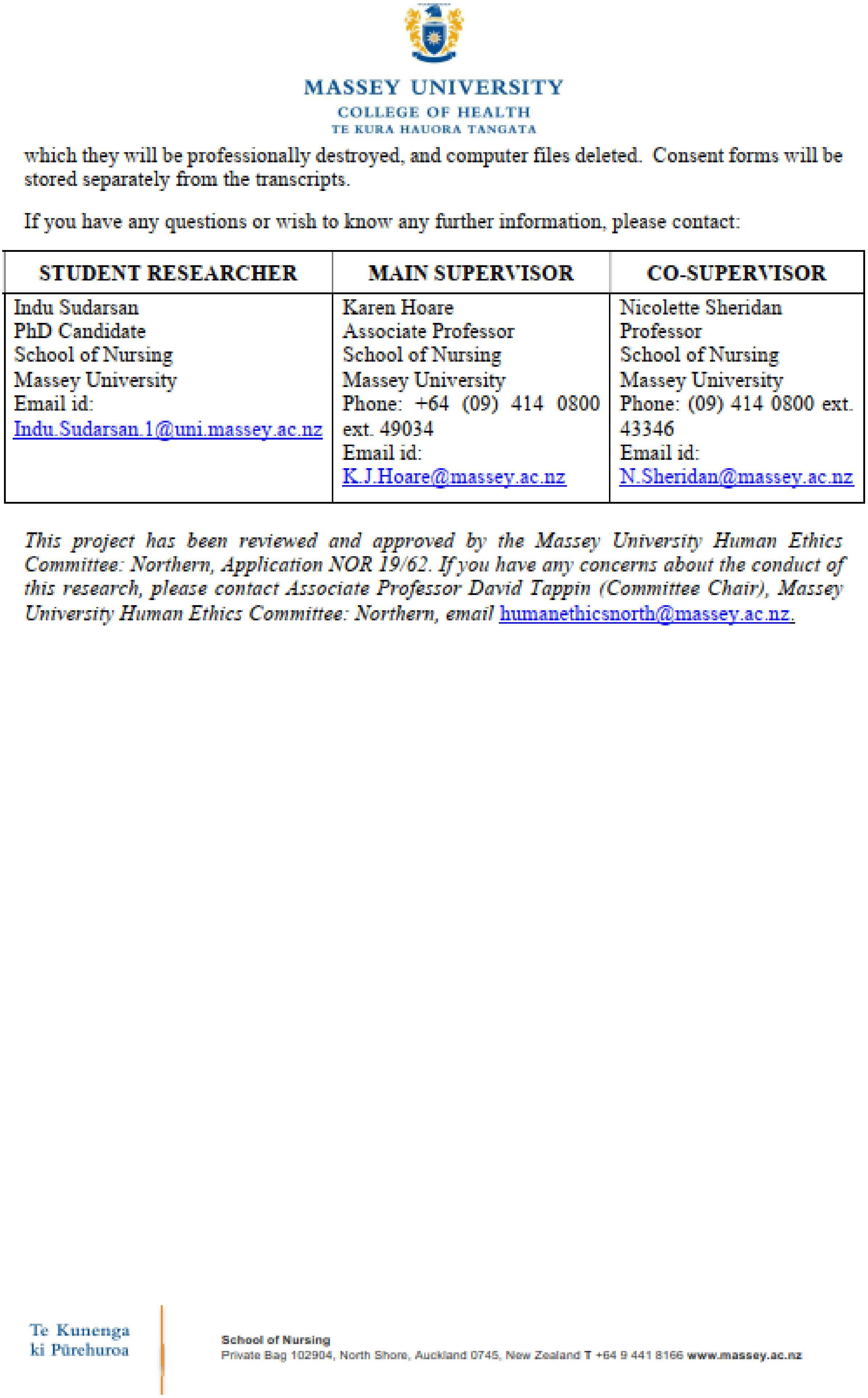
I will arrange a time and venue of your choice to interview you and your child. The interview will last approximately one hour for you and up to half hour for your child. The interview with your child may be arranged for a different time and location. The interviews will be digitally recorded and later transcribed (written out) for analysis by myself and my supervisors. Information from the interviews will be analysed and some quotes from the information may be used in my thesis, presentations, reports or publications. Confidentiality with respect to your identity cannot be guaranteed, but no information will be identifiable to a particular child or caregiver.

Right to withdraw from participation

You will be free to withdraw from the study and interview at any time, but information already provided cannot be withdrawn. A copy of the research report will be sent to participants upon request.

Data storage:

Digital audio tapes will be erased on the completion of the research project, prior to that they will be kept securely in a locked cabinet and be the property of the researcher. The digital tapes will be transcribed by myself. Transcripts (the written version of the interview) will be kept in a locked cabinet for six years in case they are required for future publication purposes, after



MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

which they will be professionally destroyed, and computer files deleted. Consent forms will be stored separately from the transcripts.

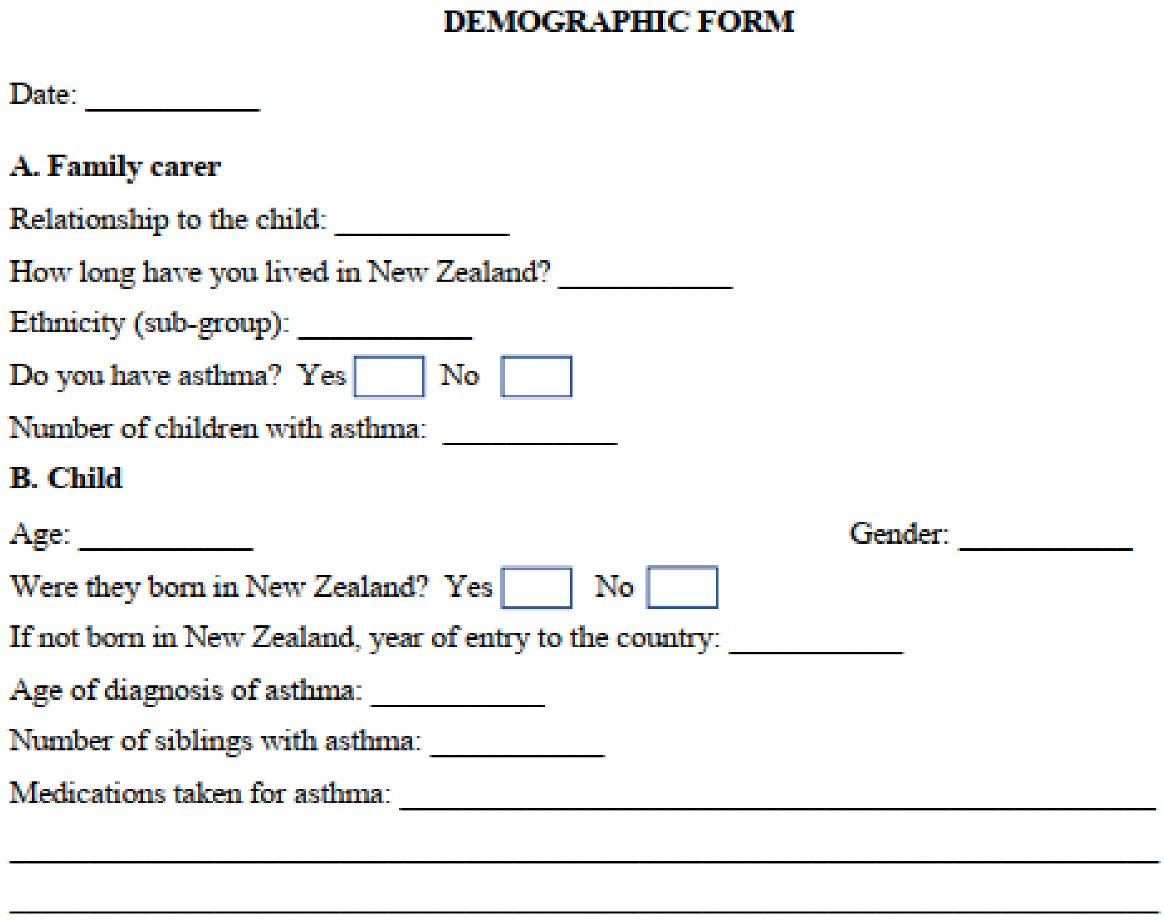
If you have any questions or wish to know any further information, please contact:

STUDENT RESEARCHER	MAIN SUPERVISOR	CO-SUPERVISOR
Indu Sudarsan PhD Candidate School of Nursing Massey University Email id: Indu.Sudarsan.1@uni.massey.ac.nz	Karen Hoare Associate Professor School of Nursing Massey University Phone: +64 (09) 414 0800 ext. 49034 Email id: K.J.Hoare@massey.ac.nz	Nicolette Sheridan Professor School of Nursing Massey University Phone: (09) 414 0800 ext. 43346 Email id: N.Sheridan@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 19/62. If you have any concerns about the conduct of this research, please contact Associate Professor David Tappin (Committee Chair), Massey University Human Ethics Committee: Northern, email humanethicsnorth@massey.ac.nz.

Appendix J

Demographic Form



DEMOGRAPHIC FORM

Date: ___________

A. Family carer

Relationship to the child: ___________

How long have you lived in New Zealand? ___________

Ethnicity (sub-group): ___________

Do you have asthma? Yes ☐ No ☐

Number of children with asthma: ___________

B. Child

Age: ___________ Gender: ___________

Were they born in New Zealand? Yes ☐ No ☐

If not born in New Zealand, year of entry to the country: ___________

Age of diagnosis of asthma: ___________

Number of siblings with asthma: ___________

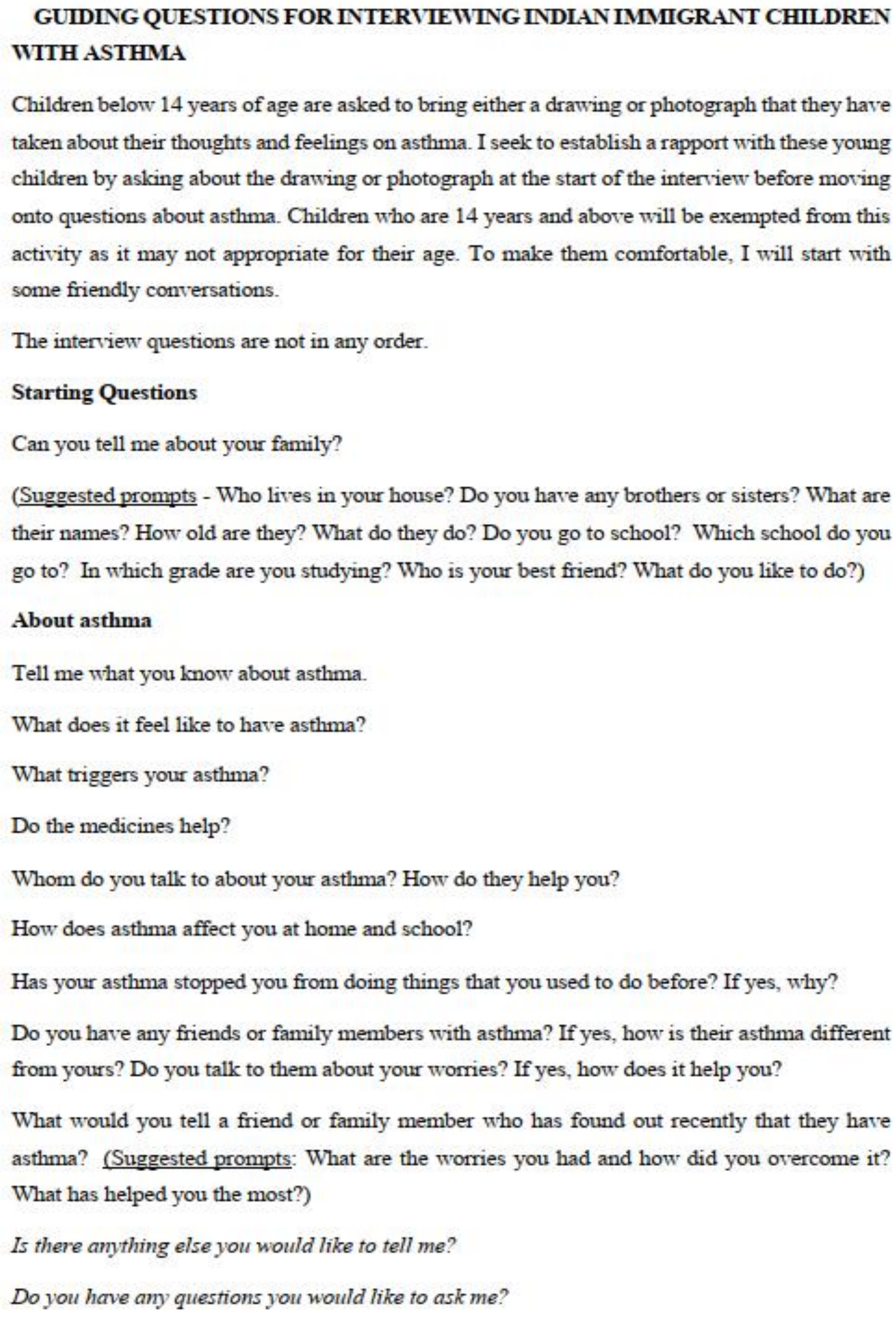
Medications taken for asthma: ____

____

____

Appendix K

Child Interview Guide



GUIDING QUESTIONS FOR INTERVIEWING INDIAN IMMIGRANT CHILDREN WITH ASTHMA

Children below 14 years of age are asked to bring either a drawing or photograph that they have taken about their thoughts and feelings on asthma. I seek to establish a rapport with these young children by asking about the drawing or photograph at the start of the interview before moving onto questions about asthma. Children who are 14 years and above will be exempted from this activity as it may not appropriate for their age. To make them comfortable, I will start with some friendly conversations.

The interview questions are not in any order.

Starting Questions

Can you tell me about your family?

(Suggested prompts - Who lives in your house? Do you have any brothers or sisters? What are their names? How old are they? What do they do? Do you go to school? Which school do you go to? In which grade are you studying? Who is your best friend? What do you like to do?)

About asthma

Tell me what you know about asthma.

What does it feel like to have asthma?

What triggers your asthma?

Do the medicines help?

Whom do you talk to about your asthma? How do they help you?

How does asthma affect you at home and school?

Has your asthma stopped you from doing things that you used to do before? If yes, why?

Do you have any friends or family members with asthma? If yes, how is their asthma different from yours? Do you talk to them about your worries? If yes, how does it help you?

What would you tell a friend or family member who has found out recently that they have asthma? (Suggested prompts: What are the worries you had and how did you overcome it? What has helped you the most?)

Is there anything else you would like to tell me?

Do you have any questions you would like to ask me?

Appendix L

Caregiver Interview Guide

GUIDING QUESTIONS FOR INTERVIEWING FAMILY CARE GIVERS OF INDIAN IMMIGRANT CHILDREN WITH ASTHMA

Starting Questions

Can you tell me about yourself and your family? How long have you been living in New Zealand? Why did you choose to migrate to New Zealand? How do you find your life in New Zealand compared to India?

About asthma

1. Your meaning of asthma

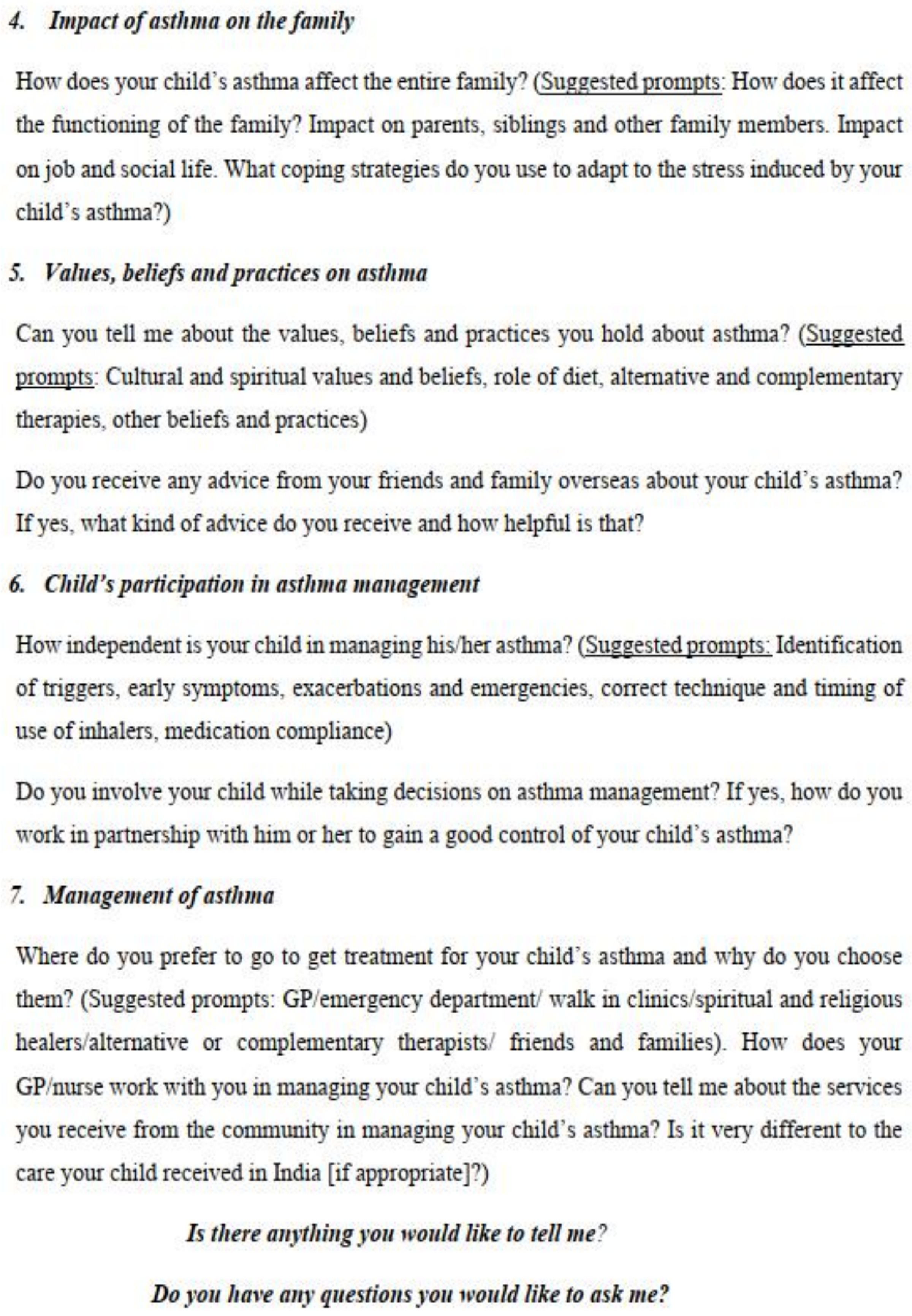
In the time that you have been caring for your child, what have you found out about asthma? (Suggested prompts: What does asthma mean to you? What do you think that the causes and triggers are? What are the symptoms you commonly come across and what are your thoughts on its management? Can you tell me about the services that you know of that exist in the community for children with asthma?).

2. History of child's asthma

Can you talk to me about your child's asthma? (Suggested prompts: Can you briefly tell me about the time when you first had concerns, from the time just before your child was diagnosed? What symptoms did he or she start with? What do you think that the cause was? How did you address your earliest concerns? Was there any delay in diagnosing the disease? How did you feel when your child received the diagnosis of asthma? How did you meet your information needs at that time? How did your family and friends react to it? What support did you receive from your family, friends and health professionals at that time? How is your child's asthma now? How has it progressed? How do you manage the symptoms now? What support currently do you receive from your family, friends and health professionals in terms of your child's asthma?).

3. Impact of asthma on the child

How does asthma affect [name]? (Suggested prompts: Physical and psychological impact, at school [impact on studies, sports, relationship with peers], good days and bad days, support he or she receives, coping strategies used).



4. Impact of asthma on the family

How does your child's asthma affect the entire family? (Suggested prompts: How does it affect the functioning of the family? Impact on parents, siblings and other family members. Impact on job and social life. What coping strategies do you use to adapt to the stress induced by your child's asthma?)

5. Values, beliefs and practices on asthma

Can you tell me about the values, beliefs and practices you hold about asthma? (Suggested prompts: Cultural and spiritual values and beliefs, role of diet, alternative and complementary therapies, other beliefs and practices)

Do you receive any advice from your friends and family overseas about your child's asthma? If yes, what kind of advice do you receive and how helpful is that?

6. Child's participation in asthma management

How independent is your child in managing his/her asthma? (Suggested prompts: Identification of triggers, early symptoms, exacerbations and emergencies, correct technique and timing of use of inhalers, medication compliance)

Do you involve your child while taking decisions on asthma management? If yes, how do you work in partnership with him or her to gain a good control of your child's asthma?

7. Management of asthma

Where do you prefer to go to get treatment for your child's asthma and why do you choose them? (Suggested prompts: GP/emergency department/ walk in clinics/spiritual and religious healers/alternative or complementary therapists/ friends and families). How does your GP/nurse work with you in managing your child's asthma? Can you tell me about the services you receive from the community in managing your child's asthma? Is it very different to the care your child received in India [if appropriate]?)

Is there anything you would like to tell me?

Do you have any questions you would like to ask me?

Appendix M

Critical Search Terms and the Expanded Terms

The Searched Term	The Expanded Terms
chronic*	asthma* OR wheez* OR resp* OR eczema* OR cancer* OR diabetes* OR autism* OR development* OR congenital* OR illness* OR sickness* OR health* OR "long term*"
"South Asia*"	India* OR Pakistan* OR Bangladesh* OR Punjab* OR Gujarat*
child*	pediatric* OR paediatric* OR adolesc* OR teen* OR "young adult*"
migrant*	immigrant*
"care giver*"	carer* OR caregiver* OR parent* OR famil*

Appendix N

List of Full Text Screened Articles

Sl No	Article title	Author(s)/year/ country	Decision	Explanation	Source
1	Beliefs and practices regarding autism in Indian families now settled abroad: An internet survey	Ravindran and Myers/ 2012/USA	Included	The internet survey examined the beliefs and practices of 24 immigrant parents (from USA, Canada and Kuwait) having a child with autism	Database searching
2	The experiences of British South Asian carers caring for a child with developmental disabilities in the UK	Heer et al/2015/UK	Included	The qualitative study explored the experiences of seven British South Asian parents (five mothers and two fathers) caring for a child with developmental disabilities using interpretative phenomenological analysis	Database searching
3	Childhood cancer-parenting work for British Bangladeshi families during treatment: An ethnographic study	Kelly and Kelly/2012/UK	Included	The ethnographic study detailed the day-to-day management experiences (including the social and cultural aspects) of cancer treatment for British Bangladeshi children and their parents.	Database searching
4	Family-centred care: a qualitative study of Chinese and South Asian immigrant parents' experiences of care in paediatric	Watt et al/2012/Canada	Excluded	The constructivist grounded theory study described Chinese and South Asian immigrant parents' experiences of family centred care in paediatric oncology settings in Canada.	Database searching

	oncology			*Findings specific to SA immigrant parents could not be extracted.*	
5	Immigrant to Canada, newcomer to childhood cancer: A qualitative study of challenges faced by immigrant parents	Klassen et al/2012/Canada	Excluded	The constructivist grounded theory study explored any special challenges faced by Chinese and South Asian immigrant parents of children with cancer and to identify supportive factors. *Findings specific to SA immigrant parents could not be extracted.*	Database searching
6	Communication and language challenges experienced by Chinese and South Asian immigrant parents of children with cancer in Canada: Implications for Health Services Delivery	Gulati et al/2012/Canada	Excluded	The constructivist grounded theory study explored the role of communication and language in the healthcare experiences of immigrant parents of children with cancer living in Canada. *Findings specific to SA immigrant parents could not be extracted.*	Database searching
7	Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child.	Croot et al/2012/UK	Included	The qualitative study explored the coping strategies of Pakistani parents living in the UK and caring for children with severe learning disabilities. It examined factors that influenced	Database searching

				participants’ choice or ability to use the different strategies.	
8	Parenting children with intellectual and developmental disabilities in Asian Indian Families in the United States	Zechella & Raval/2016/USA	Included	The qualitative study described unique experiences and challenges of Asian Indian immigrant parents (15 Asian Indian parents (8 mothers, 7 fathers)) of children with intellectual and developmental disabilities in USA.	Database searching
9	Indian immigrant parents of children with developmental disabilities: stressors and support systems	John et al/2016/USA	Included	The study examined the stressors and perceived quality of social support among Indian immigrant families of children and adolescents with a developmental disability in the USA.	Database searching
10	Pakistani mothers’ experiences of parenting a child with autism spectrum disorder (ASD) in Ireland	Habib et al/2017/Ireland	Included	The qualitative study used a constructivist interpretative paradigm and a culturally sensitive approach to explore the parental experiences of Pakistani mothers (n=7) living in Ireland who have a child with autism spectrum disorder (ASD)	Database searching
11	Perceptions of disability among south Asian immigrant mothers of children with disabilities in Canada: implications for	Daudji et al/2011/Canada	Included	The descriptive qualitative study described perceptions of disability among South Asian immigrant mothers (n=5) of children with disabilities in a large multicultural urban centre in	Database searching

	rehabilitation service delivery			Ontario, Canada, and explored how these perceptions influence rehabilitation services.	
12	Cultural beliefs and coping strategies related to childhood cancer: The perceptions of South Asian immigrant parents in Canada	Banerjee et al/2011/Canada	Excluded	The constructivist grounded theory study aimed to describe cultural beliefs and coping strategies related to dealing with childhood cancer identified through a qualitative study of the caregiving experiences of first-generation South Asian immigrant parents of children with cancer. *Secondary data analysis*	Database searching
13	Understanding the experiences of South Asian parents who have a child with autism	Theara & Abbott/2015/UK	Included	The grounded theory study investigated the experiences of South Asian parents (Nine parents, five mothers, two sets of mothers and fathers) living in the UK who have a child with autism.	Reference tracking
14	The cultural context of caregiving: qualitative accounts from South Asian parents who care for a child with intellectual disabilities in the UK	Heer et al/2012/UK	Included	Through a hermeneutic and phenomenological approach, study set out to develop a culturally sensitive account of Sikh and Muslim parents' experiences of caring for a child with intellectual disabilities.	Reference tracking

15	Pakistani children’s experiences of growing up with Beta-Thalassemia Major	Mufti et al/2015/UK	Included	Through Interpretive phenomenological analytic approach, the study provided a rich account of children’s experiences of living with β-TM, its management, and the meanings ascribed to these experiences.	Reference tracking
16	The impact of thalassemia on Southeast Asian and Asian Indian families in the United States: A qualitative study	Liem et al/2011/USA	Excluded	The qualitative described the challenges including sociocultural and socioeconomic barriers, faced by an urban immigrant population in the United States by Thalassemia major *Findings specific to Asian Indian immigrant parents could not be extracted.*	Reference tracking
17	A qualitative study to identify parents’ perceptions of and barriers to asthma management in children from South Asian and White British families	Lakhanpaul et al//2017/UK	Included	The qualitative study explored perceptions and experiences of asthma and asthma management in British South Asian and White British families, identified barriers to optimal management and informed culturally appropriate interventions to improve management.	Reference tracking
18	Qualitative study to identify ethnicity specific perceptions of and barriers to asthma	Lakhanpaul et al//2019/UK	Included	The qualitative study explored the perceptions and experiences of asthma in British South Asian children using semi-structured interviews.	Reference tracking

	management in South Asian and White British children with asthma				
19	Cultural factors impacting asthma management in Asian Indian children	Mehrotra et al/2014/USA	Included	The case report outlined the cultural factors and health beliefs in the Asian Indian population which impacted the care and outcome of these patients.	Reference tracking

Appendix O

JBI Critical Appraisal Checklist for Analytical Cross-Sectional Studies

John, A., Bower, K., & McCullough, S. (2016). Indian immigrant parents of children with developmental disabilities: Stressors and support systems. *Early Child Development and Care, 186*(10), 1594-1603. https://doi.org/10.1080/03004430.2015.1116297

Sl no	**Checklist questions**	**Response**
1	Were the criteria for inclusion in the sample clearly defined?	Yes
2	Were the study subjects and the setting described in detail?	Yes
3	Was the exposure measured in a valid and reliable way?	NA
4	Were objective, standard criteria used for measurement of the condition?	Yes
5	Were confounding factors identified?	No
6	Were strategies to deal with confounding factors stated?	No
7	Were the outcomes measured in a valid and reliable way?	Yes
8	Was appropriate statistical analysis used?	Yes

Overall appraisal: Included

Appendix P

CASP Qualitative Checklist

Sl No	Assessment questions	Lakhanpaul et al., 2019	Lakhanpaul et al., 2017	Mehrotra et al., 2014	Kelly & Kelly, 2012	Mufti et al, 2015	Ravindran & Myers, 2012	Habib et al.,2017	Theara & Abbott, 2015	Zechella & Raval, 2016	Croot et al, 2012	Daudji et al., 2011	Heer et al., 2015	Heer et al., 2012
1	Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2	Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3	Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4	Was the recruitment strategy	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

	appropriate to the aims of the research?													
5	Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6	Has the relationship between researcher and participants been adequately considered?	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	Can’t tell	Can’t tell	Can’t tell
7	Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
8	Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
9	Is there a	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

	clear statement of findings?													
10	How valuable is the research?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
11	Overall appraisal	**I**	**I**	**I**	**I**	**I**	**I**	**I**	**I**	**I**	**I**	**I**	**I**	**I**

Abbreviations: I – Included

Appendix Q

Consolidated Criteria for Reporting Qualitative Studies (COREQ): 32-Item Checklist

Sl. No. Item	Guide Questions/Description	Reported on Page #
Domain 1: Research Team and Reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	222
2. Credentials	What were the researcher's credentials? e.g., PhD, MD	Title page
3. Occupation	What was their occupation at the time of the study?	222
4. Gender	Was the researcher male or female?	222
5. Experience and Training	What experience or training did the researcher have?	222
Relationship with Participants		
6. Relationship Established	Was a relationship established prior to study commencement?	222 Self-citation provided in text for further references (Sudarsan et al., 2022a).
7. Participant Knowledge of the Interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	222 Self-citation provided in text for further references (Sudarsan et al., 2022a).
8. Interviewer Characteristics	What characteristics were reported about the inter viewer/facilitator? e.g., Bias, assumptions, reasons, and interests in the	222 Self-citation provided in text for further

	research topic	references (Sudarsan et al., 2022a).
Domain 2: Study Design		
Theoretical Framework		
9. Methodological Orientation and Theory	What methodological orientation was stated to underpin the study? e.g., grounded theory, discourse analysis, ethnography, phenomenology, content analysis	222
Participant Selection		• Self-citation provided in text for further references (Sudarsan et al., 2022a). • Appendix D
10. Sampling	How were participants selected? e.g., purposive, convenience, consecutive, snowball	222–224
11. Method of Approach	How were participants approached? e.g., face-to-face, telephone, mail, email	222–224 Appendix D
12. Sample Size	How many participants were in the study?	223–224 (Table 11)
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Not reported
Setting		222 Self-citation provided in text for further references (Sudarsan et al., 2022a).
14. Setting of Data Collection	Where was the data collected? e.g., home, clinic, workplace	222 Self-citation provided in text for further

		references (Sudarsan et al., 2022a).
15. Presence of Non-participants	Was anyone else present besides the participants and researchers?	N/A
16. Description of Sample	What are the important characteristics of the sample? e.g., demographic data, date	223 (Table 11)
Data Collection		222–224 - Self-citation provided in text for further references (Sudarsan et al., 2022a). - Appendix D
17. Interview Guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	222 Appendices K and L
18. Repeat Interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual Recording	Did the research use audio or visual recording to collect the data?	222 - Self-citation provided in text for further references (Sudarsan et al., 2022a). - Appendix D
20. Field Notes	Were field notes made during and/or after the interview or focus group?	Appendix D
21. Duration	What was the duration of the inter views or focus group?	222 Self-citation provided in text for further references (Sudarsan et al., 2022a).
22. Data Saturation	Was data saturation discussed?	224

		Appendix D
23. Transcripts Returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: Analysis and Findings		
Data Analysis		
24. Number of Data Coders	How many data coders coded the data?	222
25. Description of the Coding Tree	Did authors provide a description of the coding tree?	225–243 213 (Figure 26)
26. Derivation of Themes	Were themes identified in advance or derived from the data?	225–243 213 (Figure 26)
27. Software	What software, if applicable, was used to manage the data?	224
28. Participant Checking	Did participants provide feedback on the findings?	Yes
Reporting		
29. Quotations Presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g., participant number	225–243 Tables 12 (236–237) & 13 (242–243)
30. Data and Findings Consistent	Was there consistency between the data presented and the findings?	225–243 Figure 26 (213), Tables 12 (236–237) & 13 (242–243)
31. Clarity of Major Themes	Were major themes clearly presented in the findings?	225–243 Figure 26 (213), Tables 12 (236–237) & 13 (242–243)
32. Clarity of Minor Themes	Is there a description of diverse cases or discussion of minor themes?	N/A