

Voices through my hands: An auto-ethnographic study of the lived experiences of a South African child of Deaf adults



Jane Harrison

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Supervisor: Dr Brian Watermeyer

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Declaration

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Acknowledgements

My GOD, you have been my refuge and strong tower and you have charged your angels to watch over me. You have granted me a crown of beauty instead of ashes, joy instead of sorrow, raiment of praise instead of a spirit of desolation. All I have I owe to you.

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Dedication

I dedicate this thesis to my parents – I am who I am because of you. Thank you for teaching me the true meaning of being resilient, to persevere, to work hard, and for showing me the beautiful way of Deaf culture

Abstract

There is a dearth of literature about the lived experiences of hearing children of Deaf adults (CODAs) within the South African context that this study attempts to address. Most African publications examining issues of Deafness focus on the experience of Deaf people themselves. Not much attention is given to the fact that children of Deaf adults may have their own experiences which are tied to the Deafness of their parents. Through a critical examination of my own experiences as a CODA, I sought to answer the following question: In which ways has my position in my family as a CODA, my identification as a Coloured person, my gender, and the context of Apartheid South Africa influenced my sense of self?

Aim: The aim of the study is to provide the reader with rich, first-person information regarding the social, political and cultural circumstances of my formative years, in the context of being female, coloured, and having parents who are Deaf, against the backdrop of the South Africa of the 1980s. I draw attention to the intersections within my life as a bicultural, Coloured female in South Africa. Using a qualitative research method, auto-ethnography (specifically an evocative ethnographic method) to generate and analyse data, I endeavour to connect my story to wider cultural, political and social processes. The analysis was informed by literature from d/Deaf studies and a conceptual framework that included models of disability, the notion of intersectionality, and theoretical ideas concerning identity formation.

Objectives: I explore: i) the key elements of context that combined to shape my experience of being raised as a CODA; ii) my experiences of identity formation; iii) the ways in which the intersection of various social life attributes that include race, gender, bicultural identity, and disability have intersected to frame my lifeworld as a CODA.

Methodology: I used the auto-ethnographic approach and specifically, evocative auto-ethnography. I drew upon the thematic analysis method to analyse the data.

Findings: The auto-ethnographic material depicts my lived experience as a CODA. A key finding relates to bicultural identity formation in a context of South Africa that has been profoundly shaped by Apartheid. While negotiating a terrain that is characterised by rampant racial discrimination and the difficulties that surround an identity that is both of the Deaf and hearing worlds, my story shows up a number of active responses to my life-world, rather than a passive acceptance and internalisation of its contradictions.

Conclusion: This study supports the use of auto-ethnography as a way of exploring the experience of identity formation in CODAs in a context where the ambiguities of life as a CODA are complicated by identity intersections with race, gender and culture.

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Acronyms and Abbreviations

CODA	(Hearing) Children of Deaf Adults
DeafSA	Deaf Federation of South Africa
DPO	Disabled People's Organisation
SASL	South African Sign Language
StatsSA	Statistics South Africa
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

Definition of terms

Biculturalism:	To be immersed in two different cultures, within the same country (Singleton & Tittle, 2001).
Child of Deaf Adults (CODA):	A hearing child born to one or two Deaf parents (Bull, 1998; Bishop & Hicks, 2005).
d/Deaf:	The preference of writing ‘Deaf’ with a capital D instead of lower-case ‘d’ refers to a person who associates themselves with Deaf culture and Sign Language, and who is acknowledged and accepted by the Deaf community. Not all deaf people subscribe to Deaf culture, therefore the distinction between ‘deaf’ and ‘Deaf’ (Skelton & Valentine, 2003). An individual who identifies with ‘deaf’ may be considered as an ‘outsider’ by the Deaf community on the basis that they do not share the same language or subscribe to the same culture as the Deaf community (Skelton & Valentine, 2003). People who become deaf at a later stage in life due to age or medical problems might not necessarily form part of Deaf culture and would instead see themselves as deaf or hard of hearing (Reagan, 2002).
Deaf culture:	Deaf culture has its own language and beliefs with a strong sense of community based on the “shared experiences of a particular human experience, that of Deafness” (Singleton & Tittle, 2001, p. 222).

1 Chapter 1: Introduction

I am a child of Deaf parents (CODA), raised in South Africa, a country where the social organisation has been profoundly shaped by Apartheid. Being a mouthpiece and ears of my Deaf parents, I became an adult, in some ways, very early in life. I will argue that my status as a CODA meant that I had to develop adult characteristics at an unusually early age.

And yes! Through the course of this thesis, I will attempt to describe some of this story.

In this study, I undertook a critical examination and exploration of my lived experience as the eldest child, born and raised by my Deaf parents in Apartheid South Africa in the 1980s. I begin this introductory chapter by offering a brief background of my life as a CODA. In addition, I discuss the context in which this study took place, the research problem, question, aim, objectives, and purpose and significance of the study. At the end of the chapter, I present an outline of the chapters that form the rest of this thesis, to signpost the way in which it unfolds. As a background to this study, and in the following section, I briefly introduce my experience of being a CODA who was raised in Apartheid South Africa in the 1980s, a time of acute social upheaval and violence in South Africa, as the anti-Apartheid movement and the Nationalist government clashed.

1.1 Background of the study

I am the eldest of two children born to Deaf parents in Cape Town, South Africa and like my sister, I am hearing. We both sign and South African Sign Language (SASL) is our first language. On my father's side of the family, a few relatives can sign, but most if not all of my mother's family members cannot sign. That means that her family is not able to communicate with her in appropriate ways that suit the nature of her impairment and that of my father, her husband. That is where I, a CODA, fit in. In a study of the life experiences of CODAs, Preston (1996) found both positive and negative accounts of what it is like to share experiences in Deaf culture. In his analysis of gendered roles in CODAs, he identified that it is most often the eldest female child who takes on the role and responsibility of the family interpreter. While my sister and I are both fluent signers, I assumed the role of the interpreter.

Before I was five years old, when most toddlers were exploring their lifeworlds and playing with peers and toys, I was being trained to become the mouthpiece and ears of my parents. For

me, it meant assuming some adulthood roles and responsibilities in ways that affected my life both positively and negatively. With an ever-changing scene in a range of environments, I became the voice of the doctor, nurse, school teacher, social worker, grandparents and anyone else who could not communicate appropriately and directly with my mother and father. As maturity and resilience were demanded of me, I responded in the best ways that I could. However, I often felt as if I was up on a stage performing a part that I never auditioned for, which intersected with my growing up in Apartheid South Africa in the 1980s. At that time, my Coloured racial identity occupied an ambiguous position which was characterised by experiences of stigma and discrimination.

However, the focus of this thesis is not only on my racial identity or about whether I am hearing or Deaf, but also about being able to find ways to reconcile with the different identities that I hold, that of being a CODA, of being hearing, of being 'Deaf,' of being Coloured, of being female, of having to connect to my experience of difference and of being 'the girl in the middle.' I questioned whether it was common for CODAs who witness the breakdown of communication between Deaf and hearing worlds to be virtually compelled to take up the role of an interpreter at an early age. However, while CODAs may be praised for their roles within the family, a key question is how they, themselves, experience this role, and how it impacts on the trajectories of their lives. Such issues, especially within an African context, are rarely explored, hence my quest to pursue this study.

In this study, I use evocative auto-ethnography, under the umbrella of a qualitative research approach to illuminate my lived experience as a CODA. I draw attention to the intersection of various identity markers within my life as a bicultural, Coloured, female CODA raised during the years of Apartheid. I connect my story to a wider economic, cultural, political and social set of circumstances and explore how these factors influenced my life both positively and negatively, as I journeyed through a process of seeking to frame my identity. However, through the research process, it has become clear to me that I am not a passive recipient of the difficulties that characterise my lifeworld as a CODA, but I have found that at many points I have exercised agency and asserted myself as I negotiated the multifaceted terrain which I encountered.

1.2 Context of the research

In this section, I provide an outline of the setting from where the research question and research problem of this study emerged. I begin by presenting Figure 1 below, which shows the geographic location of the study, then I provide a brief overview of the context in which the study was undertaken.



Figure 1: Geographic location of research

(Source:

<https://encryptedtbn0.gstatic.com/images?q=tbn:ANd9GcT1JQjXZdVyIaKtnAvcW4k92sXEDFkEsJ6pV61TYHXyUvp0KO20>)

With a population of about 57 million people, South Africa is situated on the continent of Africa, where, as shown in Figure 1 above, it shares land borders with Zimbabwe, Botswana, Mozambique, Lesotho, Namibia and Swaziland (World Atlas, 2018). South Africa's history is deeply rooted in structural violence, which began with the colonisation of South Africa in 1652 and the establishment of British rule in 1806 (Adhikari, 2006). The same source notes that

driven by racism, the National Party Government (NP) implemented a system called Apartheid in 1948, which was aimed at facilitating the segregation of people along racial lines and the promulgation of laws that entrenched white supremacy over other races. Such laws saw people being assigned to distinct categories that include ‘white’, ‘black African’¹, ‘Coloured’, and ‘Indian’, which later became Asian (Trotter, 2000). The racial group designated as ‘Coloured’ descended from intimate partner relationships and intermarriage between early white settlers, indigenous black Africans, and Asian slaves (Adhikari, 2006). Legislation such as the Group Areas Act guided the relocation of people, often by force, as people of Colour were moved out of urban areas into townships (Bank & Minkley, 1998).

The transition of South Africa into a democratic state in 1994 is probably one of the most significant moments of the country’s political history (Steyn, 1998; Adam, 1996). Furthermore, the first democratic elections were held in the same year and with the inauguration of Nelson Mandela as president, a new South Africa was anticipated. Steyn (1998) states that the peaceful transition brought new hope, excitement and the promise of restoration for the oppressed colonised non-white people of South Africa. Nevertheless, the inequalities that coincide with social identity, as well as racist ideas regarding ‘innate characteristics’, remain a reality within some parts of the South African milieu of today. Steyn (1998, p. 111) asserts that the thinking of all South Africans still requires decolonisation, and that “decolonization...requires...an imaginative creation of a new form of consciousness and way of life.”

On reflection, I realise that the experience of growing up in the 1980s in Apartheid South Africa as a Coloured CODA exposed me to politically constructed disputes of race and racial identity formation. For example, I was confronted with the questions: what is a Coloured? What constitutes my Coloured-ness? As a Coloured woman, these are the questions I grappled with and have debated about since my childhood and still do today. I outline the significance and purpose of this study in the following section.

1.3 Significance and purpose of the study

As far as I know, this is the first time that the lived experience of a South African CODA is being subjected to a formal evocative auto-ethnographic study, which therefore represents

¹ For the purpose of this thesis, “black African” will refer to people of (for example) Xhosa or Zulu descent.

novel information that has not yet been published. I hope the research will make a significant contribution to the body of knowledge by making recommendations towards the formation of a CODA framework that informs policy and practice in the disability, education, health and social services sectors. While this study has enabled me to gain a deeper understanding of my lived experience, I believe that my experience may share some similarities with other CODAs in South Africa and probably beyond. With this study, I begin to give voice to the experiences of people who have grown up in such circumstances in South Africa, and I hope that this work will stimulate the undertaking of further studies in this area.

1.4 Research problem

There is a paucity of literature about the lived experiences of CODAs who were raised in Apartheid South Africa. While some authors in the Global North have written about CODAs, scholars in the Global South, including in South Africa, have neglected the subject, hence the contextual lived experiences of CODAs remain largely unknown. Most African publications that examine issues of Deafness focus on the experiences of Deaf people themselves, thereby paying little or no attention to the fact that CODAs may have their own unique experiences that are tied to the Deafness of their parents. Consequently, the injustices and inequalities that may characterise the life worlds of CODAs may remain unattended to. An in-depth understanding of CODAs and their lived experiences is useful, given its potential to contribute towards influencing the transformation of society in relation to the ways in which CODAs may be excluded or disadvantaged. By critically examining and exploring my own lived experience as a CODA, I sought to move such experiences from the sidelines of society to the centre in order to inform disability policy and practice primarily, as well as the work of civil society and disabled people's organisations.

1.5 Research question

What were the lived experiences of being raised as a female Coloured CODA in Apartheid South Africa in the 1980s?

1.6 Research aim

In this auto-ethnographic study, the aim was to describe, explore and analyse the key elements of context that combined to shape my experience of being raised as a CODA in Apartheid

South Africa in the 1980s. I sought to provide a rich set of accounts that are embedded in a layer of analysis with the aim of enhancing understanding of the circumstances faced by young CODAs in South Africa.

1.7 Research objectives

The research objectives were:

- to record memories and thoughts in a reflexive journal;
- to monitor developments and experiences within the intersection of various social life attributes that include race, gender, bicultural identity and disability, which framed my lifeworld as a CODA;
- to perform thematic analysis in order to identify, analyse and generate themes and patterns derived from the data, that which is the lived experience of being raised as a CODA in Apartheid South Africa in the 1980s;
- To review, define, categorise and name themes that speak directly to the research topic.

1.8 Outline of thesis chapters

Chapter 1 contained the introduction of this thesis and pointed to the paucity of studies on the subject and gave a brief background of my experience of being a CODA. In addition, the context within which the study was undertaken was discussed, as well as the research problem, question, aim, objectives, purpose and significance.

Chapter 2 will encompass part I of the literature review and begin with an outline of the conceptual framework that guided the study. It includes theoretical discussions on disability, intersectionality, and theory of developmental stages within a framework of identity formation. Furthermore, issues of Deafness and being a CODA will be discussed.

Chapter 3 continues with part II of the literature review, and concerns issues of Apartheid, Coloured identity and the shaping of identity in CODAs in South Africa, which was characterised by widespread racial discrimination. The inclusion of this chapter was necessitated by the fact that my lived experience, including my identity formation as both a Coloured and a CODA in the Deaf and hearing worlds, was rooted in the Apartheid system of South Africa of the 1980s.

In **Chapter 4**, the methodology used in this study will be outlined and my philosophical standpoint explained. In doing this, I discuss the evocative auto-ethnographic approach under the umbrella of a qualitative research paradigm and the thematic analysis approach which was used to analyse the data. I highlight the strengths and limitations of auto-ethnography, and I end the chapter by discussing issues of trustworthiness and rigour.

In **Chapter 5**, the findings of the study will be presented. These are embedded in an interpretative analysis that focuses on understanding my lived experience of being raised as a CODA in terms of five main sub-headings: 1) multilingual status; 2) multiple cultures; 3) role reversal; 4) identity formation; and 5) racial discrimination.

Chapter 6 contains the conclusion of the study and recommendations for policy, services, disabled people's organisations (DPOs) and civil society. The chapter ends with calling upon other scholars to undertake further studies in this under-researched area, mainly in the Global South and particularly in Africa and South Africa.

2 Chapter 2: Literature Review – Part I - Deafness and being a CODA, a conceptual framework

2.1 Introduction

Despite the paucity of studies that explore the childhood and adulthood experiences of children of Deaf adults in South Africa, CODAs are a unique minority group that deserves research recognition given the intricacies of their life worlds (Preston, 1994; 1996). Other than erratic media reports, the only literature on CODAs to emerge from South Africa have been two studies by Selzer (2010) and Theunissen (2008). Selzer (2010) piloted a study on the standardisation of South African Sign Language (SASL) for use in Parliament, but he made only limited comments about the paucity of literature on CODAs. Theunissen (2008) focused on the counsellors who were providing services to Deaf and hard of hearing individuals and CODAs. For the purpose of this review, I was left with no choice but to draw primarily on literature from the Global North, although recent publications in the area have declined.

This chapter forms part I of the literature review and it provides an overview of Deafness and being a CODA, as well as the conceptual framework that guided the study. The subsequent chapter comprises part II of the literature review, focusing on issues of the Apartheid system in South Africa and identity formation. While the chapters contain some areas that overlap, they were split in terms of their focus in order to promote readability.

2.2 Conceptual framework

This study is guided by a conceptual framework of identity formation that includes the intersectionality model, the social model of disability, and Erikson's theory of the stages of development. The framework offers conceptual ideas relevant to understanding the shaping of identity.

2.2.1 Intersectionality

Law Professor Kimberlé Crenshaw introduced the term 'intersectionality' in 1989. Intersectionality acknowledges the interdependence of various identity markers in framing people's experiences and identities. According to Yuval-Davis (2006) and Sokoloff and Dupont (2005), oppression is not a one-dimensional issue, but a result of the intersection of various social life attributes that may include race, class, gender, sex and disability. In this study, an intersectional lens was used to guide the analysis of the different social attributes that

intersect to frame my identity and experience. Intersectionality also focuses on the aspect of difference, hence it recognises the intersection of different identity markers in different contexts (Walters, 2005). For example, a Deaf coloured woman's lived experience in a system of dominance and racial discrimination in Apartheid South Africa would not be similar to that of a Deaf white woman in Canada. I, therefore, use the intersectional model to guide the analysis of my contextual experience. However, it appears that the 'architects' of the intersectional model were primarily focusing on the ways in which the identity markers of gender, race and class were creating the marginalisation of black women (Crenshaw, 1989). The identity marker of disability was neglected. I therefore discuss the concept of disability as framed by the so-called medical and social models of disability.

2.2.2 The social and medical models of disability

The social model of disability has been useful in the discipline of disability studies, to the point that it is generally regarded as a standard learning tool in this discipline (Samaha, 2007). The model was formulated in Britain in the 1970s by activists from the British Union of Physically Impaired Against Segregation (UPIAS), who was challenging the dominance of the medical model of disability (Hammell, 2006). In the medical model, which is pervasive in most societies, disability is perceived as a medical issue, based on the belief that the difficulties associated with disability lie with the person (Kanter, 2011). The main focus of the medical model of disability is therefore on 'fixing' disability through greater access to health care and rehabilitative services at the individual biological level. Following this reasoning, deafness, as part of the broad spectrum of disability, is seen by outsiders as an illness that needs to be cured (Shield, 2005). However, Yuval-Davis (2006) suggests that the problem is not with the person but with a society which assumes that persons with disabilities are unable to participate in all aspects of life by virtue of their impairment (Swain et al., 2013).

In contrast to the medical model, the social model of disability has a more inclusive and proactive approach, which regards disability as a social issue rather than a medical concept (Barnes, 2011). The model maintains that the problem of disability is located within society and not within the bodies of individuals. Disability is, therefore, a result of HOW societal and environmental factors are organised in ways that pay minimal attention to the concerns of persons with disabilities (Barnes, 2011; WHO, 2011). In relation to Deafness and from a

perspective of the social model, it is society that fails to provide Deaf people with access to all aspects of social life (Gregory, Bishop, & Shelton, 1995; Seligman & Darling, 1997). For example, the problem that a Deaf person does not have access to information on HIV prevention strategies does not lie with the Deaf person, but with the failure of the HIV prevention programmes to provide information in appropriate formats such as SASL. In this study, I use the social model of disability to examine the interaction between myself and my Deaf parents and the society in which we live. This study is in part grounded in identity formation, hence I also draw upon Erikson's theory discussed below.

2.2.3 Erikson and identity formation

Erikson (1950) proposed that a person's identity is framed by his or her sense of the ways in which he or she is different from other people, as well as the social identity that the person obtains from being a member of various groups that may include cultural affiliation, family and employment. In his seminal theory of eight developmental stages, Erikson describes identity formation of the infant, toddler, pre-schooler, school-age child, adolescent, young adult, middle-aged adult and older adult extensively (David, 2014; McCleod, 2018). Erikson states that identity formation reaches its peak in the adolescent years, where development shifts from what is done to an individual, to what the individual does (David, 2014). At this stage, an adolescent is on a journey of self-discovery to find out what his or her identity is, while at the same time trying to negotiate the terrain of social interaction. Furthermore, he or she is trying to 'fit in' and to establish the difference between right and wrong, what is moral and what is not. The onset of a person's sexual maturity, physical growth and career choices result in a scenario where a person tries to formulate a stable identity in ways that draw upon their childhood experiences. Erikson stated that identity crises arise when there is confusion and instability, in settings where adolescents struggle to make choices and to deal with the alternatives that they encounter. He further asserts that the confusion that surrounds this stage of development may result in young adults' identifying real or imagined differences, bonding in particular factions and over-identifying with mentors and heroes. David (2014) proposed that some adolescents may try to delay their entrance into the years of adulthood by withdrawing from responsibility. I used Erikson's (1950) theory of the stages of development to analyse and seek understanding of what influenced my identity development as a CODA. Below I discuss the complex, multi-faceted phenomenon of Deafness.

2.3 The phenomenon of Deafness

Deafness is regarded as one of the single largest prevailing forms of disability (Storbeck & Martin, 2010). People lose their hearing in different ways, such as illness, trauma or age, and some may be born deaf (Jambor & Elliot, 2005). The same authors state that while people may share the same condition of not being able to hear fully, they might not share the same beliefs and practices that make up the philosophy of the Deaf community. This is significant because the “shared experiences of a particular human experience, that of Deafness” also brings people together (Singleton & Tittle, 2000, p. 222). Singleton and Tittle (2000) state that some of the experiences of Deaf people have been described as disabling, estranged and oppressive. Such descriptions suggest that some Deaf people may feel that their experiences within the hearing world are negative, which contributes to the limited interactions that may exist between the Deaf and the hearing worlds (Filer & Filer, 2000), in a context where Deaf people are regarded as persons with disabilities.

2.3.1 Defining Disability

How do we define disability? While the dominant definitions and classification of disability have undergone a number of changes over the decades, the concept is still widely contested according to the World Health Organization’s (WHO) *World Report on Disability*, and it holds different meanings in different parts of society (WHO, 2011). The understanding of impairment and the limitations thereof are not the same for all people, described by Kaplan (1999) as being complex and knotty. However, in this thesis I draw upon the definition of disability as it is framed by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Article 1 (United Nations, 2006), which states that “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.” The prevalence of disability and deafness are described statistically below.

Estimates of the size of South Africa’s Deaf population vary, as numbers are not easy to measure. The World Report on Disability (WHO, 2011) approximates that persons with disabilities represent 15% of the world’s population (I am working from this figure, as reliable

statistics for South Africa are not available). Statistics South Africa (StatsSA), in its *Census 2011 Disability Report* (StatsSA, 2011) released in September 2014, indicated that the disability population of South Africa stood at 7.5% of the total population. Storbeck (2010) suggested that of the South African population of about 57 000 000 people, an estimated 8 550 000 (10%) are disabled, and approximately 3.5% of these have some grade of hearing loss. DeafSA (2007) further estimated that, within this group, the number of Deaf people who accept SASL as their first language is projected at around 500 000 to 600 000.

The greatest single barrier to social participation experienced by this group is in the domain of communication, and SASL enables people who are Deaf or hard of hearing to communicate with others who are proficient in this language. Sign language is defined by Selzer (2010) as a language that is visual-gestural. SASL was generated and used by Deaf people in South Africa to converse with each other. Sign languages, which differ between countries and within countries, are fully-fledged natural languages, communicated mainly through the hands, facial expressions and body (Magongwa, 2010).

Sign languages, therefore, are not based on spoken language, as they possess their own grammar and syntactic rules that can communicate the entire array of human experiences (DeafSA, 2006). Research demonstrates that approximately 66% of Deaf people in South Africa are functionally illiterate (Storbeck & Martin, 2010). Worldwide, vast numbers of persons with disabilities have been excluded from participating in most aspects of life, including in the social, political and economic arenas (Barrat, 2007). Owing to their inability to communicate with the hearing world, Deaf people are arguably among the most marginalised minority groups in society (Peter et al., 2008). Power and Leigh (2003) point out that the essence of disability in Deaf people is that communication, and not deafness, is the primary challenge. Murray et al. (2007) state that, in comparison to disability, Deaf people are more disadvantaged, caused by perceived language barriers.

The concepts ‘etic vs emic’ are vital in facilitating an understanding of the complexities of the Deaf/hearing debate (Murray et al., 2007). An etic perspective refers to the medicalised construction of the outsiders’ views; the perspective that deafness is a disability (Murray et al., 2007). Supporters of this view regard Deaf people as “deprived of the experience of stimulants and magnificent sounds of nature in a quiet, tragic and empty world” (Baker, 1999, p. 126). The primary focus of this view is on what Deaf people are unable to do and not on what they

are able to do. In contrast, an emic view refers to the insider's perspective of deafness, which refers to the cultural construction of Deafness, described by Hoffmeister (1996) as a person's capability to interact and participate in Deaf culture. Proponents of this view argue that Deaf people should not be defined solely by their inability to receive audible information. Deaf culture "is a subculture like any other and it has its own values and norms which include a common language, a shared awareness of cultural identity and history, distinctive behavioral norms and patterns, cultural artefacts, endogamous marital patterns, and a network of voluntary, in-group social organizations" (Reagan, 1995, p. 243).

Supporters of this view, state that the Deaf community should not be viewed as a disability group with a medical problem but as a distinct cultural and linguistic minority group, disadvantaged by a barrier of language and not a barrier of disability (Singleton & Tittle, 2000; Murray, et al., 2007). The same authors argue that Deaf people can communicate easily among themselves using Sign Language, and hence it is inappropriate to regard their mode of communication as sub-standard. It is important to note that a person who is Deaf may not consider him or herself as being disabled or view the inability to hear as a loss; the person may also not see his or her deafness as being pathological (Smith et al., 2014).

It is argued that the outsider perspective creates fertile ground for multiple forms of discrimination, which may create barriers for Deaf people to access opportunities for self-development. It could result in possible exclusion from most aspects of society that may include education and employment (Pal, 2011). One reason why the hearing world may view deafness as some form of disability is that hearing people may have no or little understanding of Deaf culture (Filer et al., 2000). However, Deaf people may claim that it is the hearing people who are 'disabled' because they are unable to understand Sign Language or to 'fit' in with Deaf culture. Lane (2005) asserts that the people who are most 'qualified' to talk about how Deafness can be understood are Deaf people. Being denied the opportunity to self-define in this way may make Deaf people vulnerable to multiple forms of stigma and discrimination. Such prejudice is also experienced by CODAs as discussed below.

CODAs may be exposed to discrimination and stigma by virtue of being born to Deaf parents. They may feel the need to protect their parents from negative treatment that may be perpetrated by hearing people (Bishop & Hicks, 2005). In other words, they may seek to protect both

themselves and their parents against insults and negative views about deafness, which some CODAs regard as dangerously misleading. Preston (1994) indicates that CODAs may in some instances suppress feelings of sadness and anger, as a way of protecting their parents from negative criticism. Furthermore, CODAs constantly have to engage with, and navigate through, both the hearing and Deaf cultures in ways that may result in CODAs' questioning their sense of belonging within the two cultures. This may potentially lead CODAs to restrain their different identities. For instance, when they are trying to immerse themselves in the Deaf culture where they interact with the Deaf community, they may experience a need to deny aspects of their identity.

2.4 The Deaf community and Deaf culture

Clark (2003) explains that the Deaf community represents a group of individuals who identify with a common language, namely Sign Language, which is viewed as the most important component that binds the Deaf community together. According to Singleton and Tittle (2000), people may either be born in Deaf communities or they may choose to belong to such communities when they discover that they are unable to identify with the world of hearing people, or they may simply choose not to identify with the hearing world. Incorporation into the Deaf culture often occurs during childhood or the adolescent years, when the relevant person interacts with Deaf individuals in environments such as residential schools. Singleton and Tittle (2000) explain that the Deaf community also includes family members of Deaf people, Sign Language interpreters, and people who work or socialise with Deaf people who identify with Deaf culture. The same authors state that gaining entry into this community is not automatic; as a 'hearing person', one would need to, first of all, have a cultural understanding of Deafness as well as to be proficient in Sign Language.

Concurring with Singleton and Tittle (2000), Napier (2002, p. 142) states that "people become members of the Deaf community through their audiological status, linguistic fluency in Sign Language as well as through social and political support for the Deaf community." Higgins (1980, p. 171) explains as follows:

"While membership in the deaf community is based on identification with the deaf, membership in the community supports and strengthens deaf people's identity and

adjustment to deafness. A sense of wholeness and belonging is achieved within the deaf community, which is lacking within the hearing world.”

However, Mindes (1999) explains that Deaf culture is not the same for everyone across the world. Deaf culture interconnects with identity markers such as race, gender, class, education, ethnicity, and sexual orientation amongst others, resulting in diverse Deaf cultures across societies. There are many Deaf populations around the world, however, they communicate using different Sign languages. Membership into the Deaf community is contextual and is also determined culturally and not by medical diagnosis. The main focus is on a contextual Deaf culture (Jambor & Elliot, 2005; Reagan, 2008). While all these issues are fundamental prerequisites of Deaf culture, there are also additional dimensions of diversity within such membership, which includes not only people with different levels of hearing loss but also CODAs (Preston, 1994). As CODAs’ engagement in Deaf culture is significant, their roles are discussed in the following section.

2.5 Hearing children of Deaf adults

Statistics in the United States of America indicate that 90% of children born to Deaf parents are hearing (Moore & Lane, 2003). Nevertheless, not all deaf-parented families are the same as some parents may both be Deaf and full Sign users, or one parent may be Deaf and the other hearing. In other instances, both parents may be Deaf but one parent may communicate using Sign Language and the other may communicate orally. Preston (1994) asserts that the most predominant type of parent configuration in this regard is that of parents who are both Deaf and who both Sign. Families such as these are required to bridge the disunion between both the hearing and Deaf worlds, and CODAs often become the ears and voice of their parents, thereby becoming the link between the two worlds in which they are expected to be culturally competent. Malik and Jabeen (2016) submit that children of Deaf adults exist within two cultural, social and linguistic systems, exposing them to an unusual family situation.

CODAs do not all subscribe to Deaf culture. Neither can it be said that all CODAs see themselves as different from their Deaf parents (Malik & Jabeen, 2016). The description of CODA is meant for people who feel excluded and “as not quite fitting into the Deaf/hearing categories; people who want to carve out a third niche for themselves” (Bishop & Hicks, 2005, p. 192). The point is that CODAs form part of a linguistic and cultural minority group. They

are raised as part of the Deaf community and they acquire Sign Language, which becomes their mother tongue (Bishop & Hicks, 2005). The same authors are of the view that CODAs are regarded as Deaf people, except for the fact that they are able to hear. According to Shield (2005) and Bishop and Hicks (2005), if Deafness is part of an ethnic culture, then it follows that CODAs may also be Deaf, even if they are able to hear.

Nevertheless, even though CODAs are raised within a Deaf culture, their membership is not 'natural' as they do not fully experience Deafness and the total stigma that is attached to the disability (Shield, 2005). Notwithstanding the fact that CODAs identify with both cultures, the different social experiences of the Deaf world and the hearing world are likely to expose them to a different view of Deafness (Preston, 1994). Thus, the sentiment of not fully belonging to either system raises questions about the identity of CODAs as some may identify with one and not with the other (Filer & Filer, 2000). It raises the vital questions of what the actual experiences of CODAs are and how such experiences impact the trajectories of their lives, despite the fact that they are likely to be praised for the unique roles they play in their families.

There is a widespread assumption in the literature that CODAs are born 'into' responsibility and that they 'feel' responsible for their families (Clark, 2003). *Drum*, a South African family magazine (September 1983), published a story of a young girl and her Deaf parents under a caption that read: "A little happiness in a silent world." The story depicted the young girl as a "bouncing ball of happiness" who "answers intelligently" and that, while the parents were living in a "world of silence", they were "compensated" by the birth of their "perfectly normal" daughter, who serves as a "mouthpiece" for her parents. This is one of the few stories published in the South African media on the perceived role of CODAs in relation to the assumption of responsibility within their families.

Preston (1994), who is both a CODA and a leading author who has done extensive research on adult children of Deaf parents, notes that children assume the role of the interpreter at an early age. Some authors, who are also CODAs (Hoffmeister, 1996; Clark, 2003; Bull, 1998; Napier, 2002), concur with Preston's findings. Stories such as the one published in *Drum* magazine (September 1983) and other print and visual media publications in South Africa, portray CODAs as being a communication link and a conduit of access for their Deaf parents to the wider hearing society. However, the experiences of CODAs in that regard have not been formally researched in the South African context. The actual nature of the roles that CODAs

play within families and the way they feel about such roles and responsibilities have remained largely unknown. This auto-ethnographic study seeks to make a contribution towards filling this knowledge gap.

2.6 Deaf parenting and relationships with hearing children

While hearing parents are vulnerable to social challenges such as single parenting, poverty and substance abuse, Deaf parents are also vulnerable to such stresses (Singleton & Tittle, 2000). However, one key concern of such families are likely to revolve mostly around communication and navigation of Deaf culture. While CODAs often assume the role of interpreter within families, CODAs may express feelings of frustration when they have to communicate certain issues, particularly regarding their own feelings about different subjects, to their Deaf parents (Buchino, 1990). The same author notes that CODAs may refrain from telling others about their frustration, because they may not want to be regarded as hearing children who are disloyal to their Deaf parents (Buchino, 1990). The risks that come with communication challenges are many, as further illuminated in the following paragraph.

Economic, political and social risks within Deaf parented families could be increased as Deaf parents may not have access to information in the same way as non-Deaf parents (Singleton & Tittle, 2000). The same authors provide an example of a school meeting where a Deaf parent needed to discuss his or her hearing child's academic performance and attendance at the school. As there were no Sign Language interpreters at the school, the parent was not able to communicate with the hearing teacher. In this instance, the Deaf parent was not afforded the same access to information about the academic performance of their child as may have been provided to a hearing parent. While Deaf parents are often regarded as people who are unable to raise hearing children, some studies (Strom, Daniels, & Jones, 1988) argue that regardless of issues such as communication and cultural mediation, Deaf parents' parenting skills are not of a lower standard.

Studying the experiences of Deaf parents in the USA raising their hearing children, Lawson (2008) highlighted strong bonds between Deaf parents and their hearing children. A number of scholars, including Malik and Jabeen (2016), have found that despite limited access and disabling factors, Deaf parents raise resilient and resourceful children and CODAs are viewed as successful and competent individuals (Malik and Jabeen 2016). According to Singleton and

Tittle (2000), the literature on Deaf parenting indicates parental competency and care for their children. However, some parents state that Deaf parents are basically “raising foreign children” who may not be acculturated members of the Deaf community (Singleton & Tittle, 2000, p. 227). One could argue that in seeking to create counter-narratives to combat dominant, negative ideas or myths about Deaf parents, some researchers (Singleton & Tittle, 2000; Lawson, 2008; Malik & Jabeen, 2016) end up seeking to define what Deaf parents ‘are’ and what they ‘are not’ in ways that may give an incomplete picture of the world. In some instances, the assumption is that CODAs are simply language brokers that ‘parent’ their parents, as discussed further below.

2.7 Child language brokers and the risk of parentification

The roles assumed by CODAs may occur in different ways, such as being language brokers and interpreters between the hearing and Deaf worlds. Language brokering, according to Morales & Hanson, 2005, is a term used for someone who has fluency in both languages, that of the parent and the dominant one. A language broker does not just know the languages, but he or she also acts as an interpreter. Chao (2002) states that language brokering of CODAs begins when they are between the ages of seven and twelve. In most cases, it is the eldest sibling that assumes this role, with the firstborn female children being more likely to undertake the role of language brokers than male children (Love, 2003; Preston, 1995). The study undertaken by Mallory et al. (1992) suggests that all the parents participating in the research expected their eldest child to undertake the interpreting role in most situations and act as language brokers.

Morales, Alejandro and Aguayo (2010) compiled a study on child language brokering with a Mexican migrant family that was adjusting to a new culture in the USA, with parents who spoke Spanish but were unable to speak English. The family shared their experiences with their youngest son, the language broker who interpreted English to Spanish and vice-versa, in various situations including department stores, the dentist’s office and parent-teacher meetings. Both the parents and the son reportedly found language brokering to be stressful and exhausting. Furthermore, the son sometimes had difficulty translating and interpreting, leading to frustration and despondency among all parties involved.

Frank (2014) asserts that CODAs may alter messages, thereby giving themselves the power to control meetings while running the risk of causing conflict in the family. The reality that may be faced by many Deaf parents is that they often have no option but to rely on their hearing children; hence, if CODAs twist the message in negative ways, the result may be detrimental to the well-being of their parents. Preston (2008), Bull (1998) and Buchino (1993) assert that the role of interpreter places strain on the relationship between the Deaf parent and the hearing child, particularly in cases where the child has to interpret frequently. In the same vein, Buriel et al. (2006) state that language brokering is related to high occurrences of depression, within contexts where such brokering often results in children undertaking the role of 'parenting' their 'parents'.

Mercado (2003) suggests that there are irregular levels of parentification and role reversal in families where children assume the role of language brokers. Role reversal and parentification refer to a situation where the child is emotionally and psychologically accountable for the parent (Earley & Cushway, 2002). Authors such as Filer (2000) argue that if the roles between the Deaf parents and CODAs are clearly defined, the risks of parentification of parents by children in scenarios of role reversal can be minimised. Authors such as Downing and Dwyer (1981), McQuillan and Tse (1995) and Shannon (1990) report that child language brokers may show increased confidence, independence and maturity, and they may forge trusting relationships with their parents. Weisskirch (2006) reports that child language brokers may acquire positive qualities, further suggesting that by serving their parents that way, they may turn out to be confident individuals, with unselfish and pleasant natures. Conversely, CODAs are called 'unselfish', as they need to learn to value other people's needs and concerns more than their own. Parents may instinctively like children who are caring and thoughtful, hence they may ignore the possibility that the children focus excessively on the needs of others.

2.8 Conclusion

In this chapter, I discussed various concepts that articulate the meaning of Deafness and their link with the Deaf community and Deaf culture. In addition, I examined the ways through which CODAs interact with their Deaf parents, families and other community members, the parenting approach of Deaf parents and the nature of relationships parents aim to foster with their hearing children. With the exception of a few media publications, a paucity of literature on CODAs in South Africa is evident, as well as a dearth of recent literature on the subject

from the Global North. There is, therefore, a need for scholars, particularly in Africa, to undertake research in the area of CODAs, considering that it is grossly and contextually under-researched. In the following chapter, I present Part II of the literature review which examines factors that influence the shaping of identity in relation to both race and disability in South Africa, and in this case, Deafness.

3 Chapter 3: Literature Review – Part II - The Apartheid system and identity formation

3.1 Introduction

Following Part I of the literature review, the focus of this chapter (Part II) is on aspects of the environment which contributed to my identity formation, such as biculturalism and being a CODA in Apartheid South Africa, a country which was and continues to be characterised by widespread racial discrimination. This chapter serves to describe my identity formation as a Coloured CODA in both the Deaf and hearing worlds in the Apartheid system of South Africa in which I was raised during the 1980s. The period was characterised by violence and turmoil and was at the pinnacle of the confrontation between the anti-apartheid movement and the state. The chapter unfolds under the following subheadings: 1) Apartheid, 2) Coloured identity, and 3) The shaping of identity in CODAs.

3.2 Apartheid

The history of South Africa was established through the social engineering of successive racist governments, which began with the colonisation of South Africa in 1652 and the establishment of British rule in 1806 (Seekings, 2008). It is deeply rooted within a system of economic, social, educational and political oppression, established on the fundamentals of social engineering and government formulated racial philosophies and laws. Apartheid, meaning ‘separateness’ in Afrikaans, was formally proclaimed in 1948 by the National Party as a policy designed by the commanding architect, Dr. Hendrik Verwoerd. Driven by racism, the National Party implemented the system for purposes of segregation and formulation of laws that entrenched white supremacy over other races (Salo, 2004). The International Convention on the Suppression and Punishment of the Crimes of Apartheid, sanctioned by the United Nations General Assembly on 23rd October 1973, defines Apartheid as a collection of:

“...inhumane acts committed for the purpose of establishing and maintaining domination by one racial group of persons over any other racial group of persons and systematically oppressing them” (Dugard, 2008, p. 1).

In the words of Nelson Mandela, Apartheid “labelled all South Africans by race, making colour the single most important arbiter of an individual” (Mandela, 1994, p. 130). Erasmus and Pieterse (1999, p. 170) state that:

“Apartheid South Africa was a racially-defined democracy for white citizens. People classified as ‘African’ were subjects relegated to ethnically defined ‘independent states’ referred to as ‘Bantustans’. People classified as ‘Coloured’ and seen as ‘of mixed-race’, along with those classified as ‘Indian’ occupied an ambiguous position within the South African polity.”

The Apartheid regime required that all South Africans be classified into defined racial categories: ‘white’, ‘black African’, ‘Coloured’, and ‘Indian’ (Adhikari, 2006). Coloureds in the Cape (the southernmost region in the country) descended from the indigenous Khoisan people, and intermarriage between early white settlers, indigenous black Africans, and Asian slaves (Adhikari, 2006). But what is a Coloured? What constitutes my Coloured-ness? As a Coloured woman, these are the questions I still grapple with, and debate within myself even to this day. Thus, this work seeks to apprehend the complexity of my lived experience as a CODA, who was raised as a Coloured person in Apartheid South Africa.

The Apartheid era was the salient marker of socioeconomic, cultural, spatial, moral and gendered differences (Salo, 2004). It was accomplished through the implementation of the Population and Registration Act (No. 30 of 1950) (repealed) by the then National Party (Jacobs, 2010). Choices of where one could reside, marry, work, worship, obtain an education, play sport, enjoy recreation and entertainment as well as access basic services were all determined by one's racial group (Thompson, 1990). Based on legislation such as the Group Areas Act (1950), ‘non-white’ people were relocated to areas that were outside of urban areas into townships (Jacobs, 2010). Subsequently, the Natives Resettlement Act (1954) further exacerbated separation of residential areas along racial lines, through endorsed enforced removals of black African, Coloured, and Indian populations to racially categorised spaces (Salo, 2004; Jacobs, 2010). Group areas were created so that they could be privately owned and occupied by certain groups, with whites allocating themselves ‘nice’ areas that would set them apart from the rest of the population (Christopher, 1994; Jacobs, 2010). As such, citizens living in the Cape Town area deemed as ‘Coloured’ by the Apartheid government were relocated to an area called the Cape Flats.

Non-white South Africans were further segregated when the Reservation Act of 1953 was implemented to separate the use of public facilities (Jacobs, 2010). This Act created separate social environments for white people and other racial groups in South Africa (Beck, 2000).

This separation was enforced with notices that I recall as 'Whites Only' or '*Blankes Alleenlik*.' Laws and regulations confirmed or "imposed segregation for taxis, ambulances, hearses, buses, trains, elevators, benches, lavatories, parks, church halls, town halls, cinemas, theatres, cafes, restaurants and hotels, as well as schools and universities" (Thompson, 1990, p. 197). The Immorality Act of 1950 further outlawed any sexual relations or marriages between white and non-white South Africans (Frueh, 2003).

Restrictions on the movements of black Africans into white areas were enforced through the Pass Law Act of 1952 (Jacobs, 2010). Simultaneously, there was also discrimination against Coloured people that included Arabs, Chinese, Indians and people of mixed-race (Jacobs, 2010; Salo, 2004). Additionally, the Labour Preference Act of 1956 declared the Western Cape as an area where all unskilled jobs were set aside for Coloured people (Salo, 2004). Specific criteria such as skin colour, facial features and characteristics of the person's head and hair, amongst other things, were used for separating Coloured people from white people (Posel, 2001). To eradicate uncertainty of a person's race, a range of tests were conducted to aid authorities to classify individuals, with one such test being the pencil test (Watson, 2007) in which a pencil was slid into an individual's hair. "If the pencil fell to the floor, the person 'passed' and was considered 'white', if it stayed wedged, the person's hair was considered too *kroes* (kinky) to be white and the person was categorised as 'Coloured' (Watson, 2007, p. 65). The classification and separated categories determined one's rights and duties. Being classified as Coloured allowed a person more rights than a black African person, but still with fewer rights than a white person (Erasmus, 2001).

Erasmus (2001) and Adhikari (2005) noted that the Apartheid system compelled Coloured people to acknowledge that even though they were not white, they were also not black African, hence giving them a more superior status compared to black Africans. However, Erasmus (2001) and Wicomb (1998, 2000) assert that while the 'mixed-race' background archaeologically constructed the intermediate status of Coloured people, an array of negative, offensive and derogatory remarks to Coloured identities were also commonplace. As a Coloured person herself, she narrates:

"I was not only not White, but less than White; not only not Black, but better than Black... The shape of my nose and the texture of my hair placed me in the middle of a continuum of beauty as defined by both men and women in my community...

I had neither sleek hair nor ‘boesman korrels’ [Khoi-San crinkly hair] (Erasmus, 2001, p. 13).

The struggle for freedom in South Africa not only required political will but a change in thinking and the need to challenge predetermined identities allotted to the oppressed people by the government. Steve Biko, founder and leader of the black consciousness movement in the 1970s, asserted:

“Being black is not a matter of pigmentation – being black is a reflection of mental attitude. Merely describing yourself as black you have started on a road towards emancipation, you have committed yourself to fight against all forces that seek to use your blackness as a stamp that marks you out as a subservient being” (Biko, 1978, p. 48).

The transition of South Africa into a democratic state is probably one of the most significant moments in our history for me. With the first democratic elections held in 1994 and the inauguration of Nelson Mandela as president, a new South Africa was anticipated (Steyn, 1998; Adam, 1996). The peaceful transition brought renewed hope, excitement and restoration for the oppressed and colonised non-white people of South Africa. Notwithstanding the fact that inequalities are socially created, perceptions of inborn identities remain a reality within the South African context of today. While the South African nation is now hailed as the ‘Rainbow Nation’², a democratic, unified and multicultural state, the remnants of the Apartheid legacy of racial segregation are still visible and continue to persist within communities.

In moving towards unity within the new South Africa, this romanticised notion of a rainbow is founded on the biblical symbol of peace (Bornman, 2006). The same author states that while the idea and new national identity of a Rainbow Nation are seen as a catalyst for change, it is problematic in nature as the rainbow is still separated in its entirety. Despite attention being drawn to ‘unity’ and ‘equality’, the reality of obvious unequal opportunities in South Africa still remains, evident in the soaring crime rates owing in part to poverty and unemployment (Steyn, 1998, p 112). The judgement and thinking of all South Africans still require

² While thought on who originally coined the phrase differs, the notion of a Rainbow Nation in relation to South Africa was propagated by Archbishop Desmond Tutu in 1989 (Baines, 1997; Steyn, 1997).

decolonisation, and “decolonization ... requires ... an imaginative creation of a new form of consciousness and way of life” (Steyn, 1998, p. 111). Therefore, it is not surprising that CODAs in South Africa may be exposed to socio-political issues and politically constructed disputes of not only Deafness but also racial identity formation. The subject of Coloured identity is discussed in more detail below.

3.3 Coloured identity

Leigh (2009, p. 4) defines identity as “...a complex and developing cognitive and social construct encompassing an array of characteristics or identity components that connect the person to specific social groups.” In other words, identity refers to the unique characteristic or personality of an individual, their self-representation and influence on their cultural worlds (Maxwell-McCaw, Leigh, & Marcus, 2000). The majority of Coloureds are located in Cape Town where, since its foundation in 1652, a “mixed Afro-Euro-Asian people, the Coloureds” were housed (Western, 2002, p. 711). As is common in most parts of South Africa, the doctrine of racial segregation is still visible in the post-Apartheid era within this city. In Cape Town, the racially structured system of inequality and the entrenched nature of Apartheid still results in the perception that people with certain skin colours, culture, and ethnicity belong to a particular race group (Bornman, 2006). The understanding of race and racial identification is therefore vital and the topic has been debated by scholars over the years.

The current and past literature on Coloured identities holds contradictory views: one view asserts that Coloured identities were imposed and constructed by the then dominant white group onto the heterogeneous group of a ‘mixed-race’ society of South Africa (Adhikari, 2006). Another view suggests that Coloured identity is continuously being redesigned by Coloured people themselves within the post-Apartheid era (Hendricks, 2001), as Coloureds seek to identify more with whiteness than blackness. In relation to the first view and as I stated before, the Population Registration Act of 1950 defined Coloured people as being neither white nor black African (Salo, 2004; Jacobs, 2010). Coloureds in 1959 encompassed everyone not “generally accepted” as either white or black African. Further categorisations of “Cape Coloured, Cape Malay, Griqua, Indian, Chinese”, “other Asiatic” and “Other Coloured” resulted in individuals from the same family being registered as stemming from different categories (Erasmus, 2001, p. 75). Erasmus (2001) and Lewis (1987) state that through racial classification and separation of different categories of Coloureds, the government was able to

systematically divide and further oppress the Coloured people. People with Indian features who had '*steil hare*' (straight hair) were identified as Cape Coloureds or Cape Malay, whereas people with flat noses and 'kroes' (curly) hair were categorised as 'other coloured'. Sharing a memory of being racially classified during the 1950s, a woman explained: "He looked at my profile from the right side, then from the left, then he examined my hair [...]. He touched my nose and asked me what my mother looked like" (La Guma, 1988, p. iii).

Erasmus (2001) says: "It [colouredness] has been negatively defined in terms of 'lack' or taint, or in terms of a 'remainder' or excess... associated... with immorality, sexual promiscuity, illegitimacy, impurity and untrustworthiness" (p. 17). Classifications of Coloureds almost always suggested that they 'lacked' either 'whiteness' or 'blackness', someone who is not white, is not black African and is also not Indian (Erasmus, 2001; Adhikari, 2005). Marike de Klerk, who would later be the First Lady when she was married to F.W. de Klerk, in 1983 described Coloured people as "non-person(s) — the people who were left after the nations were sorted out. They are the rest" (Jansen, 2018, p. 1). To this day, Coloured people endure racial slurs, insults and discrimination.

Hendricks (2001) is of the view that Coloured identity is constantly being reconceptualised by Coloured people themselves after Apartheid. Some, who self-identify as Coloured, view coloured identity as a racialised, social identity and not a social construction imposed by the former Apartheid regime. Erasmus (2001) argues that Coloured people are trying to distance themselves from 'blackness' and align themselves with 'white-identity', with whom they share a language and religion. This was demonstrated by voting patterns during the elections in 1994 when Coloured people continued to vote for the same party (National Party) that had oppressed them during the Apartheid era (Eldridge & Seekings, cited in Erasmus & Edgar, 1999). Whatever one's stance, it seems fair to say that the history of Coloured identity has been heavily shaped by racial oppression imposed by the Nationalist regime on the one hand and, on the other hand, by the cultural creativity shown in response by Coloured people themselves.

The understanding of identity has largely been contested and transformed in numerous disciplines and academic discourses from being regarded as one that is imposed by the dominant group, to being considered as one that is redesigned by the oppressed group. According to Chatman, Eccles, and Malanchuk (2005), identity is a fundamental phenomenon in primordial social theory. In South Africa, the imposed colonialism and Apartheid categories

of separation are impossible to ignore, as they serve as clear markers in the autonomy of one's identification or self-identification (Erasmus & Pieterse, 1999; Erasmus, 2001). In this primordial view, identity is understood to be already existing, an identity one is born into, with constituted and structured boundaries such as religion, language and culture. Nagel (1994) asserts that identity is both the "individual's self-identification and outsiders' identification of an individual" (p. 154). However, to say that "ethnicity is socially constructed is not to deny the historical basis of ethnic conflict and mobilisation" (Nagel, 1994, p. 237).

The notions of race, ethnicity and identity are said to be unnatural, socially manufactured, and ambiguous, constructed on particular biological, natural and cultural affiliations (Erasmus, 2001). From a social constructionist view, identity is dynamic, fluctuating and in a state of development as a result of how one responds to the changes in social settings and one becomes a product of such construction (Calhoun, 1994; Tajfel, 1982). Furthermore, it also includes the self-perception of the individual as well as shared characteristics and interactions with others (Chatman, et al., 2005). Other aspects of identity are "individuals' likes and dislikes, attitudes, beliefs, values, ideologies and worldviews, skills and competencies, as well as their social roles and descriptive attributes such as race, ethnicity, gender, social class, and religion" (Chatman, et al., 2005, p. 117). Understanding that the notions of race and ethnicity may be socially and politically fabricated is crucial, in that race is fabricated and manipulated within these discourses and further defined by a set of conditions, and shaped within political and economic contexts.

The nature of Coloured identity is therefore controversial and much debated, mostly around the ambiguity that results from 'mixed-race' descent (Gilroy, 1987; 1990; Goldberg, 1993; 2002; 2006), as well as the previously discussed view that Coloured people themselves seek to identify with white people. Erasmus (2001, p. 65) notes that a "discourse of racial and ethnic classification plays a larger part in producing certain types of identities... which makes them real when we provide them with everyday meanings". While we are now living in what is regarded as the 'new South Africa', I argue that a Coloured identity is still characterised by continued interrogation of its legitimacy and position even within the 'new' dispensation. Some scholars state that the ambiguity of racial, ethnic and cultural identity continues to influence the identity of Coloured people (Petrus & Isaacs-Martin, 2012), albeit in ways that are

experienced differently by different people. As the shaping of my identity intersects at the point of being Coloured and being a CODA, I discuss their influences next.

3.4 The shaping of identity of CODAs

The identity formation of CODAs is commonly regarded as being complex, as they form part of the dominant hearing community and their Deaf parents form part of a minority community with opposing norms and standards (Preston, 1994). Shield (2005) undertook a study exploring issues surrounding CODAs in relation to their identity formation in the context of Deaf ideologies. The author reported that while CODAs may feel that they are Deaf on the inside, they could still possess a sense of not belonging in the Deaf world by virtue of the fact that they are hearing, which could force them to adapt to and learn hearing behaviours (Shield, 2005). The same author reported that some CODAs feel marginalised in the Deaf community, as a result of boundaries set by parents' actions and telling them they are different because of their linguistic choices and abilities (Shield, 2005).

Hearing children who grow up with signing parents are bilingual and bicultural because they share their Deaf parents' language and culture, and in time, they also share the language and norms of the hearing culture (Hadjikakou, Christodoulou, Hadjidemetri, Konidari, & Nicolaou, 2009; CODA International, 2014; Preston, 1994). A study was undertaken by Malik and Jabeen (2016) in Punjab and Khyber Pakhtunkhwa Pakistan and found that the identity issues of CODAs include confusion, uncertainty, doubt, loneliness and ambiguity. This could be due to the fact that CODAs may experience internalised oppression, whereby they believe the myths that surround the phenomenon of being CODAs and they may begin to behave in ways that concur with such myths (Bull, 1998). In some instances, confusion may arise from the differences that CODAs experience by being hearing within a Deaf world.

In her autobiography, Doris Crowe illustrates an example of her experience of growing up with Deaf parents. Her father was labeled as “dummy”, and she was branded merely as “dummy’s little girl” (Bull, 1998 p. 7). Preston (1994, p. 52) quotes a CODA who said: “It is hearing people who make deafness problematic”, and argues, therefore, against the assumption that CODAs feel more comfortable in the hearing community. Furthermore, CODAs may also experience rejection from their peers in the hearing community. To exemplify the scenario, I draw the following quote from the same author.

“I’m constantly looking at my face in the mirror and [signs: “I don’t know. I don’t know who that is”]. It’s one of the first questions everybody asks me, “What was it like being the child of deaf parents? As a boy, I felt like a chameleon. I just adapted to every situation, I could be any role. And I was in that role – at least for a while. I was my mother when I had to interpret for her; I was my father when I had to interpret for him. I was the mechanic, the teacher, the car salesman. I assumed the personality of whoever was speaking at any given time. I was that person. I was whatever anybody thought I should be. You know, I fit into that mould just like a chameleon” (Preston, 1994, p. 1681).

Preston (1994) asserts that CODAs are not Deaf but not hearing, hence they are both Deaf and hearing. In other words, CODAs straddle between both the Deaf and hearing worlds (Mand et al., 2009), including in schools as discussed in the following paragraph.

An observation made by Bull (1998) is that families often do not realise that their children are bilingual and bicultural until school-going age, but teachers often lack an understanding of Deaf culture. “In addition, most hearing children in Deaf families are visual learners; thus, it may be challenging for them to process information audibly instead of visually” (Frank, 2014, p. 6). Preston (1994) noted that these children only realise their difference when entering school and may only gain acceptance and understanding of these differences in adulthood. In Preston’s book (1994), *Mother Father Deaf: The Heritage of Difference*, an ethnographic study of adult children of Deaf adults in the United States, he clearly illustrates the polarisation that happens as CODAs live in two cultures:

“When I’m sitting in a room or walking down the street, people look at me and they see this hearing person. That’s all they see. But just beneath the surface, there’s this deaf person. I’m not talking about hearing loss; I’m talking about a whole way of being. The real I am deaf. If you want to know me, you’ve got to know that part of me” (Preston, 1995, p. 216)

The above quote brings to the fore the concept of biculturalism, which, according to Leigh et al. (1998, p. 330), “...encompasses the notion that an individual is able to gain competence within two cultures without having to choose one culture over the other.” However, Theunissen (2008) states that CODAs experience an identity crisis as a result of growing up in two

opposing worlds; they hardly know about biculturalism because it is not explained to them in childhood. Two-thirds of respondents in Theunissen's South African study reportedly experienced stigmatisation by the hearing community as a result of having Deaf parents. Respondents also reported that they had not acquired bicultural identity before the age of 16 (Theunissen, 2008).

According to Nelson (n.d.), bicultural identity refers to the state of being oneself while knowing two cultures, and it is linked to being bilingual or multilingual. When a person learns an additional language and spends a considerable amount of time using that language on a continuous basis, the person inevitably adopts characteristics of that additional language. Nelson (n.d.) states that combining the new language and culture with the old language results in the person developing "a new hybrid identity." In Theunissen's (2008) study, some participants reportedly felt that their identity was still foreign to them, while others felt that they identify more with being Deaf than hearing. Respondents also reported that their parents did not know about or understand the term bicultural identity, and were thus uninformed about their child's challenges of being a member of two worlds.

Some CODAs feel that they grow up at a very fast pace compared to their non-Deaf counterparts because they often act as interpreters or mediators. They have to make decisions and be spokespersons from an early age (Lane, et al 1996). Personal and cultural identities play a vital role in the developmental stages and life experience of all children (Leigh et al., 1998). The point is that CODAs have more 'hearing' principles than a Deaf person who is raised by Deaf parents. However, CODAs and their parents are interconnected, and it is, therefore, important to understand that they have an intimate relationship with the Deaf community, sharing both the experience of culture, Deafness and disability (Mand, et al., 2009). However, limited communication, parent-child role misperception, unwanted responsibilities, and ambiguity as to their identity, may lead to frustration and strain in communication (Frank, 2014).

3.5 Conclusion

In this chapter, I discussed Coloured identity against the backdrop of Apartheid ideology, as well as the shaping of identity in CODAs. As I stated before, the necessity of this chapter arose from the fact that my lived experience, including my identity formation as a Coloured CODA

in both the Deaf and hearing worlds, was rooted and forged by the Apartheid system of South Africa in which I was raised. In the following chapter, I unpack the methodology that I used in undertaking this research.

4 Chapter 4: Methodology

4.1 Introduction

In this chapter, I articulate the methodology I used to undertake this study, as well as my philosophical standpoint that guided the study. I discuss the rationale for choosing the auto-ethnographic approach, the thematic analysis approach as well as the ethical considerations that I took into account as part of the study process. I begin by outlining my philosophical standpoint.

4.2 Philosophical standpoint

This study was guided by the constructivist critical paradigm of inquiry. A constructivist standpoint asserts that knowledge is constructed by a person via the individual's interaction with the environment (Denzin, 1997). Reality and knowledge are therefore not based on an absolute or objective single value that can be tested through strict 'scientific' methods in a laboratory. They are constructed socially as the knower interprets reality in accordance with his or her experience, thereby coming up with a number of subjective realities (Lincoln & Guba, 1985). As such, both the researcher and the participant are part of the process of constructing knowledge and, therefore, they cannot be detached from one another. However, in the auto-ethnographic approach upon which this study is grounded, I am both the researcher and the participant. As such, and following in the footsteps of Mendez (2013), I sought to understand my own experiences as a CODA in ways that I believe are setting the stage for future research building on this study.

The constructivist critical paradigm of inquiry seeks to promote the empowerment of people, to enable them to rise above the limits that are assigned to them by the intersection of various identity markers such as race, gender, class and disability (Creswell, 2013). Through the facilitation of their voice, people are equipped for self-advocacy in ways that enable them to challenge relevant social injustices. Auto-ethnography allowed me to explore my own previously silenced voice in the hope that the opening up of my voice will result in gaining personal strength and leaving an impression on policymakers and practitioners. The idea is to enable them to gain an in-depth understanding of the needs and concerns of CODAs, so that

they may be attended to. My choice of a constructivist critical paradigm of inquiry was guided by the aims and objectives of this study, which I outlined in the introductory chapter.

4.3 Research Methodology

I used auto-ethnography, under the qualitative research paradigm, to undertake this study. Qualitative inquiry is grounded in the belief that reality is composed and framed through the interaction of people with the settings in which they live (Silverman, 2000). Denzin and Lincoln (2000, p. 3) state that “...qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meaning people bring to them.” However, within qualitative studies, a researcher may take various approaches that include auto-ethnography, grounded theory, case studies, or phenomenological studies among others. I chose auto-ethnography because I deemed it to be the most appropriate approach to enable me to voice my experience as a CODA.

Auto-ethnography is a combination of both autobiography and ethnography, in which the author retroactively and selectively reflects on and writes about past experiences (Ellis, Adams, & Bochner, 2010). According to Denzin (2003), this methodology involves turning the “ethnographic gaze inward on the self (auto), while maintaining the outward gaze of ethnography, looking at the larger context where self-experience occurs” (p. 260). Auto-ethnography comes in various forms that primarily include evocative auto-ethnography and analytic auto-ethnography (Mendez, 2013). I chose to use evocative auto-ethnography because analytic auto-ethnography seeks to mediate and interpret the narratives of a distinct group of people. The focus of this study is not on generating and analysing narratives of a group of CODAs, but rather on mediating and highlighting my own experience of being raised as a CODA. I, therefore, chose to draw advice from Mendez in using evocative auto-ethnography, thereby enabling me to engage in introspection on my personal experiences, and to allow the readers to connect with my experience and feelings as both the researcher and participant.

The heart of evocative auto-ethnography lies in the ability of the researcher to intimately narrate and analyse his or her own narrative in relation to a particular subject (McIlveen, 2008). Evocative auto-ethnography permits the author to view him or herself as the phenomenon and to write an evocative narrative which is distinctly focused on his or her academic study and personal life (Ellis et al., 2011). That is not to say that the researcher just writes about his or

her personal experiences. Instead, the researcher is critical about such experiences, within the context in which the study develops (Mendez, 2013). According to Ellis (2007), evocative auto-ethnography involves a back-and-forth movement of the researcher between reporting his or her own experience, examining his or her own vulnerabilities, and at the same time illuminating the wider context within which the experience took place in an almost therapeutic way.

Kiesinger (2002) and Poulos (2008) propose that writing personal stories can be a form of therapy for authors as they write to make sense of themselves and their experiences. Adams, Jones and Ellis (2015) state that social life is disorganised, uncertain and emotional, hence if we desire to explore social life, we need to embrace a method of research that accepts and acknowledges emotional disorder. Another view is that writing “is expressive”, a “method of inquiry” (Richardson, 2000). Richards (2008) views auto-ethnography as an emancipatory discourse since the person that is being emancipated is the one who is representing him or herself, as opposed to “...being colonized by others and subjected to their agendas or relegated to the role of second-class citizens” (p. 1724).

Evocative auto-ethnography has been hailed for providing open access into the lifeworld’s of researchers within a setting where the collection of data is easy. The researcher draws upon his or her own experiences as the point of departure for investigating a distinct phenomenon. However, the research approach is not without criticism (Mendez, 2013). It is the ease of accessing data that has attracted condemnation, alongside the view that an analysis of a personal narrative is limiting in terms of the conclusions that a researcher can draw. Nevertheless, I side with Bochner and Ellis, (1996) and argue that auto-ethnography is not just about one person but is linked to the ‘world’ that the researcher lives in, and is therefore beyond the narrator. Furthermore, evocative auto-ethnography holds the potential to make a contribution to the lives of others, who did not participate in the study. The findings may trigger their own reflection on and their empathy with the presented narrative. In resonance with the assertion made by Mendez (2013), I argue that by reading about my experience of being raised as a CODA, some people may become aware of the realities of their own lives, thereby demonstrating that evocative auto-ethnography is a valuable way of inquiry.

Reed-Danahay (1997) suggests that evocative auto-ethnography is authentic, as the voice of the insider is assumed to be ‘more true’ than that of the outsider, and it is evaluated on the

detailed complex narratives and standards of ethical self-consciousness. It consents for and welcomes the peripheral view, setting the scene for the “telling [of the] story, weaving intricate connections among life and art, experience and theory, evocation and explanation” (Jones, 2005, p. 765). Furthermore, it provides insight into the area which the insider wishes to highlight, thereby evoking readers to immerse themselves in the writer’s world, to bring better understanding of the narrator in relation to the topic under investigation (Chang, 2008). For example, in sharing his journey during an inflammatory back disease, Sparkes (1996, p. 463) talks about blurring genres of academic and personal writing that “take you as the reader into the intimacies of my world...in such a way that you are stimulated to reflect upon your own life in relation to mine”.

4.4 Participant Selection

The approval to undertake this study was given by the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town (536/2017) (Appendix 1). I did not experience any challenges with access to participants as I am the sole participant in this study. However, the consideration of ethics within a research process is important to avoid any occurrence of harm to participants and to deal with any vulnerabilities that may arise due to taking part in the study (Gray, 2009). I anticipated the risk that as both a researcher and participant, I could experience distress due to remembering incidents that may have been difficult for me to deal with in the past. I, therefore, discussed this issue with my supervisor who then acted as a source of psycho-social support throughout the study process; my supervisor, Dr Brian Watermeyer, is a clinical psychologist. As I am the only participant in the study, a sampling procedure was not required. Furthermore, this study does not encompass any inclusion or exclusion criteria because I am both the researcher and participant.

4.5 Ethical Considerations

4.5.1 Informed consent

As noted by Ellis and Bochner (2000), a personal narrative is not limited to an individual because, in the course of experiencing one’s life world, the person is linked to particular settings and people who will emerge in the process of telling the story. The emergence of sensitive issues involving other people that have been or are still part of my life is a possible reality. Therefore, I obtained consent from my family members and particularly from my mother and father, after explaining to them what the study was all about. While Wyatt (2006)

states that informed consent does not free the researcher from feeling guilty about revealing the parts that other people play in the researcher's life, assuming that they would have preferred to keep such information private, I did not experience this guilt in relation to my immediate family members because they were supportive of the study. I did, however, feel a bit of guilt about my extended family members from whom I was unable to officially obtain informed consent, but I made sure that I informally conversed with them about the study to make them aware of its existence. Ellis (2007) states that, within auto-ethnography, there are no clear-cut answers or standard rules in relation to how far a researcher should go in adhering to ethics of research, and so the obscure and generic ethical principle of "do no harm" persists.

4.5.2 Beneficence

Beneficence concerns aspects of balancing the benefits of a study and the risks to participants (Gray, 2009). The methodology that I used in this study did not allow me to hide my identity, and thus it is possible that the study can be linked to other characters who feature in the narrative, including my family members. However, I proclaim that, although my family members are not direct participants in this study, they supported the study and they enjoyed listening to my narrative as I regularly read it out to them as the study progressed. They were also pleased to know that the important roles which they played in my life had been illuminated in my narrative in ways that could help other CODAs and Deaf-parented families to be understood and to perhaps gain inclusion in all aspects of life.

4.5.3 Privacy and confidentiality

This evocative auto-ethnography represents a real-life story. I am therefore not using a pseudonym in this study, but I am also not mentioning the real names of my family members, instead referring to them as, for example, my mother, father, uncle and sister. The reality is that there is a possibility that they can be identified through association with me. However, there are no guiding principles of attending to privacy and confidentiality in an auto-ethnographic study, lest one risks erasing oneself and disappearing in one's own study (Megford, 2006). I concur with Ellis (2007, p. 26), who states that "auto-ethnography itself is an ethical practice." In keeping with Ellis (2007), I have therefore striven to be as honest as possible in narrating my experience of being raised as a CODA.

4.5.4 Justice

The principle of justice means that people who participate in research should not be discriminated against and should be treated fairly, in relation to the distribution of burdens of the study as well as its benefits (Gray, 2009). The research findings presented and discussed in this thesis have helped me to understand my lived experience of being raised as a CODA in Apartheid South Africa. I hope that such findings will instigate other CODAs to reflect on their own lives and undertake studies on the subject. I plan to disseminate the findings of this study through publications in scientific journals.

4.6 Data generation

The source of my data was a reflective journal, an example of which is presented in Appendix 4. The journal assisted me in providing a background story pertaining to my discoveries and personal experience both as a CODA and throughout the research journey. Kamler and Thompson (2006) state that:

“a reflexive approach makes the subject and the object of an activity the same. The reflexive practice uses both the personal and discursive ‘I’. Reflexivity means looking for the social in the individual account, asking how particular events, categories and assumptions might have been produced through discourse, culture, political affiliations, or social practice” (p. 66).

The reflective journal process differs from person to person and depends on the purpose of the journal. Journals can be written for personal or research purposes (York, 2006) and may also be written to develop and monitor one’s professional development. My journey explored my identity development in the light of not only being a CODA, but also a Coloured female who was born and raised in Apartheid South Africa. My memories, thoughts, decisions, and observations throughout my childhood, adolescence and young adulthood were recorded in the journal. Critical reflection and particularly critical self-reflection have been an ongoing process throughout this study. It is not possible to recall, write or critique events in language that describes exactly how one lived, felt and experienced the event. However, I continually revisited my journal entries and spent time reflecting on what had already been captured during the writing of this thesis. According to Ortlipp (2008, p. 704), “keeping and using reflective research journals can make the messiness of the research process visible to the researcher who

can then make it visible for those who read the research.” My reflective journal was thus the source of my data.

4.7 Data analysis

The subject of data analysis in auto-ethnographic studies is controversial (Ellis, 2007). Some scholars argue that by writing the story, the researcher has already engaged in the process of data analysis because auto-ethnography is both a process and a product used to systematically describe and analyse cultural and personal experiences (Ellis, Adams & Bochner, 2011). Other scholars argue that the practice of writing a story that is devoid of a distinct data analysis approach is tantamount to ‘killing’ the scholarly potential of auto-ethnographic studies, be they evocative or analytic (Wall, 2016). However, there is no single standard way of analysing auto-ethnographic data, as the forms of auto-ethnography differ. Therefore, qualitative researchers are free to choose options that are relevant to their studies (Ellis, Adams, & Bochner, 2010). For example, some writers may prefer to keep their stories separate from a distinct analysis approach, while others may choose to integrate the stories and the analysis (Ellis, 2007).

I used the method described by Wall (2016) and adopted a thematic analysis approach. Hence, I showed the themes that emerged from the story in the presentation of findings. The data analysis process began by drawing data from my reflective journal and my own written narrative. Both processes enhanced my familiarisation with the data as the first step of thematic analysis (Gray, 2009). I organised my own story and repeatedly read it, before I began to manually and strategically separate words and sentences, in a process of manually coding its key elements (Wall, 2016). I identified common patterns by coding parts of the story that were relevant to my research question and theoretical concepts, but without trying to fix my story into predetermined codes. My analysis was therefore driven by the theoretical concepts that guided the study and the nature of the data, hence it was both deductive and inductive. An inductive approach which is guided by a flexible and open process, allows patterns to emerge from the data (Braune & Clarke, 2006). Drawing practice from Wall (2016), I combined the codes, putting together codes that established a particular theme, while at the same time establishing the relationships between such themes and seeking to achieve and maintain the coherence of the story. However, the narrative does not unfold in a linear fashion but rather goes back and forth, representing my past and present feelings and experience, as well as my future aspirations.

4.8 Risks involved in the study

The study caused no harm to the d/Deaf or hearing communities as the research was based on my own lived experience. I do not believe that this study portrays CODAs and Deaf families in a bad light, because it is not just focused on illuminating ‘bad’ experiences, but also demonstrates the agency of both CODAs and their family members. However, any ‘bad’ experiences that are reported are not meant to reflect negatively on CODAs, but are meant to illuminate their needs and concerns so that they may be addressed by policymakers and practitioners. Written and verbal consent was obtained from my parents. I did not collect any data from them, but I did make provisions for them to consult a psychologist in the event that the study might have caused them distress. However, they were not affected negatively.

4.8.1 Credibility

Credibility is creating trustworthiness by keeping to the research participants’ understanding of the phenomenon under study (Merriam & Merriam, 2009). As this is an auto-ethnographic study with me as the only participant, clarification of participants’ responses is not relevant. However, I interwove my narrative with literature and theoretical models that are encompassed in this study’s conceptual framework, to facilitate a comprehensive understanding of the data.

4.8.2 Transferability

Lincoln and Guba (1985) describe transferability in qualitative research as the extent to which the findings can be transferred. The findings of this study may not be transferable to other contexts as they encompass the personal views of the lived experiences of one person. However, the findings may help scholars and researchers to gain insight into and develop an understanding of the possible circumstances inhabited by CODA’s in South Africa.

4.8.3 Dependability

Dependability is the accuracy of information provided by the study findings and the actual events that happened in the natural setting (Cohen, Manion & Morrison, 2007). According to Merriam and Merriam (2009), consistency between the data collected and the study findings contribute to dependability. However, it is important to note that memory is fallible. Undertaking to write about oneself could be seen as an impossible task as it requires a continual process of self-reflexivity. The findings of this study are my memory of the events that occurred in my life, from my unique and subjective point of view, with the influence of the biases of

memory. Therefore, it means that the findings of this study are not self-evidently ‘true’ in the conventional sense, but instead, they are my own interpretation of events.

4.8.4 Confirmability

Confirmability is the degree to which others can confirm the results of the study (Trochim, 2006). Yet again, as the current study comprises only my reported lived experience, outcomes cannot be confirmed with other research participants. I am curious to discover whether the experiences and interpretations reflected in this study resonate with other CODAs, and in particular, those who are part of the Coloured community in South Africa. This study’s findings relied on regular research supervision to support confirmation of the findings. I also discussed my narrative with my parents in what could be some form of “memory-checking”, although they are not participants in the study but characters that feature in the narrative. I derived some useful comments from them, such as clarification of dates when particular events took place.

4.9 First Person Writing

I chose first person writing so that my writing foregrounds the ‘I’ in order to facilitate the process of reflexivity and to allow me to desist from hiding my own identity and my location in the study (Webb, 1992). Therefore, I have not been detached from my study but have, instead, been vocal in the study, not only through my narrative but also through explaining the decision-making process that I adopted in the study.

4.10 Conclusion

In this chapter, I outlined the methodology used to gather and analyse data. Furthermore, I discussed the rationale of choosing the evocative auto-ethnographic approach. I discussed the ethical considerations and the methods to ensure rigour that I took into account. The following chapter encompasses the findings and discussion of the study.

5 Chapter 5: Findings and Discussion

5.1 Introduction

In this chapter, I describe my lived experience of being raised as a CODA in Apartheid South Africa in the 1980s. I assume that my own narrative speaks for itself, but I search for meaning out of what I am describing by mingling my own account with literature. In other words, I offer both an expressive representation of my lived experience of being a CODA and I explore what such experience may mean. I draw on the literature and the conceptual framework to enhance my analysis. My narration and analysis do not progress in a linear fashion, but interchangeably move between my past, my present and my aspirations for the future. I illuminate what I consider to be key occurrences, people and actions, to highlight their impact and relevance to my experience and the process that I have undergone and am still undergoing. By means of this auto-ethnographic account, I try to make meaning of my experience as a CODA and, in particular, as a Coloured CODA.

In seeking to answer the research question, this chapter unfolds under five themes that emerged from my narrative and its inherent analysis: 1) multilingual status; 2) multiple cultures; 3) role reversal; 4) influences on the shaping of my identity; and 5) racial discrimination. While my lived experience may be multi-dimensional, multi-layered and complex, I feel compelled to state from the onset that I do not regard myself as a passive recipient of the complexities that are embedded in my lifeworld. As evidenced by my narrative, I have over the years sought to claim my agency in an ongoing process of resolving various crises of identity. I begin by discussing the issues surrounding my multi-lingual status below.

5.2 Theme 1: Multilingual status

My mother was my first teacher; she exposed me to spoken language by using SASL and English together. She would mouth the English words, while also finger spelling, speaking and signing at the same time. I used SASL from the early years of my life and I, in part, identify as a native signer. Having equivalent proficiency in each, I see SASL and English as my first languages, but still, SASL is my home language, while English is the first language of my hearing identity. For the benefit of my parents, I use SASL at home, but in the outside world, I use English. Some studies show that children who grow up in bilingual settings are able to

navigate two languages before the age of two (Deuchar & Quay, 2000; Nicoladis & Genesee, 1997). In other words, at that stage they are able to draw on either language in relation to its relevance and appropriateness, depending on who they are conversing with (Comeau et al., 2003; Deuchar & Quay, 2000; Nicoladis & Genesee, 1997).

However, my vocabulary was complicated as I had to progress from being bilingual to trilingual, as, at the age of two, my mother began teaching me to speak Afrikaans, which was her family's first language. Afrikaans occupied a politicised space seen as a language of white supremacy; it was accompanied by a violent and racist history which, as I have illuminated in Chapter 3, sought to oppress people of Colour (Adhikari, 2006). It was not out of choice that my mother taught me Afrikaans; she disliked the language and we therefore seldom spoke Afrikaans in our house. It is possible that other Coloured people at the time took pride in speaking Afrikaans, considering that it was associated with supremacy. Although my parents had attended a school for Deaf children reserved for Coloured and black African Deaf children (Heap, 2006), they were taught both SASL and English. However, they were still expected to communicate in Afrikaans, in a context where race and the Apartheid system intersected to frame oppression. In teaching me Afrikaans it meant that I became the 'link' to communicate with her family and others who spoke the same language, interpreting from English to SASL, from Afrikaans to SASL and vice versa.

Scholars such as Buriel et al. (2006) and Frank (2014) explored the ways in which CODAs facilitate communication by interpreting Sign Language and English. CODAs are bilingual and bicultural, as they share the language and culture of their Deaf parents but also acquire the dominant, spoken mode of communication and become members of the hearing community. For me, in South Africa, my experience of interpreting as a CODA could not just be limited to interpreting between SASL and English. Influenced by the Apartheid system, I also had to learn to interpret a third spoken language, that of Afrikaans, an additional language. My mother has always been proud of the fact that I am fluent in three languages, English, SASL and Afrikaans, and that I am able to interpret everything that is said in her presence. In my childhood years, she would often jokingly say that she had to teach me Afrikaans so that I could tell her when anyone was gossiping about her. Interpreting SASL and English as a child was stressful enough, and having to translate from one spoken language into another was added

responsibility. For example, when Afrikaans was spoken, I had to translate it into English first, to make sense of it in my head, and then translate it into SASL so that my parents could understand the full context of what had been said.

Whenever I used the wrong words, I would be very embarrassed. For example, I remember visiting the dentist, and in conversation, she mentioned that she had flu; I signed to my mother that the dentist had said that she had the 'floor.' Luckily for me, the dentist could not sign. While my mother felt proud of me, experiences such as these made me feel stupid and frustrated. I wished that the dentist had been able to use SASL as she would have made life easier for me. Napier, Rohan and Slayter (2005) suggest that the languages of bilingual people alter later with their evolving life circumstances. Within the colonial context of Apartheid and to my frustration, my own languages were altered in my childhood in the 1980s to include Afrikaans over and above English and SASL. However, CODAs may at times not be allowed to disclose their frustration to others, for fear of being labelled as disloyal to their Deaf parents (Buchino, 1990). I kept my frustration to myself in the circumstances where my sister and I were stigmatised together with our parents on the grounds of their Deafness.

While I was growing up, my parents were referred to by others as 'deaf and dumb'. Similar to Doris Crowe's experience described in Chapter 3, I would often hear people refer to my Deaf parents as '*dommies*' (dummies). My parents were generally regarded as people who spoke broken English and had funny voices. Consequently, my sister and I were perceived as people who had speech problems, and our hearing was repeatedly tested. I knew that behind my back I was also referred to as 'dumb' – after all, that is how my parents were viewed. On reflection, I now realise that oblivious to the social model of disability (Barnes, 2011), in etic constructions of deafness, some people regard Deaf people as sub-standard beings. This interpretation is in accordance with the archaic medical model of disability in which deafness is considered an illness of not being able to hear (Murray et al., 2007).

I do not believe that I had significant problems with my speech development, but I recall having a lisp and being teased for it. This lisp, combined with the fear of being called dumb, led me to start practicing my speech each day. While Bishop and Hicks (2005) state that CODAs commonly feel the need to protect their parents from negative perspectives about deafness, in

this case, I was concerned about protecting myself from labels and stigma. I would always need to first visualise the sign in my head and pronounce it to myself before uttering the word from my mouth. I had and still continue to, constantly step back into the Deaf world to ‘understand’ and then step back into the hearing world to express myself.

The above scenario had a real negative effect on my participation in school, as I could hardly answer any questions in class for fear of mispronunciation or lisping. I don’t think my teachers ever noticed that I was fingerspelling words underneath my desk during tests. I would sign to myself, in order to make sense of what I was reading. Knowing SASL, it seems, was good for my grades, but it also resulted in a lack of confidence that limited my willingness to express my thoughts. I knew the word in my head, but my mouth simply would not utter it. I had a constant fear of embarrassing myself and sounding stupid and was fearful that my stupidity would be linked to the impairment of my parents. As an adult today I still have the same fears. This stepping between two worlds was overwhelming and emotionally draining, but I would still manage to remain calm. Furthermore, I didn’t want to be associated with demeaning assumptions and words such as ‘dom’ (stupid) or ‘dommie’ (dummy). Fortunately for me, I was surrounded by very supportive teaching staff and classmates, and I can’t recall a time when I received bad grades in my primary school years. On the contrary, I would often be asked to read to the class and I tutored some of my classmates with their Afrikaans reading.

Nevertheless, I often found it difficult to express myself verbally in a group and the same challenge has persisted into my adult years. Now, as an adult, I continue to find it difficult not to speak with my hands, as I feel that using spoken language is not enough – that my words are not expressive enough. Like a painter expressing myself on canvas, I need my audience to see what I am saying. Frank (2014) states that because hearing children in Deaf families are typically visually-oriented learners, processing information orally rather than visually may be a challenge for them. Similar to the findings of Singleton and Tittle (2000), from my early childhood years, my use of language has been changing along with a changing environment, or simply as the need arises.

According to my mother, I was fluent in SASL by the age of two, and by four I was a fully-fledged family interpreter, often filling the role of the sole conduit of communication of my

family with the outside world. As a result, I was regularly exposed to situations that exceeded my level of maturity at that time, forcing me to function as an adult while still a child. I became an interpreter without my even realising it, because nobody appeared to understand my mother and my father. My usefulness as an interpreter depended on my having achieved fluency in SASL as well as being an English and Afrikaans speaker, as the Deafness of my parents and language intersected to frame my experience. Hadjikakou et al. (2009) found that when CODAs do not become fluent signers, their interaction and communication with their parents are likely to be limited and superficial. As I was fluent in SASL, this was not the case for me.

However, my relationship with my parents, and more so my mother, became strained during my teenage years. My mother decided that I should attend a Catholic school for girls. Her decision not only angered me but I also felt disrespected. After all the adult responsibility I had assumed for my parents, they had now decided that I was not able to make my own decisions. It was at this time that I began to secretly hate SASL. I felt that the Deafness of my parents had wholly consumed me and forced me to take up a responsibility that I did not ask for, thereby depriving me of a normal childhood. When considering Erikson's theory of developmental stages, identity formation reaches its peak during the adolescent years, with the onset of maturity bringing a phase where one begins to desire to frame a form of stable identity (Erikson, 1950). Reflecting on my feelings and experience of that time and drawing on Erikson's theory, I was beginning to raise questions about who I really was in relation to decision-making, SASL, and the hearing world during my teenage years.

Although I began resenting SASL as it had consumed a large part of me, it is still the mode of communication that connects me with my parents and vice versa – a 'bridge' across the difference between them and I. For example, when I was thirteen, I cut my right-hand thumb and injured a tendon that needed an emergency surgical procedure. I experienced excruciating pain. The doctor approached my bed as I was being pushed into the theatre, and he began to explain what he needed to do. Before he even finished, I responded by saying "please fix my hand, my parents are Deaf and I need my hands to communicate with them." Even though I was in pain, I was constantly thinking about my parents. My resentment that SASL was a limiting factor in the educational choices that I wanted to make as an adolescent, coupled with the belief that I had to 'take care' of my parents, created conflict in me and marked the

beginning of what I would call an identity crisis. Erikson (1950) explained that identity crises may arise when there is instability and confusion, in scenarios where adolescents struggle to make choices and to deal with the alternatives that they encounter. Nevertheless, reality demanded that I soldier on with my life as a CODA within a multicultural context, which I discuss below.

5.3 Theme 2: Multiple cultures

International studies indicate that CODAs are bicultural and bilingual (Leigh, 2009; Hoffmeister, 2000; Singleton & Tittle, 2000; Torres, 2003). However, in South Africa, this may differ as some CODAs are exposed to more than two languages and may view themselves as multicultural and multilingual, and further have to connect with a South African community which embraces many other languages and cultures. One of the common norms of growing up in Apartheid South Africa was that one had to be subjected to a legislated set of racial descriptors which determined who, what and where one ought to be, thereby adding another dimension to my identity formation.

In conversations that I have had with other people on the subject of race and culture, I first of all start by identifying myself as an African and not necessarily part of a racial group. After identifying myself as African, I may then say I am a South African, I am female, I am racially classified as Coloured, I am a CODA and I use English, Afrikaans and SASL. In the hearing community, I am the girl with the Deaf parents and in the Deaf community, I am a CODA, a Mother Father Deaf child. I feel that I have always been categorised and labelled, beginning in childhood and up to this day. I feel that I have never really found a place where I developed a sense of belonging. The multiplicity of cultures, Deafness, race, nationality and gender have therefore intersected and contributed to the identity crisis of which I became conscious in my adolescent years.

According to Bull (1998), the confirmation and acceptance of personal and cultural identity of CODAs may only occur in adulthood, after encountering people with similar demographics. Until that point, CODAs may remain split between two worlds and split in their identity. I feel that I have not yet fully resolved the issue of my own identity, albeit the fact that I have done

well in some areas of my life in relation to autonomy, trust and initiative, the markers that are suggested by Erikson (1950). For example, I have secured employment and I continue to oversee the welfare of my now elderly Deaf parents, in a dichotomous Deaf/hearing cultural world. Whether d/Deafness is classified on the basis of hearing ability or cultural association, both definitions set up a dichotomy between hearing and d/Deaf, such that in some instances, being one means not being the other (Pizer et al., 2012). Preston (1994) noted that many CODAs only realise their conflict regarding self-identity at a later age, some only in adulthood. Singleton and Tittle (2000, p. 27) made the provocative statement that Deaf parents are in effect raising ‘foreign’ children. The implication here is that while parents are part of the Deaf community, their children are bicultural and bilingual, with access to cultural and community life outside of the Deaf world. Personally, I have always felt different, but the same. I grew up in two worlds – different to my parents’ world but bound by a Deaf culture which separated me from my peers, to whom I was, in turn, bound by hearing and society’s definition of normalcy.

As indicated earlier, the support that I received from my classmates resulted in my feeling protected, and allowed me to develop a sense of freedom. The playground served as my hearing world while the classroom and fingerspelling drew me back into the Deaf world. However, time at school was blissful; in fact, to avoid my duties at home, I would do homework at a friend’s house and participate in extra-mural activities. In this way, for a while, I escaped my responsibilities at home. I loved music and dancing, and I participated in every school play. School plays provided another space where I felt I could be myself, but this too came at a price. The worst part was stepping onto the stage. As I prepared to perform my part, whether as a vocalist or an actress, I would be filled with emotions of anxiety, fear of sounding stupid on the stage, and anger.

Although I was excited to escape to the hearing world, I was also saddened by the fact that my parents would not be there to watch me perform. Nevertheless, I would find comfort in telling myself that there was no point in them attending as they would not be able to hear me sing. I felt that my parents’ inability to hear created a barrier for me – my family was abnormal and their disability limited me. I tried to compensate for everything by not limiting the help that I gave them. In a study conducted by Buchino (1993), CODAs reported satisfactory and good

relations with their parents. This is in contradiction to the findings of Allsop and Kyle (1997) and Bishop and Hicks (2005), who reported that CODAs recounted difficulties in sustaining good relationships with their Deaf parents, especially during adolescence. Preston (1994) reported that most CODAs view deafness as negative, being a cultural minority, and as a disability, as viewed in the medical model of disability. From my own experience, the event of strained relations with my parents arose when they wanted to make decisions for me, such as the school I should go to, when I felt I had been their ‘parent’ from my early childhood. Preston (1996, p. 1682) suggests that the responsibilities of CODAs create the misconception of family dysfunction: ‘a child in charge of a disabled parent’.

The point is that having to traverse these different and differently valued worlds that create conflict and struggle in CODAs is challenging. Deafness and disability were not an experience of my own. Instead, mine was one that was derived from my parents’ interactions, realities and dynamics within an environment that was not very accommodating to their needs. With regard to multiple cultures in my life in my positioning as a CODA, I have recognised that I am not Deaf, but I am also not fully in the hearing world. My racial identity is located, to some at least, on a borderline. In relation to culture, I am a Coloured African. On the one hand, I feel that I have not yet resolved my identity crisis, but at other times I feel that the responsibilities that I assumed in my childhood set the stage for me to progress towards some form of stable identity, not Deaf but also not hearing, Coloured but African culture, female but CODA. It is evident that the disability of my parents and intersections of my race, culture and gender shaped the process of my identity formation as a CODA in a context where I also assumed a parentified role at a very early age, as discussed below.

5.4 Theme 3: Role reversal – being born into responsibility

By being the interpreter for Deaf parents from an early age, a role reversal of parentification of a child may occur. Buchino (1993, p. 44) describes role reversal as when children feel that they are responsible for taking care of their parents, and in turn, the parents feel that the children should take care of them. From as early as three years old, I always accompanied my mother wherever she went. As a result, the opportunities for ordinary childhood developmental activities were reduced. I was always the interpreter, the ‘ears and mouth’ of my mother, an

extension of her. My father converted the space in front of our door into a play area for me – that way, I would always be nearby. I would have preferred to climb the tree by the roadside or play games with the neighbours' children. But my mother would explain that there were cars on the road and that if I was run over or if anything happened to me, she would not be able to hear me cry because she is Deaf. I understood the play area to be a safe place for me to play; instead, it was there so that I could be near to my parents at all times. I find it interesting to juxtapose this fact with the assertion by Strom et al. (1988), who state that in spite of communication and mediation challenges experienced by Deaf parents, they are still capable of being good parents. Lawson (2008) revealed that Deaf parents often develop strong bonds with their hearing children, in the sense that the children often stay closer to their parents to facilitate communication. I knew I had to facilitate communication between my parents and hearing family and community members, and thus, as the interpreter, I always had to be nearby.

In the following vignettes, I describe examples of the responsibilities placed on me in the reversed roles, and the effect these had on me.

5.4.1 Fallopian tubes

I was five years old when my mother and I were at the hospital following the birth of my sister. The issue was that she had the option of undergoing sterilisation, and I had to interpret the conversation. Questions and answers flew, and while I was concentrating on allaying my mother's fears and reassuring her that everything was going to be okay, some of the words like 'fallopian tubes' were too long for me. Besides, I would have rather been playing with my dolls. But I had to focus – I was the only person my mother trusted. CODAs begin to play the role of interpreting at different ages but in my family (and in South Africa), I started interpreting at the age of three. By the time I was five, I was already taking my role of interpreting outside the home, as my mother would often call on me to facilitate communication between her and the outside hearing world.

There was no doubt in my mind that my role came with responsibility, but it also came with power, regardless of whether I wanted it or not. This role reversal had a profound effect on my relationship with my parents. I had to grow up faster than my peers and I often felt that I was 'in charge' of my parents, but at the same time, I understood that I had a responsibility towards

them. I discovered that the role of interpreting was placing me, as a child, in positions that would commonly be assumed by adults. My parents played their role of providing for my needs very well, but there were always situations in which I had to take charge, regardless of how young I was. This responsibility meant that I missed out on being a child. Looking at my life and seeing a big gap, I felt I had been disconnected from my childhood, as if there was some sort of longing for something deeper, within a feeling of entrapment.

As noted by Mercado (2003), there are abnormal levels of parentification and role reversal in family situations where children assume the role of language brokers. As a child, I felt as if I was responsible for taking good care of my parents. Singleton & Tittle (2000) argue that a clear definition of roles between Deaf parents and their children is a way of minimising role reversal, and the role of interpreting adds to the development and independence of the CODA. However, I question the practicality of such a recommendation, particularly in my African context of communalism, where disability is regarded as a family affair and family members are expected to help one another regardless of age. Various identity markers such as disability, race, ethnicity, gender, class, and nationality intersect to frame the experience of Deafness for both parents and CODAs. Whichever way you look at it, being myself was a struggle; I was always anxious, and I struggled to stay in my own world because whatever I did in my day-to-day life would always take me back into the 'straddle'.

5.4.2 Ambulance

An incident occurred when I was twelve. My seven-year-old sister was playing at a neighbour's house. I heard someone shouting at the gate, saying that my sister was hurt. Her finger had been closed in a door, and she was bleeding profusely. My first response was to tell my mother, then I ran to my sister's side. Crying and in shock, I asked the neighbours to call an ambulance, as we did not have our own car to take her to the day hospital. When the ambulance arrived, we were told that only one person could accompany my little sister. Without hesitation, I climbed into the ambulance as there was no doubt that I had to be the mother and that it was my responsibility to make sure that my sister was taken good care of. Even if my mother was able to accompany her, there would still be the challenge of the communication barrier. Her struggle to communicate with the nursing staff would result in frustration or even humiliation.

Furthermore, the healthcare environment is ridden by several barriers, including staff who are not SASL users, and I had to protect my mother in this scenario.

My actions were spontaneous. I felt that it was my responsibility to protect both my sister and my mother. On reflection, I attribute this event to the notion that CODAs are ‘born into’ responsibility and they often feel responsible for their families (Clark, 2003). In addition, interpreting services in South Africa at that time were not always available or accessible, leaving some CODAs with no choice but to interpret for their families. The situation is unfortunately still the same in South Africa today. I felt the need to protect my mother from the embarrassment and frustration of having to deal with ambulance and healthcare staff who may not be fluent in SASL. If my mother had accompanied her instead of me, my young sister would have had to take up the interpreter role on top of being injured and in pain. Authors such as Umaña-Taylor (2003) and Weisskirch et al. (2010) confirm that, in circumstances where role reversal occurs, children accept responsibility for their parents. I concur with such an assertion, because I feel I would often take responsibility for my parents, particularly my mother and my younger sister. Perhaps, as stated in the story of the good fortune of deaf parents to have a ‘happy’ and ‘clever’ little girl (Drum Magazine, 1983), my parents had been compensated by the birth of a ‘normal’ daughter.

5.4.3 Terrible news

It was a weekend and our family home was unusually quiet; the mood was sombre; death was lurking on our doorstep. Unbeknown to my mother, my grandfather had been admitted to hospital after his fishing vessel had capsized and he had nearly drowned. My mind was racing with thoughts about how my mother would react. I knew that her father meant a lot to her, but it was my responsibility to tell her that her beloved father was gravely ill. I considered a dozen different ways to tell her but also questioned why it had to me, and why her siblings couldn’t break the news. I thought about lying, and saying that my grandfather was just in the hospital with a minor ailment and he would be fine, but then I thought that was tantamount to deceiving my mother, and she had always relied on me for the truth. My grandfather and I had always been close. He was my confidante and counsellor, and an important parental figure in my life. Inside, I was frantically praying that God would not take him away as I felt there was no one else who would understand me the way he did. I also knew that I could not shed any tears,

because I could be called any moment and my mother would notice. As I entered the house, I looked at my mother's face, and I saw that she was looking confused and angry: "*What is going on?*" she asked. I relayed the message, my own emotions held at bay. My mother began to cry hysterically, asking between sobs whether my grandfather was going to be well; she was pleading with me to tell her the truth. My own emotional response and feelings of distress had to be sacrificed in my role as the responsible one.

My mother is not only Deaf but she also has epilepsy and is, therefore, often hospitalised. As interpreter services are not readily available in South Africa, I have to be her aide. Now, in my adulthood, I take time off work to be at the hospital and when I leave for the night, I type out a note with instructions for nurses who will be interacting with my mother. I post it on the wall behind her hospital bed, thereby giving both myself and my mother the comfort that communication will not be a challenge in my absence.

The role that I assume as a CODA is one that silently speaks of protection and responsibility of my parents and family members. I am constantly assuming that nobody understands my parents and that assumption is confirmed through my parents' responses. Beginning in my childhood, I have always felt that I need to protect them from the ignorance of society, which makes them vulnerable. While CODAs are different to their parents in that they can hear and speak, respondents in a study undertaken in the USA among adult CODAs indicated that they are often angered by the common negative societal practices that marginalise them (Preston, 1994). In other words, respondents felt the need to protect their parents against insults and negative views about Deaf people. Preston described CODAs as "repositories of their hearing grandparents' and parents' untold stories" (p. 67). Thus, CODAs absorb the shame directed towards their Deaf parents. There is also evidence that CODAs assume parental responsibilities such as looking after finances, the health of family members and everyday challenges that a family faces (Orellana et al., 2003), leading to opaque, co-dependent relationships and unclear family hierarchies. My own experiences are testimony to this reality. However, it is important to note that parents are often concerned about the effect that the role of an interpreter has on their hearing children (Torres, 2003).

5.4.4 My father's shoes

My father had been waiting to receive special shoes from a government social welfare centre for more than 18 months, due to technical difficulties in the supply chain. It was questioned why he needed them. I had arranged to accompany him to the manager of the centre to discuss how best he could get help. I made my way to the counter and introduced myself to a rather agitated lady. I was constantly aware of my attitude, reminding myself that I was there to assist my father and I needed to tune out my frustration and anger. Without explanation, she directed me to the security desk where we needed to fill in a form, and I indicated to my father what we needed to do. What grabbed my attention was the look of confusion on the security guard's face and his reluctance to give my father the form. My immediate response was that he thought that my father was stupid.

My father's independence has always been important to me, so instead of taking over the task, I responded by telling the guard to give it to him and that he could read and write. Persons with disabilities have historically been subjected to negative attitudes, underpinned by the medical model of disability (Bedini, 2000). Deaf people have generally been regarded as being both Deaf and dumb and unable to function independently. In the centre, there was by then a small audience sitting around and my first thought was that people were still staring, even after all these years. I relate this to the limited societal understanding of persons with disabilities, which further intensifies their marginalisation, patronisation and exclusion, in settings where opportunities to see their value are missed.

My father and I sat down and, after a long time, a friendly woman and the pedorthist arrived. I explained why we were there and again we were told that it could take another three months before my father would receive his boots. My father took out a plastic bag with his broken, tattered and torn shoes in it, thereby evoking a mixture of emotions in me. I was angry with the government system, ashamed of the condition of my father's shoes, and maybe even disappointed with myself, as I was supposed to help him buy shoes and I couldn't because I had no control over the system. Unable to control myself, I turned around and walked away, with tears streaming down my face. I was asked to come back but I continued to walk away as I was consumed with so many mixed emotions. At the same moment, I realised that my father needed me and I had to set my tears aside and focus on the business of the day. My father just looked at me and shook his head and signed: "*worry don't.*" I explained to the woman that this

was about my life and I disliked seeing my father suffer. She tried to calm me down by reassuring me that she was going to do all that was possible to assist us on that day.

I asked for permission to be moved to a more private space as I was constantly aware of the stares and our lack of privacy. We were moved to a small consultation room where we were joined by three other people. After a lengthy discussion of negotiating and ‘catching up’ on my father’s medical history, we were finally told that my father was going to receive a pair of boots on that day. I relayed the message to my father and he nodded and gave me the thumbs up sign indicating how happy he was. My father signed: *“you know what I need, so me not worry.”* Back in the waiting room most of the people had already left, while others were still waiting for transport. Up to this day, the scene has not changed: Coloured people sitting on the benches, looking tired and weary.

On reflection, I realise that I was tired of the treatment that my father had received. I came to the realisation that not only was I tired, but my emotions were a mixture of anger and guilt, anger at the fact that my father had to stand in line waiting, always waiting. If he did not have me as his ‘ears and mouth’, nothing would have been done. Regardless of his disability, he is a hard worker, but his hard work meant nothing as he could not obtain the basic things in life such as special shoes. He had to rely on a system that was failing him. I was also feeling guilty because I viewed it as my fault. I considered whether I should have called and relied on the person on the phone to ‘sort it out’ and also whether I should have dealt with it sooner. As I sat on the bench, I saw so many scenes; it was like a movie of the many times I had accompanied my father.

About two hours later, the manager walked in with my father’s new shoes and my father smiled from ear to ear with sheer excitement, and in his own voice, he said: *“thank you, thank you”*, showing the thumbs up sign. As we prepared to leave, I expressed my gratitude to the centre manager. After a spontaneous hug, the manager walked away crying. The tears of the manager made me wonder if she too had connected to the pain I felt or were these tears of sympathy? I wondered if it was her own exposure to disability and the understanding thereof that caused her reaction. Even though I still felt pained and disappointed, I was satisfied that my father had finally received his new boots. Nevertheless, the fact still remains that race and disability intersected and resulted in my father receiving inferior service, in ways that heightened the level of responsibility that I had to undertake at the sacrifice of my emotions.

5.4.5 Interpreting at school meetings

In school meetings between my parents and teachers, I was the only child who had to interpret and deal with my own academic progress. I also had to deal with sympathy, beginning with the repeated “*Oh, shame*” from parents of schoolmates. Despite the fact that I had a packed lunch every day, my teachers would often share their lunch with me, saying: “*it’s important for you to have a good meal every day*”. I couldn’t say that while we were poor and we lived in a wood and iron house without electricity, I was well taken care of. My understanding is that this ‘kindness’ was part of the stigmatisation of my family by the hearing community. We were seen as worthy of pity when, in fact, we were just like everyone else, except for the fact that we spoke with our hands. I felt that the negative thinking towards my parents was also directed at me. However, I would like to think that my teachers’ actions were innocent and not intended to hurt me or my parents, but perhaps teachers are socialised to believe that they should sympathise with persons with disabilities.

5.5 Theme 4: Influences on the shaping of my identity

I was raised in a time when disability was more of a disease with notions of abnormality attached to it. Stares and annoying comments were the order of the day and I often felt like a freak. As mentioned earlier, I spent most of my time in the presence of my parents, my mother in particular. I envied the freedom that my cousins had whenever I saw them playing outside. They had hearing parents, hence they never needed to accompany their parents. The feeling of entrapment drove me to visit my grandparents on my own as often as I could. These visits served as an escape from the ‘abnormalities’ of home and an attempt to satisfy my relentless desire to have a ‘normal’ childhood. At times, I felt that my family was normal save for the fact that we spoke with our hands, and the next moment I felt that my family was abnormal because it was unable to afford me the ‘normalities’ of childhood that I craved. In the midst of this ambivalence, I felt that my grandparents’ home was my safe haven away from my ‘adult life’ and it was where I was free and able to be myself.

Being away from home during the holidays brought relief from the daily pressures of my life, but it also brought about a sense of concern about how my parents would cope without me. Nevertheless, school holidays were precious days. Spending the holidays with my grandparents meant going to the beach and lots of fun. Every day was a beach day, for my cousins it was

swimming and for me it was an adventure, sitting on the harbour watching the boats come in. While seeing the beauty of the bay, I tried to make sense of the dichotomy between my surroundings and challenges on the home-front. In retrospect, I realise that in those moments while watching children splashing water, there was a great longing for me to have a carefree childhood. At that time, I was unable to make sense of my life. All I knew was that I was filled with frustration and that there was a void inside of me that needed to be filled. It was a chance to be 'normal', but this normalcy could be abruptly interrupted at any point as I could be called upon anytime to interpret for my parents back home or to undertake various tasks for them.

My grandfather was well-liked by our extended family and, as a result, we always had visitors over weekends. During the season of Lent, we had more visitors than usual. My grandfather had a generous nature and family members never left his house empty-handed. So it would be natural for them to pay my grandfather a visit, with the hope of leaving with, for example, an Easter fish. Another common experience for me when the family came over was that I could be called to come into the house at any time and everyone would be staring at me. As a little girl, I didn't think much of it other than they must like me very much. The attention from others was great and different in that it would put me in a place of praise and appreciation, or so I thought.

The relationship between myself and my grandfather was close and he placed me on a pedestal. In my thinking as a child, he wanted to show off his beautiful granddaughter. Preston's (1994) study on the firstborn children of Deaf parents revealed that the role of an interpreter produced feelings of specialness and being chosen, but also feelings of resentment towards their parents and extended family, caused by the unwanted responsibility. In Afrikaans, my grandfather would say: "*hier is sy*" (here she is) and there would be responses such as: "*haai maar sy is daarem mooi*" (she is beautiful) and "*yene, kyk hoe groot is sy*" (see how big she is). My grandfather would have a big grin on his face. He would respond very proudly: "*ja, sy is haar ma se mond en ore*" (yes, she is her mom's mouth and ears). For me that was a confusing statement as my parents had their own ears and mouth, so what did he mean? At this young age, my parents' Deafness was part of my 'normalcy.' While my cousins played outside, I had to sit inside the house and answer questions about my family, my schoolwork, what grade I was in, and many more. The response would always be "*maar sy is darem slim*" (but she is very clever).

The times that my parents were present meant that when the adults were having conversations, my place would always be with the adults. I would be required to interpret all the conversations. I was special to my parents, unique to outsiders, important and valued by my grandfather but reluctantly excluded from the extended family. In other words, I never held the same space as my cousins; I was in a paradigm of my own. As the responsibility of being a CODA forced me to mature faster, it allowed me to hold conversations with people who were much older than me, one of them being my grandfather. We would speak for hours and he often referred to me as being ‘witty’ and ‘eager’. I shared my fears and frustrations about being a CODA with him and he always managed to allay my fears, responding with a religious view that God had blessed me with Deaf parents because he knew that I would be able to take good care of them. This positive reinforcement from him helped me in my journey with my parents but it also led me to question why God would give a child such a huge responsibility.

Whenever visiting family members would get ready to leave, well wishes were often shared and the directive to me would be: “*djy moet mooi na jou ma-hulle kyk ne*” (you must take good care of your parents). As a child, I never paid much attention to that specific statement. My response concurs with the assertion made by Bull (1998) that understanding and accepting the difference often does not happen until later in life when one finds empathy with others one can identify with.

The prodding by my grandfather’s visitors made me feel like a fish in an aquarium, a priceless species that everyone wants to see. It is like children tapping on the glass and exclaiming how beautiful the fish is. That is often how I felt, and still do, in relation to the responses that I get from people I knew while I was growing up and people that I meet during this later part of my life. My role as a CODA has been characterised by comments and questions, looks of confusion turned into admiration, that has remained the same over the years. On reflection, I try to make sense of these events, wondering whether they saw me as different to my parents or a perfect extension of them. Society enforced feelings of isolation and weirdness on me. In my view, the attention and admiration is related to the myth that children whose parents have disabilities are also disabled. In other words, my experience is that the socialisation of my community could have been that persons with disabilities are not able to give birth to what society deems as ‘normal’ children.

5.5.1 Not Deaf

Now in my adulthood and after experiencing some problems with my hearing, I decided to consult an ear, nose and throat specialist. On arrival, I gave him a brief background of my medical history and informed him that both my parents are Deaf and that the challenges related to my hearing could be related to that of my parents. I had already made up my mind that I am hard of hearing. After undergoing some tests, the doctor decided that I would need to undergo a surgical procedure, to which I agreed. The operation was successful and on the last step after three weeks of monitoring the healing process, I was informed that my hearing was now going to be tested. As I entered the cubicle, I felt somewhat conflicted, concerned that I would be diagnosed with normal hearing but also excited and convinced that they would finally confirm that I have some level of hearing loss. Being Deaf meant that I would finally find a place where I belong. I would now claim to be Deaf and not hearing because I had not yet found my place in either of these two worlds. Some of my experiences confirm this notion as I get irritated by people who do not face me when they speak, which I interpret as that my hearing is poor. My colleagues know that I struggle to hear them when they speak to me from behind a computer. In my mind, it is because my hearing is poor. The audiologist had a satisfied look on her face as she indicated that I could now proceed back to the doctor's room.

As growing up in my world meant that I was half hearing and half Deaf, this had always been the frame of my identity and my socialisation did not encourage me to be anyone else. Psychologically I am hearing, yet psychologically I am also Deaf. It is a complex mix of trying to determine what I really am, with regards to hearing. With a smile on his face, the doctor said: *"I have good news for you, you have normal hearing."* I was confused and angry, and several contrasting questions ran through my mind. I questioned why I am not Deaf, but also why I was simultaneously feeling a huge sense of relief that my hearing is normal. I thanked the doctor and as I left, I felt an immense outburst of anger rising up in me, an anger that I was unable to contain. I got into my car and slumped over the steering wheel, crying my eyes out, questioning where I really belong. I was conflicted and the explanation I got from the doctor was not what I was looking for.

If the doctor had pronounced me Deaf or as having some level of Deafness, it meant that I could have gained 'entry' into and claimed my place within the Deaf community, not as a CODA but as myself in my own right. Singleton and Tittle (2000) noted that being a family member of Deaf people is no guarantee of one's automatic entry into the Deaf community. A

hearing person would still need to, first of all, have a cultural understanding of Deafness as well as be proficient in Sign Language. Although I understood Deaf culture and I was proficient in SASL, I still felt confused about whether or not I truly belonged to the Deaf culture. The diagnosis confirmed that my hearing was normal, but I subscribe to both the hearing and the Deaf worlds, albeit feeling that I have limited ‘rights’ in both. Higgins (cited in Weiner, 1997) describes the CODA’s relationship with their parents or the Deaf community as being that of advocacy for the Deaf, thereby suggesting that such a status results in the hearing child expressing feelings of rejection by the hearing community. Such an assertion resonates with my own feelings; the doctor’s diagnosis made me feel like I was being rejected by the Deaf world, and efforts to frame a stable identity did not result in a clear-cut answer to clarify where I belong.

5.5.2 So.... *who am I?*

While growing up, I was exposed to the politics and practices of both the hearing and Deaf worlds. Thus, when introducing myself to Deaf people using SASL, I would often say ‘Mother Father Deaf, me hearing’ in order to gain acceptance. By contrast, when meeting hearing people for the first time, I would not introduce myself as a hearing child of Deaf parents, just me – our shared normalcy, and our ‘fitting together’, was assumed. On reflection, I feel that it is the imposition of Deafness and the psychological experience of Deafness that pulls me in two different directions. Everything about me within the hearing world defines me as hearing, and in contrast, I am deaf in the Deaf world. Evidence shows that not all CODAs see themselves as being either hearing or Deaf; some regard themselves as being Deaf despite being able to hear (Preston, 1994). I regard myself as both.

I question whether I am a hearing person raised in a Deaf community or a Deaf person trapped in a hearing body. I’m somewhere in between, holding onto conflicted emotions. As my family is different, I too am different and bound to them by birth and a language. I can never fully belong in the Deaf culture nor in the hearing culture. People would make comments such as: “*what a special girl she is*” or “*you are so lucky*”. I did not know what they really meant with ‘lucky’. Did they mean lucky to have Deaf parents or lucky that I was born with normal hearing? Were they suggesting that my parents are unlucky to not have normal hearing? I often wondered. Regarding identity formation, Erikson’s theory explains that the confusion that surrounds identity formation, particularly during the adolescent years, may result in one

identifying both real and imagined differences (Erikson, 1950; McLeod, 2018). I describe an example of a recent experience below.

5.5.3 Coloured Affairs

As an adult, I recently found myself walking along the long corridors of the Civic Centre in Parow, a working-class Cape Town neighbourhood, when a familiar stench penetrated my nostrils, awakening perplexing memories and emotions from what I had experienced decades before. Suddenly, I was a small child again, walking down the corridor of the Coloured Affairs office, a government department which handled the affairs of Coloured people, such as applications for disability grants. Thinking back, I remembered approaching a desk where a stern-faced woman asked: “*Ja, hoe kan ek help?*” (Yes, how can I help?). I remember looking at my mother who signed to me: “*tell her why here, need help why, problem with disability have.*” I recall relaying the message to the woman behind the desk and the immediate change of her facial expression from being stern to “*Oh! Shame*” (a South African expression of sympathy).

Her voice was filled with pity as she handed me a piece of brown paper with our ‘unique’ number and she showed us our seats. I could hear the murmuring voices of agitated people waiting to be helped, along with the subtle whispers of “*shame*”. Everyone stared at us, rows and rows of Coloured people waiting for their number to be called. The stench I recall is what I refer to as the ‘poor Coloured smell’ – a mixture of poverty, stale tobacco, and smouldering fire, coupled with the smell of weak tea and peanut butter. The smell brought emotions from a deep-rooted place, and that day in Parow the smell left me feeling sick to the core, reviving memories of poverty and of how people who had been impoverished by the actions of exclusion of the Apartheid government were struggling. Furthermore, sitting on those hard benches was frustrating – I was indeed one of those Coloured Affairs Coloureds, due to not only the stigma of my mother being Deaf but also purely by virtue of being a Coloured. In this scenario where disability and race intersected, I experienced both my own oppression and that of my family. I was so distraught by this memory that I stayed home from work for the next three days, to avoid having to pass that building. It became clear to me that this was one of the many distressing experiences that had been suppressed over the years.

The impact of the South African laws and policies related to identity formation has always been a contentious issue for Coloured people. A negative influence on self-image can be attributed to the country's history of oppression and humiliation caused by the Apartheid system (Adhikari, 2006). Historically, the strong emphasis on race, class and power was a major source of identity formation for black African people and for those deemed 'Coloured'. Strauss (2013) suggests that the divisions of intra-black racism were created largely by the discourses of racialisation, within which human worth was measured through subjectivity and judgement according to perceptions of moral proximity to whiteness. Issues of racialised identity were visible in my family and community, especially from my mother's side. For example, when a young girl started dating, someone in the family was bound to remark: "*Moetie net enige man vatti ho, djy moet dink aan die kinders se hare*" (don't just take any man, you must think of your children's hair).

The above statement is meant to caution a Coloured person from dating someone who has "*kroes*" (coarse) hair. My mother was very strict and always made sure we were neat and tidy, no dirty noses, no dirty clothes, and, of course, the hair would always be done well. Like clockwork, every Saturday afternoon my mother would wash my hair and afterwards, we would go outside where she would spend almost an hour brushing my hair until it had dried. I would hear whispers from my cousins saying: "*haai sy dink sy is kwaai omdat sy steil hare het*" (she thinks she is better than us because she has straight hair). On reflection, I associate such mindsets with the fact that during the Apartheid era, criteria for discrimination included skin colour, facial features, and the type of hair to separate people on the grounds of race (Posel, 2001). In relation to my cousins, I was not a fighter but in order to get back at them, I would make similar remarks by calling them names such as: "*jou kroes kop*" (coarse head), or "*jou lelike swart gat*" (ugly black ass). While I could not, at that time, understand that my behaviour was wrong, I was aware that issues of hair and complexion were what separated me from my dark-skinned cousins.

The infamous 'pencil test', discussed in Chapter 3, was one method used to decide whether a person was classified as belonging to the 'black African' race (Watson, 2007). Despite this 'in or out' categorisation, Coloured identity has historically been associated with ambiguity (Petrus & Isaacs-Martin, 2012). A discourse that classifies ethnicity and race has a great role to play in the production of certain kinds of identities, and when such identities are provided

with everyday meanings, they become real (Erasmus, 2001). Some people, who self-identify as Coloured, view Colouredness as a coherent cultural identity, and not a social construction imposed by the Apartheid regime, but for others, the identity is imbued with shame and uneasiness about ethnicity (Hendricks, 2001). They assumed that their Colouredness was “an inbred quality that is the automatic product of miscegenation or an artificial identity” (Adhikari, 2006, p. 468).

Whatever one’s stance, it seems that historically, the identity of Coloured people has been heavily shaped by racial oppression imposed by the Nationalist regime on the one hand, and by the cultural creativity shown in part as a response by Coloured people themselves on the other hand (Adhikari, 2006). When speaking English, I was often reminded by my nephews and nieces that: “*djy is toggie wit nie*” (you are not white), “*nou moetie vi jou so hou ni*” (don’t pretend to be), “*ons is Bruin mense*” (we are Coloured people). To me, that meant I could only be Coloured and I should take care not to cross the boundaries. I felt so uneasy with the fact that my hair and my use of English had set me apart from my cousins, nephews and nieces, but I was also positively set apart by being chosen as a language broker. In some ways, I was continuously negotiating the ambivalences of being special, not belonging, not being ‘normal’ and being seen as if I am ‘too big for my boots.’

5.5.4 Stereotypes portrayed in the media

Apart from the issue of hair, there are other assumed representations of Coloured people through various forms of media and public dialogue that are often based on stereotype. One stereotypical example, which is taken to mean that they are uncivilised or ‘*gam*’, is that Coloured people have no front teeth. Such damaging stereotypes have reinforced a notion that being Coloured is shameful. Some Coloured people, both English and Afrikaans, have left the ghettos to escape Coloured ‘shame’. In terms of identity, I see myself as a South African first, then a female, and thereafter I am ‘statistically’ Coloured in a scenario where I draw on my nationality, gender and race to try to frame a stable identity. However, I argue that the colour of my skin in the current democratic dispensation does not define me as a person, as I am free to assert my own humanity. I experience my Colouredness as an unchangeable part of myself. The cultural meanings and stereotypes associated with the word Coloured imposed by the

Apartheid government are inescapable to me, as they are very much alive in my family and community. How can one escape being Coloured? It's not easy.

On a recent trip to Johannesburg, a student asked me whether I was really Coloured and from Cape Town. My immediate response was "Why?" He told me that the media had informed his view about the behaviour of Coloured people and how they speak, having been portrayed as people without front teeth who have a funny accent. My response was that not all Coloured people speak in the way that is portrayed by the media. In that moment, I felt angered, disgusted by the thought that I could be seen as the exaggerated Coloured stereotype, often portrayed in the media as '*gam*' (uncivilised). I am annoyed by the assumption made by people about how I should behave as a racialised Coloured person. I do not consider myself as similar to the media's stereotypical portrayal of the behaviour of Coloured people. But then, what can one do, in a South African context where the colonial government regarded Coloured people as being flawed as they are neither black African nor white (Erasmus, 2001)?

However, I am free to assert my own identity. I am aware that it is not my role to change societal perceptions of Coloureds in a South Africa where the Apartheid racialised categories of separation are hard to ignore (Erasmus, 2001). Perhaps, the perceptions of race, ethnicity, stereotyping and the terminology that accompany the term Coloured are ones that I cannot escape, as the social construction and internalised division imposed during Apartheid are evident in my community and family. Being Coloured comes with emotional challenges and afflictions. It is more than genetic makeup and racialised politics; it is a fusion of shame, poverty, exclusion, internalised oppression and of not having been liberated from the Apartheid regime. It's like being born Deaf: you are that way and nothing I do or say can change it, even if I wanted to.

5.5.5 Whites Only

I was five years old and we were standing at the train station on our way to the hospital for my mother's antenatal visit. A big maroon and yellow locomotive pulled into the platform. I indicated to my mother that I wanted to get into the carriage and she pointed to a board on the train that said: "Whites Only/Net Blankes". We walked to one end of the platform, to a carriage with a sign that said: "Non-Whites/Nie Blankes". Always obedient, I took hold of my mother's hand as we boarded the train. The train ride was uncomfortable; the plastic seats were hard.

However, I was now looking forward to the outing with my mother, and I forgot the sign and that we were not able to enter the “Whites Only/Net Blankes” carriage.

Later on, I remembered the experience and it sparked many questions in my mind about why we were not allowed on the train and what was meant by ‘Whites Only.’ I thought that it could well be the norm. However, I felt excluded and rejected, and I started to wonder what would have happened if I was white. As the years went by, the memory of that day has always been fresh in my mind. I kept feeling that to prevent people from entering places on the grounds of the colour of their skin was not right. It was part of the aim of achieving racial separation in public facilities and was enforced with Whites Only notices, and it extended to trains and other public transport modes as well as cinemas and schools (Jacobs, 2010). My mother and I did not discuss the incident. Apartheid was not discussed in our home, so no one explained to me what the Apartheid system meant. However, my mother seemed to know that we were not allowed to enter the carriage for whites only.

5.6 Theme 5: Racial discrimination

Learning about the Apartheid system of racial discrimination was almost accidental for me because no one had explained it to me even though it was visible in my immediate environment. As a child, my favourite place for an outing was the beach, more so the beach where my grandparents lived. It is there where the impact of the Reservation Act of 1953 and the division between black African, white and Coloured bathers was noticeable. There was a section called ‘*die eerste strandjie*’ (the first beach) where many New Year’s days were spent despite the empty beer bottles and broken glass in the sand. The next section was an open stretch of beach with a parking lot and just after an adjoining stream, there was a section named by the locals as ‘White Beach’. Unlike my peers, my inquisitive nature led me to venture and swim on the other side. I had a propensity to push boundaries, to experience different things. Perhaps the confusion that surrounded the aspect of who I really am led me to want to know what this separation was all about; I needed to understand what was happening on the other side.

Whatever the reason may have been, I tried to prevent these impositions from restricting me as a person, despite there being constant reminders in my family. I questioned whether the fact that my skin was lighter or that I had straight hair could be seen as having more white features.

These issues of race and variations of skin colour often held an almost unpleasant and awkward position between myself and my family. I recall my cousins telling my grandfather: “*die kint willie hoor nie, sy bly daar by die wit mense se kant gaan swem*” (this child does not want to listen, she keeps on swimming at the white people’s side). For me, I was different in that I had parents who were Deaf and I was both hearing and Deaf, but as a child I never noticed the difference between myself and people of other races, and comments such as “*djy dink jy is wit*” (you think you are white) were meaningless to me. Instead, such comments led me to think that being white must be somewhat exclusive as it could set people apart.

As an adult, I have yet to see the change in the way people of colour are racially perceived. While we now live in a ‘new South Africa,’ my experience of being a CODA, Coloured and a female have not changed at all. Similar to my childhood days of accompanying my parents to hospitals and government offices among other places, I still have to accompany them to this day. Deaf people still do not have the support of interpreters in the healthcare system and the challenge of access remains similar to that of the Apartheid era.

5.7 Conclusion

There is evidence that my lifeworld as a female, Coloured CODA in South Africa is complex, multi-layered and multi-dimensional. The result is nuanced experiences influenced at most by the intersection of various identity markers that include disability, gender, race, age, nationality, culture and language, within dual hearing/Deaf worlds. From as early as the age of three and as a CODA, I have managed and negotiated far more terrains than the role of interpreting; diverse situations often called and still call on me to contain a host of vulnerabilities that are experienced not only by me but by my Deaf parents as well. I am charged with making sense of or somehow digesting the ills and inequalities of society, as they are channelled through the oppressive treatment of my Deaf parents. Their effort to gain access to healthcare and social services, which dates back to the racist Apartheid regime, remains a challenge for them and has not changed.

In spite of all the complexities that characterise my lived experience, I have not been and I am not a passive recipient of the oppression that characterises my lifeworld. Dating back to my childhood, I constantly seek to claim my agency and to make a positive difference in my own

life and that of my Deaf parents and other family members. In the following chapter, I draw conclusions from the entire thesis and make recommendations for policy and practice.

6 Chapter 6: Conclusion and Recommendations

The findings of this evocative auto-ethnographic study show that my lived experience as a CODA cannot be described in a clear-cut, straightforward manner as it is multi-layered and multi-dimensional. It highlights the need to raise awareness about the positive and negative situations that hearing children of Deaf parents face in their families and in society at large. In the following section I discuss the recommendations that arose from the findings of this study in ways that seek to inform both disability policy and practice. I pay attention to issues of policy, services, civil society, DPOs and CODAs, beginning with recommendations for policy below.

6.1 Policy recommendations

- Employ SASL interpreters in social services outlets to facilitate communication between Deaf and hearing people.
- Develop and implement governmental Human Resources policies for the recruitment of staff in the Departments of Health, Education, and Social Services to include the employment of adult CODAs to eliminate challenges experienced by Deaf parents and their children.

6.2 Service recommendations

International and local NGOs should work with government departments to identify the challenges faced by CODAs and their Deaf parents in order to provide more appropriate services.

6.3 Recommendations for DPOs and civil society

- DPO's and civil society organisations that are involved in development work should take steps that aim to collaboratively promote and embrace Deafness as a cultural difference rather than a disability. Such awareness will reduce patronisation, marginalisation and exclusion.

- Educate the hearing community about the culture and values of the Deaf community and raise awareness of the impact of labelling Deaf parents as disabled on hearing children of Deaf parents.

6.4 CODAs

- Adult CODAs in South Africa should undertake research to facilitate hearing of their own and other CODAs' experiences.
- CODAs should work with DPOs and civil society to highlight the plight of young CODAs and challenge practices of oppression to promote their well-being and that of their parents and the Deaf community.

6.5 Limitations of research

As noted in Chapters 1 and 4, I was both the population and the sample of this study. Although I am part of the broader CODA community, it is not possible to generalise the findings of this study to other CODAs who may have had different lived experiences while being raised by Deaf parents.

6.6 Concluding thoughts

This evocative auto-ethnographic study has illuminated my lived experience of being raised as a CODA in Apartheid South Africa in the 1980s. The findings contribute to the body of knowledge in this field, which currently lacks published research. Recommendations for the development of policy, services and civil society for the support of CODAs and their Deaf parents were made. I have used my own voice in a way that I believe has 'transported' my lived experience from the borders of my consciousness to the forefront. In spite of the complexities that surround my lived experience as a CODA, I have not been and I am still not a passive recipient of such challenges. I continuously claim my agency as I negotiate the challenging terrain for CODAs in South Africa. I call upon other CODAs, particularly in the Global South and Africa, to pursue research that illuminates the experiences of CODAs to inform policy and practice.

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7 Appendices

Appendix 1: Ethical approval, University of Cape Town

Consent Form for participating in the study.

I, CAROL CUPIDO hereby give consent for this study done by JANE ANNE. I have read the information provided above.

Signed C. Cupido Witness Scott

Date 18. 06. 2018

Researcher

Jane Harrison

Student

DHRS

Supervisor

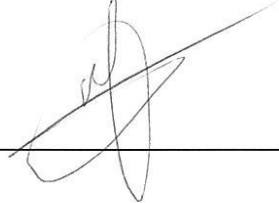
Dr Brian Watermeyer

Senior Research Officer

DHRS

Consent Form for participating in the study.

I, EDWIN CUPIDO hereby give consent for
this study done by JANE-ANNE I have read the information
provided above.

Signed Edwin Cupido Witness 

Date 18-6-2018

Researcher

Jane Harrison

Student

DHRS

Supervisor

Dr Brian Watermeyer

Senior Research Officer

DHRS

Appendix 2: Informed consent letter



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za

Website: www.health.uct.ac.za/fhs/research/humanethics/forms

23 August 2017

HREC REF: 536/2017

Dr Brian Watermeyer
Health and Rehab
H-floor, OMB

Dear Dr Watermeyer

PROJECT TITLE: VOICES THROUGH MY HANDS: AN AUTOETHNOGRAPHIC NARRATIVE ON THE LIVED EXPERIENCES OF A SOUTH AFRICAN CHILD OF DEAF ADULTS (CODA)-Master's candidate-J Harrison

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 August 2018.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

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

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

The HREC acknowledge that the student, Jane Harrison will also be involved in this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB000001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 312.61 and 312.62.

HREC 536/2017

Appendix 3: Example of reflective journal notes

I've been having ear infections & Trouble with my hearing in my left ear for a while. After two years of GP visits I finally make an appointment to see the specialist. After several tests it is decided that I need a procedure to have grommets inserted. I link grommets to hearing. The operation is successful and the next step is to have my hearing tested. Convinced I am Deaf.

Disappointed that I am not Deaf

Why? I've lived my whole life as a Deaf person trapped in a hearing body.