

**“WHY ME, LORD?” SOME SOCIAL FACTORS ASSOCIATED WITH THE  
RECEIPT OF A DONOR HEART IN SOUTH AFRICA.**

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## **ABSTRACT**

Since the first human-to-human heart transplant in the world was performed by Prof Chris Barnard in Cape Town in 1967, heart transplantation has become the gold standard to treat people suffering from end stage heart failure. This thesis explores heart recipients' perceptions and experiences of their chronic heart illness before and after transplantation. It examines the medical experience in terms of the clinical diagnosis, the standard of communication about the illness and the proposed treatment, and the post-transplant regime. It also reflects how recipients make sense of heart disease and learn to live with a transplanted heart. The thesis also shows the extent to which the recipients' culture and individual identity impact such complex medical issues as end stage heart failure and transplantation. Qualitative research was undertaken in private sector heart transplant programmes in South Africa. The study is underpinned by Mishel's (1990) uncertainty theory as well as by social constructionism.

## ACKNOWLEDGEMENTS

This thesis – and the research project which buttresses it – was never merely an academic construction. It is rooted in my life. Specifically, it reflects my experience of this second life, which I have been privileged to live since receiving a donor heart in a transplant operation on October 11, 2016.

When I was diagnosed with end-stage heart failure in August of that year and told that I would die unless I received a heart transplant urgently, I was working on a master's degree in the School of Journalism and Media Studies at Rhodes University. It was one of my strange duties in that surreal season to write to my then thesis supervisor, Anthea Garman that, as I was dying, I was withdrawing from the programme immediately. After my transplant, as I recovered from illness, grew stronger, and considered what this experience might mean, it seemed the most natural thing to consider submitting the entire corpus of my story of heart disease, death and re-birth, to a rigorous sociological inquiry. With apologies to Socrates, the unexamined *second* life is not worth living. This thesis reflects part of that examination.

My undergraduate sojourn in the Rhodes sociology department almost 40 years ago was unexceptional, due entirely to my own efforts, or lack thereof. The department has been most welcoming of my late-life return to its precinct. I must especially mention head of department Professor Gilton Klerk, former masters programme co-ordinator Professor Monty Roodt and department administrator Ms Juanita Fuller, for their support and encouragement. Having Ms Janet Chisaka as my thesis supervisor has been one of the highlights of my master's programme, although I may well have been responsible for many additional stresses and strains added to her lot. Thank you, Janet, for your willingness to share your knowledge, insight into and experience of the field; for the meticulous manner in which you reviewed every submission; for the easy engagement we enjoyed, which belied the seriousness with which you regarded this project and the commitment you expressed at every turn.

I am unimaginably grateful, and happy, to be alive. I could never have gotten here without the unwavering support of my loved ones - my spouse and partner, Belinda, our children Heath and Rebecca, their respective spouses Kelly and Marco, extended families and many friends from near and far. When one is really very ill, when the fight to live has almost left one, the importance of family to take up the fight is immeasurable. My family has been here, fighting for me at every step, for as long as I can remember. And they have been present through this journey of reflection and study.

Amid unimaginable grief, a family who did not know me and who remain unknown to me, decided to donate their loved one's organs for transplantation. It was, at once, an expression of generosity, compassion and graciousness.

To the cardiothoracic surgeons, cardiologists, transplant unit co-ordinators and heart transplant recipients who have allowed me to reflect something of their work and journeys in this thesis, I am more grateful than you can ever imagine for your willingness to participate in this study. I would like to think this research contributes to the body of knowledge on heart disease and transplantation. Perhaps it fuels a longer, deeper investigation into the field.

After I had conceptualized the research, I began reaching out to heart transplant recipients, inviting them to participate in this study. In response to the question I had formulated in the research topic, "Why me, Lord?", one of them replied: "Why me? Why not me?"

It is a riposte with which I concur. With all *my* heart.

## CONTENTS

<b>Chapter 1: Introduction</b>	<b>1</b>
<i>1.1 The research project</i>	<b>1</b>
<i>1.2 Context of the research: Heart failure and transplantation</i>	<b>2</b>
<i>1.3 Heart transplantation in South Africa</i>	<b>2</b>
<i>1.4 Goals of the research</i>	<b>2</b>
<i>1.5 Stories of heart transplant recipients</i>	<b>3</b>
<i>1.6 Structure of the thesis</i>	<b>3</b>
<b>Chapter 2: Illness, existential crisis and social context</b>	<b>5</b>
<i>2.1 Introduction</i>	<b>5</b>
<i>2.2 Embracing uncertainty</i>	<b>5</b>
<i>2.3 Asserting social construction</i>	<b>9</b>
<b>Chapter 3: Literature review</b>	<b>11</b>
<i>3.1 Introduction</i>	<b>11</b>
<i>3.2 A sociological understanding of heart transplantation</i>	<b>11</b>
<i>3.3 The epidemiology of heart transplantation</i>	<b>13</b>
<i>3.4 Constraints on heart transplantation</i>	<b>15</b>
<i>3.5 Diagnosis and communication</i>	<b>17</b>
<i>3.6 The ethics of transplantation</i>	<b>19</b>
<i>3.7 Functional status before and after transplant</i>	<b>20</b>
<i>3.8 Biographical identity and culture - and their disruption</i>	<b>22</b>
<i>3.9 Miracle or medicalisation</i>	<b>25</b>
<i>3.10 The gift of life and a sense of appreciation to the donor or the donor's family</i>	<b>26</b>

<b>Chapter 4: Research design, methods and procedures</b>	<b>29</b>
<i>4.1 Introduction</i>	<b>29</b>
<i>4.2 The research field</i>	<b>29</b>
<i>4.3 Sampling</i>	<b>30</b>
<i>4.4 In-depth interviews</i>	<b>30</b>
<i>4.5 Questionnaire</i>	<b>31</b>
<i>4.6 A dilemma in autoethnography</i>	<b>31</b>
<i>4.7 Breaking bread and sharing tears - the impact of hearing others' stories</i>	<b>32</b>
<b>Chapter 5: Case Study Presentation</b>	<b>33</b>
<i>5.1 Introduction</i>	<b>33</b>
<i>5.2 My own story</i>	<b>33</b>
<i>5.3 The epidemiology of heart transplantation</i>	<b>36</b>
<i>5.3.1 Introduction</i>	<b>36</b>
<i>5.3.2 Tracing heart disease</i>	<b>36</b>
<i>5.3.3 Transparent protocols</i>	<b>36</b>
<i>5.3.3.1 Recipient perspectives on protocols</i>	<b>36</b>
<i>5.3.3.2 Surgeon perspectives on protocols</i>	<b>38</b>
<i>5.3.4 Hearts are free, transplants cost an arm and a leg</i>	<b>40</b>
<i>5.3.5 Congenital conditions and transplantation</i>	<b>41</b>
<i>5.4 Diagnosis of heart disease</i>	<b>42</b>
<i>5.4.1 Introduction</i>	<b>42</b>
<i>5.4.2 The first diagnosis</i>	<b>42</b>
<i>5.4.3 Communication – the good, the bad and the ugly</i>	<b>43</b>

<i>5.5 Call waiting</i>	<b>47</b>
<i>5.5.1 Introduction</i>	<b>47</b>
<i>5.5.2 The call</i>	<b>47</b>
<i>5.5.3 Getting ready to die</i>	<b>49</b>
<i>5.6 Functional status before and after heart transplant</i>	<b>51</b>
<i>5.6.1 Introduction</i>	<b>51</b>
<i>5.6.2 Words that matter</i>	<b>51</b>
<i>5.6.3 Quality of life before transplantation</i>	<b>51</b>
<i>5.6.3 Post-transplant regimes</i>	<b>52</b>
<i>5.6.5 Working life</i>	<b>55</b>
<i>5.7 Identity and its disruption</i>	<b>56</b>
<i>5.7.1 Introduction</i>	<b>56</b>
<i>5.7.2 The disrupted body, personality, life</i>	<b>56</b>
<i>5.7.3 The birth heart</i>	<b>56</b>
<i>5.7.4 The donor heart</i>	<b>57</b>
<i>5.7.5 The post-transplant self-image</i>	<b>58</b>
<i>5.7.6 The significance of donor characteristics</i>	<b>59</b>
<i>5.7.7 Replacing one chronic condition with another</i>	<b>60</b>
<i>5.7.8 Disruption of family</i>	<b>60</b>
<i>5.8 Miracle or medicalisation</i>	<b>62</b>
<i>5.8.1 Introducton</i>	<b>62</b>
<i>5.8.2 Of gods and doctors</i>	<b>62</b>
<i>5.8.3 Faith as an impediment to receiving or donating a heart</i>	<b>63</b>

<i>5.9 The gift of the donor</i>	<b>65</b>
<i>5.9.1 Introduction</i>	<b>65</b>
<i>5.9.2 The gift of life</i>	<b>65</b>
<b>Chapter 6: Conclusions</b>	<b>68</b>
<i>6.1 Why me?</i>	<b>68</b>
<i>6.2 Assessing the research goals</i>	<b>68</b>
<i>6.2.1 The medical experience</i>	<b>68</b>
<i>6.2.2 Internalising the imminence of death</i>	<b>68</b>
<i>6.2.3 Culture, identity and spirituality in sense-making of disease &amp; transplant</i>	<b>69</b>
<i>6.2.4 Miraculous gift of luck-of-the-draw?</i>	<b>69</b>
<i>6.3 Researcher impressions</i>	<b>69</b>
<i>6.4 Further research</i>	<b>69</b>
<b>References</b>	<b>71</b>
<b>Appendix 1: Interview question schedule: Heart recipients</b>	<b>79</b>
<b>Appendix 2: Interview question schedule: Clinicians &amp; co-ordinators</b>	<b>82</b>

## **Chapter 1: Introduction**

### *1.1 The research project*

This qualitative research project examined South African heart transplant recipient perceptions of their heart disease and transplantation treatment. It was undertaken within a sociology of health and illness paradigm and was intended to draw the lived experiences of heart transplant recipients into the general rubric of organ donation and transplantation. My interest in this study was primarily to learn what it has been like for others to live with heart disease, to pass through end stage heart failure and subsequently to receive and live with a donor heart, as I have done. Personal narrative, including autoethnography, were key tools in unlocking information about recipients' lived experiences. Responses were also drawn from clinical professionals and transplant co-ordinators involved in four heart transplant programmes in private hospitals in Cape Town, Johannesburg and Durban.

### *1.2 Context of the research: Heart failure and transplantation*

The main function of the heart is to pump oxygenated blood to the rest of the body (Kittredge 1989: 101). Heart failure is a structural or functional impairment of the heart's ability to fill with or eject blood (Ponikowski *et al* 2016: 2136; Yancy *et al* 2013: e246). For most heart failure sufferers, their heart is too weak to perform its function to effectively eject oxygenated blood to the rest of the body; for others, the heart may be stiff and unable to adequately fill with blood (Heart Failure Society of America 2019; Yancy *et al* 2013: e246). The result is reduced volume of blood in the circulatory system, inadequate perfusion of other organs, leading to reduced functional abilities and quality of life (Pfeffer *et al* 2016: 1). Heart failure manifests through various stages in dyspnoea or shortness of breath (even at rest), fatigue, fluid retention, pulmonary congestion and oedema, difficulties in eating, and struggles with other ordinary daily activities (Mayo Clinic, 2017, 2018; National Heart Lung & Blood Institute n.d.; Pfeffer *et al* 2016: 2); Ponikowski *et al* 2016: 2136; Yancy *et al* 2013: e246).

End stage heart failure, also known as "advanced" or "refractory" heart failure, is defined by persistently severe and repeated symptoms of heart failure, including renal function deterioration, weight loss, low blood pressure, fatigue during minimal exertion such as dressing or even during rest, inability to walk, escalated diuretic use and repeated hospitalisation (Pfeffer *et al* 2016: 5-6). Over time, these symptoms will become impervious to medication, with end-of-life palliative care the probable treatment offered to the patient. In such instances, a heart transplant from a deceased donor is the only viable treatment to save

the patient's life (Ponikowski *et al* 2016: 2187; Yancy *et al* 2013: e280). At this stage, heart transplantation "is considered the gold standard for the treatment of refractory end-stage heart failure" (Yancy *et al* 2013: e283. See also Almgren 2018: 1; Haeck *et al* 2012: 167; Ponikowski *et al* 2016: 2137-8).

From a surgical perspective, the heart transplantation procedure is routine, even if it holds the potential for a dramatic turnaround in a patient's health (Yale Medicine, 2019). According to Stehlik and Lindenfeld (2016: 273), heart transplant recipients can expect, on average:

to live 10 years following transplantation and many have much longer survival. Return to work, pregnancy, and physical activity are possible for recipients and most have a good quality of life.

### *1.3 Heart transplantation in South Africa*

Heart transplants have been performed since the 1960s, initially in the research laboratory and subsequently in clinical settings (Barnard, M. 1967: 1260; Kittredge 1989: 13, 14; Louw 1967: 1257). The first human-to-human heart transplant in the world was performed by Professor Chris Barnard at Groote Schuur Hospital (GSH) in Cape Town on December 3, 1967 (Barnard, C. 1967: 1271; Barnard & Pepper 1969: 299). The lack of "efficient and safe immunosuppression" resulted in high numbers of deaths of transplant recipients around the world (Stehlik and Lindenfeld (2016: 255). Tissue grafts or organ transplants are regarded as bacterial attacks on the body, activating the body's natural immune system to produce antibodies which destroy the graft or organ (Kittredge 1989: 20-22). An effective immunosuppression drug, Cyclosporin, was discovered and approved for general use in 1982, and transplantation took off again, with vastly improved long-term survival rates among heart transplant recipients (Haeck *et al* 2012; Kittredge 1989: 49; Stehlik and Lindenfeld 2016: 255; Yancy *et al* 2013: e283).

### *1.4 Goals of the research*

This thesis explores how heart transplant recipients make sense of or create meaning in their journey through heart failure and transplantation within the South African healthcare and social contexts. The following key questions guided the research:

- What was the medical experience, both in terms of symptoms and healthcare treatment before heart surgery, which led to a diagnosis and treatment plan, and what was it after transplantation in terms of treatment regimes, check-ups and lifestyle?

- How do recipient patients internalise the news that their death is imminent when they are first advised of this and what influences their decisions to accept transplant treatment?
- What place respectively do culture, individual identity or sense of self, faith or spirituality have in sense-making around chronic heart disease and transplantation?
- Do heart transplant recipients attribute their transplantation to a miraculous gift or the luck of the draw?

### *1.5 Stories of heart transplant recipients*

In order to explore the journeys of heart transplant recipients, I have opted to listen to their stories, taking my cue from Mattingly (2006: 567) that, where and when biomedicine fails and is incapable of dealing with questions around illness and healing, story-telling – based on personal and cultural understandings - steps in, helping to “transform identity, interpret the meaning of the past and even provide images of possible futures”. Mattingly (2006: 568) points to the importance of individual stories shared and retold within a communal context, especially the importance for the ill of learning about themselves and their illness through “hearing themselves tell their stories, absorbing others’ reactions, and experiencing their stories being shared”. The importance of narrative as a means whereby people “rehearse their embodied troubles” and make sense of their changed self within a social context is also raised by Bradby (2012: 107).

### *1.6 Structure of the thesis*

Chapter two presents the two theories which underpin this study: uncertainty theory and social constructionism as a basis for studying heart transplant recipients’ understandings of their chronic illness and treatment.

Chapter three examines relevant literature in relation to the research topic, starting with a sociological examination of heart transplantation. It then examines various themes, which recur in the current case study. These themes are:

- The epidemiology of heart transplantation, the underlying causes of heart failure and the factors that typically influence a decision to transplant a donor heart into a recipient;
- Constraints on transplantation;

- The diagnosis of heart disease and the role of communication in the diagnostic process;
- The ethics of transplantation;
- The functional status and quality of life of the recipient before and after transplantation;
- Bodily, biographical and cultural identity of recipients – and their disruption:
- The place of miracle or medicalisation in sense-making on transplantation;
- The significance of *the call*, the moment when the transplant unit informs the potential recipient that a donor heart is available;
- The gift of life and sense of appreciation to the donor or the donor's family.

Chapter four sets out the methodology adopted in the case study. I also point out how the constraints of the national research ethics legislation impacted the research.

Chapter five presents the case study, starting with a brief overview of my own story before reviewing the interviews with recipients in terms of the over-arching theories of uncertainty and social constructionism, and using the themes established in the literature review.

Chapter six sets out the conclusions of the study and offers pointers to further research opportunities.

## Chapter 2: Illness, existential crisis and social context

### 2.1 Introduction

This study is underpinned by the theory of uncertainty in illness, and the theory of social constructionism. Bradby (2012: 107) states that the trauma, pain and suffering which arise from an individual's physical impairment provoke the question at the heart of this thesis, *why me?* Uncertainty about one's illness has major implications for an individual – not only in respect of the illness itself but also in other areas of one's life. A social constructionist approach affirms scientific reality but places it in the context of natural and social causes and implications.

### 2.2 Embracing uncertainty

Not knowing or the uncertainty of one's knowledge of something that exists currently, or that will occur next, confronts each of us daily. Making sense of the future or "making future" (Gilbert 2007: 5) is a critical function of the human brain. But, when we are unable to approach the future with a measure of certainty, we become anxious. Grupe and Nitschke (2013: 488-489) note that *inherent uncertainty* about the probability, timing and nature of a future negative event stymies our body's ability to prepare properly for an event and to allocate resources to adapt to it.

In the context of a sociology of health and illness, Mishel's (1990) formulation of uncertainty theory is a key theoretical framework for this study. Mishel (1990: 256) defined uncertainty as "the inability to determine the meaning of illness-related events" and a perceived threat to predictability and control. This middle range theory was proposed as a framework for an understanding of uncertainty in illness within a nursing context. It developed through a critical social theory response to individual pursuit of certainty As Mishel (1990: 257) points out:

The value of predictability, control and mastery as the natural and normal way of life is also seen in the health care setting, particularly in the mechanistic orientation of medicine. Medical science, like all fields of science, does not function separately from the major values of society.

She further suggests that patients frequently have concerns about the severity of their illness, the success of treatment, the likely impact of the illness on their life, and the ability to pursue dreams and ambitions. Such uncertainty in one area of an illness event "feeds back on itself and generates further uncertainty in other illness-related events" (Mishel, 1990: 257). She also notes that a protracted point of uncertainty is reached, coherence is lost and stable

cognitive structures that give meaning to everyday events are threatened. In addition, loss of meaning, in turn, throws the patient into a state of confusion and disorganisation (Mishel 1990: 260). Mishel (1990: 256) initially argued that patients approach uncertainty through inference and illusion (the construction of beliefs), using their social resources and the assistance of health care providers. She further argued that if the inferences are regarded as positive, the uncertainty will be appraised as an opportunity. On the contrary, if the inferences are regarded as threatening, then the uncertainty will be appraised as a danger. Illusions are generated to re-evaluate a negative situation, while a perceived harmful outcome of uncertainty may result in the activation of coping strategies to reduce the uncertainty. Thus, Mishel (1990) concurred with the view expressed above by Grupe and Nitschke (2013) that uncertainty prevents the body from drawing together resources to control the situation.

Initially, Mishel theorised uncertainty only in relation to acute illness. However, a 1986 qualitative study by King and Mishel (cited in Mishel, 1990: 257) found that “the longer chronically ill subjects lived with continual uncertainty, the more positively they evaluated the uncertainty”. Subsequently, Mishel (1990: 257) reconceptualized the theory of uncertainty to take account of chronic illness conditions and to understand how one’s experience of uncertainty could shift over time. Mishel (1990: 260) identified that, at the time the uncertainty is at its worst, the ill individual – aided by “prior life experience, physiological status, social resources and health care providers” – styles a new perspective on life which takes account of probabilities and conditions. To quote her:

The uncertainty that early in the illness was the source of fluctuation and disruption, later in the illness becomes the foundation on which the new sense of order is constructed. The uncertainty is used by individuals as the basis for self-organization as they reformulate their view of life... involving probabilistic and conditional thinking. This new world view is not the positively oriented illusions generated from uncertainty as described in the original theory of uncertainty in illness. To develop probabilistic thinking, the nature of uncertainty has to be accepted as the natural rhythm to life. The expectation of continual certainty and predictability is abandoned as a part of reality... There is a new ability to focus on multiple alternatives, choices and possibilities; to re-evaluate what is important in life; to consider variations in personal investment; to appreciate the fragility and impermanence of life situations. The new view of life allows the evaluation of uncertainty to be changed from danger to opportunity.

She concluded that it is possible for the patient to maintain a new orientation towards life, in which uncertainty (comprising instability and fluctuation) is a natural phenomenon that increases the patient’s range of possibilities. For this to happen, however, both social support

systems and healthcare providers need to affirm a probabilistic rather than a mechanistic paradigm.

Almgren (2018) has taken further Mishel's (1990) theory, highlighting the issues faced by heart recipients before and after their transplantation. These issues, Almgren stated, give rise to uncertainty and doubt about being abandoned. Recipients become uncertain about the future, their survival, recovery process, performance, and are concerned about their relationships with family and friends. She notes how the expectations, symptoms, complications and setbacks all constitute sources of uncertainty for the heart recipient (Almgren, 2018: 6). The lifelong adherence by the heart transplant recipient to immunosuppressant treatment means that heart transplantation is considered a chronic condition (Almgren 2018: 12; see also Kittredge 1989: 47 and Sharp 2006: 107-108). The uncertainty experienced by the heart recipient ranges from the quick, acute sickness whose identity may not entirely be known or understood (Almgren, 2018: 13). It then morphs into a serious chronic illness defying a range of treatments to the point where only two choices are offered – either life-saving heart transplantation treatment, or the inexorable decline to the point where the rest of the body shuts down due to the failure of the heart to pump oxygen-rich blood to other organs. There is no confirmed timeframe for this process and no guaranteed outcome. Uncertainty and fear reign. If transplantation is an option, the would-be recipient must wait to receive a donor heart in time. After the transplant, she or he must consider and deal with challenging factors, which will presage life or death, including the possibility of organ rejection, and the side-effects of the medication (Almgren, 2018: 13). She further argues that less uncertainty during illness and through recovery is among a range of indicators which determine a good quality of life for heart transplant recipients. Uncertainty will underpin the heart recipient's "unmet expectations, disappointments, unachieved life goals, lost life roles, symptoms, fatigue and inability to work" (Almgren 2018: 12-15). This will eventually affect the individual's ability to cope with a new heart and the uncertainty will affect their sense of identity and their relationships which continue over time (Almgren 2018: 17).

Mattingly (2006: 569) observes that the perception that illness is connected to meaning, is rooted in Christian, Jewish and early pagan beliefs - and we may state, based on research in South Africa, such perceptions are also rooted in African spirituality and beliefs (Etheredge, 2015: 176). Mattingly (2006: 256) shows how clinical interactions are hermeneutic, that is, both clinicians and patients must interpret and negotiate what it means for the patient to be ill

and how treatment may best be administered. She suggests that patients especially (I would argue it also applies to clinicians) must consciously participate in diagnosis and treatment considerations. Albeit reluctantly, clinicians are drawn into a better understanding of a patient's lifestyle, even their beliefs and values, in order to understand what may motivate them to comply with treatment regimes. A *meaning-centred approach* to the encounter between patient and clinician allows the patient to bring a distinctive approach to "making sense of the disease, its causes and its impact" (Mattingly 2006: 566). This approach stands in contradiction to bio-medical's individualism and even the clinician's professionally influenced and cultured beliefs about the patient, the body and illness.

Mattingly (2006) uses interpretive community theory alongside reception theory to explore illness sense-making. Both theories have been applied mostly to individual and group sense-making of mass media texts, especially visual texts like television broadcasts, with a text taken in and reinvented within a local community (Mattingly 2006: 570). Fish (1980: 14) argued that any thought an individual thinks, has its "source in some or other interpretive community" and the individual is "as much a product of that community (acting as an extension of it) as the meanings it enables him to produce". In the context of audience research, Fish (1980: 147) noted that sustained attention must be given to the "features and details of respondents' talk as they developed their interpretive accounts".

Mattingly (2006: 571) argues that reception theory has "relevance for consumers of oral and written biomedical texts as well". Through the invention of local interpretive communities, a patient comes to know "the ebb and flow of chronic illness and to witness what that means in the never-ending process of negotiating health care with shifting casts of health professionals and changing bureaucratic processes" (Mattingly 2006: 571). The encounter between clinicians "with their professionally influenced cultural beliefs about illness, the body, and patients, who bring their own beliefs and values to the table", ensures that patients emerge not simply as recipients of healthcare but as "active agents who help shape it" (Mattingly, 2006: 570). Barker (2010: 157) refers to "illness support communities" which play an important role in the diagnoses of contested illness.

Veres (1997: 89-90) explores a former time when a community would have been a common tribe or nation bound by blood ties and locality "where co-operation and solidarity were essential for survival". This exemplifies the reality of the linkages among heart transplant recipients and their respective linkages to the members of their transplant team or others who have been part of their journey from the first sign of illness. Veres (1997: 94) says this idea of

community is of individuals involved in “meaning-giving and meaning-accepting”. Zelizer (1993) has also shown how the concept of an interpretive community can be applied to both receivers and producers. While she has mainly focused on interpretation of key public events, her theorizing has shown how meaning is derived for the individual within a socio-cultural context, with communities arising “through patterns of association derived from the communication of shared interpretations” (Zelizer 1993: 27-28).

### *2.3 Asserting social constructionism*

Barker (2010) and Brown (1995) assert the case for a social constructionist approach to the sociology of health and illness. Brown (1995: 34) argues that social construction allows for an examination of how social forces such as class, race, gender, language, technology and culture “shape our understanding of and actions toward health, illness, and healing”. He acknowledges a Foucauldian approach to exploring the “ever-changing, indeterminate ‘realities’ of the situation”, but also argues that there is a “selective” realist position in social constructionism. His own view is that social constructionism represents a synthesis of “symbolic interactionism and structural / political-economic approaches” (1995: 36). Barker (2010: 150) argues that our ideas about, and responses to, illness – especially our own illness - are rooted in our social relations, our class or culture. That is the “core conceptual contribution of social constructionism” to the sociology of health and illness (Barker 2010: 150). There is a biological basis for illness and disease; there exist in the real world, bodies with biophysical shortcomings, whether they occur as a congenital or adult condition. However, it may not be immediately clear whether the illness or disease is abetted by social conditions; nor might it be clear what causes the shortcoming. Indeed, the act of defining any medical condition is inherently a social constructionist one, even if it comes to us after natural or biomedical scientific research. It is even possible for doctors to make an objective, clinically-sound diagnosis of heart failure and end stage heart failure based on a congenital heart defect (CHD) or adult disease, but the individual, institutional and societal responses that flow from such diagnosis are not self-evident. This avoids any diminishing of real, biophysical shortcomings in the body. This approach, states Barker (2010: 150) clearly recognises the possibility “that a condition can be both real and socially constructed”. As Barker (2010: 152) points out the consequence of medicalisation is that it obscures the social forces that influence an individual’s health and well-being, valorising medical intervention at the expense of political, economic or social change. However, it is far from correct to suggest that the patient is a passive participant and recipient of medical approaches punted within

healthcare and associated institutions. On the contrary, while medicalisation thrives in authority and institutional structures, patients also increasingly lay claim to medicalisation solutions.

Turner (1992) distinguishes an ontological divide within the social sciences in respect of how the body is viewed. On the one hand, foundational theoretical frameworks examine the *lived experience* of the body, or *the phenomenology of embodiment* or how biological conditions impinge on humans' everyday life, or "the complex interaction between the organic systems, cultural frameworks and social processes" (Turner, 1992: 40). On the other hand, anti-foundationalism perspectives conceptualize the body *as a discourse about the nature of social relations* or an effect of such discourse; or reflect "how bodily practices are metaphors for larger social structures", or understand the body as "a social construction of power and knowledge in society" (Turner, 1992: 40). He contends that from an epistemological point of view, those who oppose the idea of a social construction of reality regard the body as existing independently of the forms of discourse which represent it. Thus, proponents of a socially constructed reality regard the body as just another outcome of a discursive practice (Turner, 1992: 48).

Turner (1992: 9) is especially concerned with medicalisation or "the transformation of general social problems into technical medical concerns, and the elaboration of medicine as the basis of social control". He warns against applying sociological theory "as if one had to choose between competing and incommensurable paradigms" (Turner, 1992: 9). Instead, he argues for an approach which, at least in part, should be determined by the nature of the problem and by the level of explanation which is required. Turner (1992: 35) highlights Max Weber's claim that sociology is the *interpretive understanding* of social action undertaken by embodied social beings. Eschewing either-or theoretical approaches to bodies and diseases, Turner (1992: 57) identifies a theoretical space "for a phenomenology of disease in which the social researcher is concerned with the lived experience of pain, discomfort and alienation". I agree with Turner (1992) that one does not need to choose between these opposing paradigms but that a *methodological pragmatism* may be in order.

For Wainwright (2008: xi), a solution to any ontological divide lies in a realist orientation to the study of health and illness. Modern medicine can take humanity forward, and sociological inquiry can help us to understand the social and cultural obstacles to achieving humanity's potential. He further notes that there exists an objective reality, which can be known by humanity, although social and cultural influences may impact that knowledge (Wainwright 2008: 11).

## Chapter 3: Literature Review

### 3.1 Introduction

This literature review sketches out some of the key ideas, major debates or contentious issues which occur in relation to heart transplant recipients' meaning-making of their journey through heart disease and transplantation (Kamler & Thomson 2006: 28). It begins with a sociological understanding of heart transplantation (including examining the South African context), reviews the epidemiology of transplantation, and highlights the constraints on transplantation especially the shortage of donor hearts. It continues with a brief look at diagnosis and the communication which takes place within the diagnostic procedures, before assessing the ethical challenges attendant on transplantation. Such challenges include the decision-making processes in respect of which recipients ought to be preferred for a donor heart. The heart patient's functional status and quality of life, identity and their disruption, the place of God and doctors, occupy a significant place in the imaginary of the recipient. Finally, this review explores the idea of *the gift*, the giving and receiving of the donor heart and the implications of that act.

### 3.2 A sociological understanding of heart transplantation

In a Rhodes University doctoral thesis which examined pharmacy students' understanding of patients' medication practice in chronic treatment, Kevin Williams (2005) highlighted his own heart failure diagnosis and subsequent transplantation. Williams (2005: 25) understands the sociology of health and illness' concern with "the social taking cognizance of the individual". In the context of heart transplantation, this concern is not about asking why a person is sick and why they may or may not receive transplant treatment, but "what set of structures has influenced, and continues to influence, the life chances of members of the group to which she/he belongs (Williams, 2005: 23).

Bury (1982: 2) points out (quoting Wright Mills 1959) that health and illness represent an interplay of "private troubles and public affairs", as our experiences of ill health immediately affect the carrying out of everyday tasks, the presentation of self, as well as our relationships with others. This approach to the character of health and illness places them at the centre of the sociological imagination which can help to reveal how we make sense of our ailments and find ways of overcoming them in the context of the social groups we belong to (Wainwright, 2008: xi). Bury suggests that we recognise the duality of medicine in respect of belief. On the one hand, medicine respects "the authenticity of belief" held by doctors or patients. On the

other hand, medicine offers the possibility of a “critical evaluation of the justification of belief and the involvement of beliefs in the distribution of power” (1982: 179).

The interplay between private and public, what Shildrick (2015: 21) terms the *relationality of self to other*, is nowhere more explicit than in the context of heart transplantation, where the death of one individual ensures the life of another. Having analysed the intertwined relationship between *body and world*, Gunnarson (2016: 368 & 371) has identified a pervasive discourse around organ transplantation, characterising it as being:

A straightforward lifesaving, health-bringing, and normalising therapy. It conceptualises transplantation as an ‘end game’, a cure, as the successful end to a protracted struggle against disease and death. According to this discourse, organ transplantation is a simultaneously miraculous and routine biomedical therapy, held back only by the current ‘shortage’ of donor organs.

Gunnarson (2016) describes heart transplantation as occurring within a dominant discourse driven by organised medical institutions. This discourse offers little real opportunity to counter the narratives presented to recipients who are, in any case, desperately ill, a status which may prevent the recipient from being contrarian. Organ transplantation is neither straightforward, nor a successful cure. It is a treatment which benefits but also complicates the recipient’s life.

In January 1968, just over a month after he had performed the world’s first heart transplant, Barnard was preparing to transplant a donor heart into his second ever heart recipient, Philip Blaiberg. He reflected on what he had understood up to that point, to be the goal of transplantation:

For the first time I fully understood that the goal of medicine was not to prolong life – the real goal should be to improve the quality of life. If, by improving the quality of life, we also prolonged it, which we often did, then that was a bonus. (Barnard & Brewer 1993: 211)

It is not an open and shut case, however. As Almgren (2018: 11) states, the goal of heart transplantation remains both to enhance quality of life and to prolong survival. Gunnarson (2016: 19) focuses almost exclusively on the lived experiences of donor organ recipients and, specifically, on kidney recipients. He points out that there are few studies that focus on organ recipients’ experiences of living with a transplant in the long term. There are even fewer which study what a recipient experienced on their way to transplantation, their experience of organ rejection and re-transplantation. He argues that contemporary biomedicine is deeply rooted in cultural, historical, economic and political circumstances and, in turn, produces and reproduces pervasive norms, values, desires and intentions (Gunnarson 2016: 24).

Fox and Swazey (1992: 31) regard the intrinsic *seeking, giving and receiving* of a human organ as the reason transplantation remains “one of the most sociologically intricate and powerfully symbolic events in modern history”. They have argued that there is enduring research significance in organ transplantation. Such research must include exploring themes of uncertainty, gift-exchange, the allocation of scarce material and non-material resources, “life and death, identity and solidarity, and purpose and meaning” (Fox & Swazey 1992: xiv). Sharp (2006: 7), meanwhile, considers the ideas of transplantation that recipients and healthcare providers share about the organ donor and death, and where these ideas might converge.

### *3.3 The epidemiology of heart transplantation*

Epidemiology is concerned with the factors that typically determine or influence the occurrence of an illness or “other health-related events” (The Free Dictionary 2019). Brown (1995: 38) emphasises the importance of social causation in illness – understood in terms of structural elements, proximate causes such as migration and workplace hazards, and mediating causes such as social networks. Wainwright (2008: 5) states that the traditional diseases of poverty have been replaced by diseases of affluence such as heart disease. Ponikowski *et al* (2016: 2138) indicate that the prevalence of heart failure is between 1-2% of adults in developed countries, although they stress that this is dependent on the definition of heart failure which is applied. Among adult Americans over the age of 40, between two and eight people out of 100 (depending on age cohorts) will develop heart failure and, in total, there are about 5.1 million people in the United States suffering from heart failure. Up to half of those diagnosed with heart failure will die within five years (Heart Failure Society of America 2019; Yancy *et al* 2013: e249). At least 7% of all cardiovascular deaths in the US are due to heart failure (Yancy *et al* 2013: e249). The worldwide occurrence of heart failure is estimated at 23 million people (Bui *et al* 2011: 30). Only a third of those listed for transplantation receive a heart transplant due mainly to donor shortages (Ponikowski *et al* 2016: 2185).

Mayosi’s (2007: 1176) study showed that cardiovascular diseases accounted for up to 10% of all medical admissions to African hospitals, with heart failure contributing between 3% and 7% of those admissions. About 20% of heart failure patients suffered from dilated cardiomyopathy and up to a third of all patients died within four years of the onset of symptoms (Mayosi 2007: 1177). Dilated cardiomyopathy is characterised by the heart muscle

becoming dilated or bloated, impairing the heart's ability to pump oxygenated blood to the rest of the body (The Free Dictionary 2019). Cardiovascular disease is the leading cause of death in South Africa, and one in six deaths in the country is attributable to this (Koen 2019). Given the global epidemiology of heart disease, Koen's (2019) estimation of 500 000 as the number of people suffering with end stage heart failure in South Africa, is likely to increase before it gets better.

At the time that Professor Chris Barnard performed the first heart transplant in 1967, GSH was the pre-eminent state medical facility in the country. However, healthcare operated within a dual health system and depended on racial classification: access to healthcare facilities and all amenities in South Africa, was regulated by apartheid laws (Andersson & Marks, 1988: 667-8). Resources benefitted whites only and the health needs of the majority of South Africans were ignored. From the late 1980s the apartheid government started to allow certain specialty services to be undertaken in private sector hospitals (Andersson and Marks 1988: 678).

Post-apartheid South Africa's healthcare system remains bifurcated, between public and private sector care – the former funded and managed by government, the latter by private corporations. While, in theory, the race of a patient plays no role in where she or he may be treated, economic disparity means that the majority of South Africans cannot afford the rates charged by private sector healthcare service providers and must seek treatment in government hospitals, unless they have access to medical aid insurance (Coovadia *et al* 2009: 826). Heart transplantation is regulated by Chapter 8 of the National Health Act (National Health Act No. 61 of 2003), which sets out overarching considerations on how any and all organs may be transplanted. This includes prescriptions on who may remove or transplant an organ, who may receive a donor organ in a transplantation and the Minister of Health's role in certain scenarios relating to organ or tissue use. However, there is a lacuna in the legislation, as the specific regulations on transplantation, which were presaged in section 68 of the Act, were never published. This has meant that there are no official guidelines on transplantation emanating from, recognised or endorsed by the national Department of Health (Pepper 2019). As a result, professional and clinical bodies including the South African Transplant Society have formulated their own guidelines based largely on best practice protocols in other jurisdictions, or practices in South Africa which have emerged over the years. Most recently, taking its cue from the World Medical Association, the South African Medical Association (2019) published a set of ethical guidelines for organ transplantation. These guidelines

encompass principles such as the financial neutrality of organ donation and transplantation, informed consent of both donor and recipient parties, optimal care of both donor and recipient, efficient and fair management of those awaiting transplantation, non-discrimination on the basis of non-medical criteria, and the licencing of transplantation centres. By pointing out that the guidelines and protocols that are in place in South Africa are not official, I am not suggesting that the provisions are problematic. I am noting that they may be incomplete, that they are not officially sanctioned by the government, and they are not embedded into the understanding of all those with a stake in South Africa's transplantation programmes, including donors and recipients, and potential donors and potential recipients. As Thompson (2019) states, transparency and fairness are ethically important aspects of donation, and South Africans "will increasingly demand to know how organs are allocated to patients on a waitlist". As a result, he argues that the country will require sound policy and decision-making approaches that are applied consistently. Given heightened sensitivity about discrimination, access to organ transplantation must be ensured regardless of ethno-cultural identities and socio-economic circumstances. In addition, "the role of race, religion and culture in organ donation in a society as diverse as South Africa and with our history must be sensitively considered" (Thompson 2019).

Thompson's (2019) call resonates with Neuberger's (2011: 5) argument for transparent policies that are clear and apparent to all. The type of policies that the organ donation and transplantation community must set in place in South Africa, should comply with the minimum standards that Neuberger has highlighted, and must include defining the:

aims of the allocation process and desired outcome (whether maximizing benefit or utility or ensuring equity of access), inclusion and exclusion criteria, criteria for futility and suspension and removal from the transplant list, appeals processes, arrangements for monitoring and auditing outcomes and processes for dealing with noncompliance. Furthermore, guidelines must be consistent with legislation even though this may compete with public preference. Guidelines must be supported by all stakeholders. (Neuberger 2011: 3).

### *3.4 Constraints on heart transplantation*

Transplantation is dependent on the availability of a donor heart. By virtue of human design, the donation of a heart implies that someone will have been declared brain dead at the point that they are able to be a heart donor. The notion that someone must die in order that another can live by benefitting from receiving their heart does not sit well with all people (Shildrick

2015: 24). A major constraint on heart transplantations throughout the world is the shortage of donor organs (Neuberger, 2011; Organ Donor Foundation, 2019). The number of people who could benefit from an organ transplant outstrips the number of available organs. This places a quota on this critically scarce lifesaving resource, resulting in competing claims between potential recipients for organs (Neuberger, 2011; Organ Donor Foundation, 2019). The number of deceased organ donors in South Africa in 2016 was 1.29 donors per million of the population (pmp). This compares to about 14.6 organ donors pmp in Brazil, 20.8 pmp in Australia, 21.44 organ donors pmp in Britain, 30.98 pmp in the United States and 43.4 donors pmp in Spain (International Registry in Organ Donation and Transplantation 2019). In South Africa, the low number of heart transplants is also attributable to the country's national health policy, which places a premium on state funding of primary healthcare to the disadvantage of tertiary and quaternary services – under which specialised treatment such as organ transplantations reside (Cupido 2019; University of Cape Town 2014). There may also be an impact from the low number of cardiologists practising anywhere in South Africa, but especially in government hospitals outside of major metropolitan areas (Cupido 2019).

It is not easy to compile accurate figures on the number of heart transplants which have been performed around the globe or in South Africa since 1967, because records were not kept from the beginning, nor including all transplant programmes. In the period from 1982 (closely mimicking the widespread introduction of the new immunosuppressant drug, Cyclosporin and aligning with transplant figures first being recorded internationally) to June 2012, 111,486 heart transplants were performed throughout the world (Lund *et al* 2013: 951). Given that not all transplant centres report their figures, but taking into account the figures reported by Lund *et al* (2013: 952) and others, it can be estimated that, currently, between 3,500 and 5,000 heart transplants are performed annually worldwide. Stehlik and Lindenfeld's (2016: 255) slightly more recent estimate is that between 5,000-6,000 heart transplant procedures are performed annually.

In South Africa, Hassoulas (2012) reported that from 1967 to 2003, 489 heart transplants were performed at GSH. According to figures provided by one doctor interviewed in this study, from 2004 to 2016, 443 heart transplants were performed throughout the country in both the public and the private sector hospitals. Of these, GSH contributed 38, the private Netcare Christiaan Barnard Memorial Hospital (CBMH, formerly City Park Hospital) in Cape Town performed 114 transplants, Johannesburg's Netcare Milpark Hospital performed 228 and private hospitals in Durban performed 60. The Organ Donor Foundation's (2019)

most recent statistics indicate that in total 23 adult and two paediatric heart transplantations were performed in 2016 across all the South African transplant centres. Heart transplantation is a prescribed minimum benefit for all medical aid schemes registered with the Council for Medical Schemes in South Africa (Medical Schemes Act, 1998).

Pepper (2019) has listed the barriers to tissue and organ donation and transplantation in South Africa as:

- Insufficient education in all sectors of society, including the medical fraternity;
- Cultural sensitivities around human tissue related to African traditions and belief systems; issues of literacy and language;
- Lack of a formal death-referral system which could support and facilitate the process;
- Lack of sufficient or appropriate legislation and government support;
- The [potential impact of the] Protection of Personal Information Act;
- The reluctance of state and private hospital groups to actively support the cause of donation;
- The reluctance of the funeral industry to share details of their clients with tissue coordinators;
- Refusal to share information by most forensic pathology service facilities;
- Insufficient number of tissue coordinators due to financial and other constraints;
- Lack of new entrants into the industry, no changes in leadership, limited funding opportunities, no new expertise (Popper, 2019).

### *3.5 Diagnosis and communication*

Apart from policy considerations, there are many factors associated with the receipt of a donor heart. For the individual, the realisation that one is very ill - based on one's lived reality and borne out subsequently by clinical assessment - may constitute the first set of factors confronting a potential heart transplant recipient. As Williams (2005) narrates his experience of heart failure, he notes that, despite the fact that both his father and sister had died from heart-related ailments the year before he became ill, he had great difficulty convincing doctors that he, too, was suffering from a heart condition:

The precipitating condition which I experienced was persistently misdiagnosed (as asthma, bronchitis and then pneumonia)... My subsequent descent into heart failure resulted in such severe damage that a transplant was recommended as the only alternative to my death within six months (Williams 2005: 2).

Charmaz (1991: 24) states that, for people living with chronic illness, not being able to receive the physician's validation for their illness is troubling. She notes that when it eventually comes, the physician's diagnosis is greeted "with relief and gratitude for receiving a seemingly dreadful diagnosis. A middle-aged woman with a metabolic disease said, 'Thank

God. At last I know it is something real'... They prefer facing a devastating diagnosis to defining themselves as neurotics, malingerers, or shirkers" (Charmaz, 1991: 24). Bury (1982: 172) agrees that proper diagnosis of a serious illness offers the prospect of official recognition and treatment which warrant the individual's behaviour and presentation of the symptoms. With it comes the suggestion that the individual would get 'sorted out'.

Once referred through the ranks of medical professionals to a specialist heart transplant unit, the potential heart transplant recipient must go through a rigorous clinical and psychological work-up to determine their suitability for transplantation (Almgren, 2018; Kittredge 1989; Schire & Beck 1967). Patients are assessed for functional impairment, comorbidities which may be contraindicated for transplantation, psycho-social aspects like the patient's willingness ultimately to receive transplantation treatment, the likelihood of being able to take up an active lifestyle after transplant, propensity for adherence to medication, diets and protective regimes to minimise post-transplantation challenges, and the ability to self-fund or pay for the procedure through medical aid insurance (Almgren 2018: 11-12; Kittredge, 1989: 39-46 and 56-57). The transplant unit will also check for infections and counter-indications such as co-morbidities (Almgren 2018: 11, 12). Recipients must also ensure that they partake in healthy activities while avoiding harmful substances and over-exposure to the sun (Almgren 2018: 12).

In the assessment of his treatment by healthcare professions, Williams (2005) contrasted his early experience of dealing with doctors who refused to acknowledge the pointers to cardiac failure he presented to his experience of meeting and interacting with the heart transplant team at CBMH. The team consisted of cardiologists, cardiothoracic surgeons, a clinical pharmacist, two specialist-nursing sisters, a clinical psychologist and a clinical social worker, plus paramedical professionals. The team included patients "in every decision regarding their care, from treatment options to meals... At any point the patient or caregivers may call a halt to treatment, and their wishes are respected and the team offers what palliative care they can" (Williams, 2005: page). He further notes how it was the patient's or their caregiver's prerogative to accept or turn away from heart transplant treatment. However, ultimately the team decided whether a prospective transplant recipient was placed on the waiting list. In addition, Williams (2005: 2) stated that:

At no stage are the risks minimized, nor are the life-style consequences of accepting a transplant hidden. The team makes arrangements for prospective recipients to meet privately with previous recipients and their families to discuss the decision.

However, this is not the norm. As Ivarsson *et al* (2012) showed, information and support from healthcare professionals to patients both awaiting transplantation and post-transplant, can be improved to avoid patients feeling discouraged especially after complications or side-effects.

### 3.6 *The ethics of transplantation*

Kittredge (1989: 75-80) lists the ethical issues associated with organ transplants: who should donate and who should not; who should get organs; how does society ensure a better supply of organs; who should pay for organ transplantations; and who should decide ethical questions when controversy arises, as it will. As Neuberger (2011) has shown that due to the shortage of donor organs and the large potential recipient pool, transplantation must be rationed through providing clear criteria for how potential organ recipients are selected. This includes decisions on who among those listed will receive a donor organ that becomes available. For example, age is an important influencer and determinant in some programmes, as younger patients can better withstand surgery and will have more years to enjoy the benefits of surgery (Kittredge 1989: 40). However, Neuberger (2011: 2-4) argues that such criteria may not valorize equity of access for all in need of a transplant. Alternatively, he notes that it may prioritize those at the greatest risk of death if they do not obtain a donor organ and younger recipients. He further notes that patients with a better quality of life, and those assessed to be more likely to maintain post-transplant compliance regimes are also prioritized.

In respect of heart transplantation, clinical considerations such as blood or tissue type, or size of the donor organ, may also exclude some potential recipients from being considered to receive (Kittredge 1989: 23-24; Neuberger 2011: 4). Transplant clinicians seek to obtain the best match between donor and recipient tissue types in order to minimise future organ rejection (Kittredge 1989: 39-40). While geographic equity requires that anyone awaiting a donor heart may have the same chance of being allocated an available heart regardless of where they live or receive treatment, the distance between the donor and a potential recipient may impact the ischaemic time and the viability of the donor heart (Neuberger 2011: 4). Thornton (2009: 740) raises the length of time that a potential recipient has been on the waiting list as a decisive factor. Thornton (2009: 741) also suggests that, in a case of a tie on a heart transplant waiting list between two potential recipient patients whose clinical scores are equal, moral responsibility – such as whether a recipient’s disease was self-inflicted or if the potential recipient indulges in risky behaviour such as consuming alcohol – may break the tie. He notes that “members of the public are more frugal when asked to allocate scarce

resources (hypothetically) to patients whose illness was believed to be self-inflicted” (Thornton, 2009: 741). This ethical dilemma holds a significant place in the collective imaginary of some South Africans following the apparent preference given to the then-Minister of Health, Ms Manto Tshabalala-Msimang, to receive a liver transplant despite suffering from chronic alcoholism (Beresford 2007).

### *3.7 Functional status before and after transplant*

Two people may have the same heart condition, yet experience it entirely differently, suggests Brown (1995: 45). Once diagnosed, one may curtail their physical activity, another might configure a healthy physical exercise routine.

Barr (1992) examined the psychosocial implications of heart transplant for 17 recipients in the GSH transplant programme. She found the treatment affected “both the social and emotional spheres of the recipient’s life”, radically altered their work and financial situation, effected role reversals in family life, and heightened emotional responses. But the recipient also experienced “a renewed sense of vigour, enjoyment and richness of life”.

One of the biggest challenges facing the heart transplant recipient after transplantation is the lifelong requirement to take anti-rejection medication. This ensures chronic disease continues in tandem with radical health improvements and increases the possibility of disease infection (Kittredge, 1989: 47). Most surviving heart transplant recipients report that their quality of life is vastly improved one year after transplant, compared with the impairment they experienced as a result of advanced heart disease before transplant (Lund *et al* 2013). However, the side-effects of immunosuppressant medication were highlighted by Stiefel *et al* (2012). And, in the Lund, only 35% of recipients aged between 25 to 60 years were able to return to meaningful employment (Lund *et al* 2013: 956).

Reflecting on the role of resilience in the process of adaptation to life after heart transplantation, Baran (2013) found that the recipient rebounds to life as it was before heart failure, receiving high scores on measures of persistence and determination. In terms of acceptance of their illness, heart transplant recipients received even higher scores than other groups of patients such as those suffering from diabetes or those on dialysis (Baran, 2013: 49).

However, psychiatrists Maguire and Parkes (1998:1087) suggest that any interference with our heart undermines our sense

of the world as a safe place and of our body as a stronghold... Anxiety has physiological effects upon the heart and these, in turn, may increase fear and feed into a vicious circle of fear and cardiac symptoms. In addition, open-heart surgery may also give rise to some degree of cognitive impairment, particularly in the elderly, making it more difficult for the patients to cope with the emotional demands of the operation.

They have found that the fear experienced before a heart procedure continues into the post-operative period, with “a substantial proportion of cardiac patients” remaining fearful “of exerting themselves and apprehensive even when good cardiac function has been restored by surgery” (Maguire & Parkes, 1998: 1087).

Vogels *et al* (2007: 440) have also found that decreased heart function is independently associated with cognitive impairment. In a review of 57 studies that investigated cognitive impairment in heart failure patients, Vogels *et al* (2007: 445) found that heart failure is associated with “a pattern of generalised cognitive impairment that includes primarily memory, attention, mental flexibility and global cognitive deficits”. They also found that the prevalence of anxiety and depression among heart failure sufferers was high, with 81.8% of those surveyed in the underlying studies showing these conditions. This feature also affected respondents scores on neuropsychological tests. Another finding was that cognitive impairment was likely to occur up to 62% more often in heart failure patients than in patients who were healthy or suffered other cardiovascular diseases. These findings corroborated a review by Almeida and Flicker (2001: 290) which reported that heart failure is associated with “a pattern of generalized cognitive impairment that includes memory and attention deficits”.

A Canadian study shows that issues of bereavement and loss are commonly experienced in both pre- and post-transplant patients either as anticipatory or disenfranchised grief, during which “patients may try to keep quiet, disallowing themselves the outward mourning that may be cathartic” (Poole *et al* 2014: s222-s223). They also found that bereavement and loss dominated in the pre-transplant group, reflecting anticipatory grief in patients *getting ready for the possibility of dying* and for the death of their potential heart donor. They also noted that similar instances occurred post-transplant, with the added aspect of grief for their birth hearts and for the donor and the donor’s family.

Almgren (2018:14) also highlights the fact that depressive and anxiety disorders, including post-traumatic stress disorder (PTSD) are the most frequently occurring psychiatric disorders

in heart transplant recipients during the first year post-transplantation. Thus, for both healthcare professionals and heart recipients, the goal is:

Managing the medical regimen; coping with the psychological and physiological changes inherent in the transplantation process and regaining health... Unmet expectations, disappointments, unachieved life goals, lost life roles, symptoms, fatigue and inability to work are sources of uncertainty that will potentially affect a person's ability to manage life with a new heart." (Almgren 2018: 15).

As Charmaz (2012: 49) says that dividing life into *good* and *bad* days is one way in which chronically ill people make sense of the illness that intrudes into their lives:

A good day means minimal intrusiveness of illness, maximal control over mind, body, and actions, and greater choice of activities... A bad day means intensified intrusiveness of illness, less control over mind, body, and actions, and limited choices about activities. Illness and regimen take centre stage. On a bad day, people cannot ignore or easily minimize illness.

A life founded on illness means that the patient must restructure their life around the illness (Charmaz, 2012: 76-104). She further notes that restructuring may mean hard work, limited income, more (medical) accounts to pay, limited access to services, drastic changes to lifestyle, physical depletion, physical, social and financial dependency.

Healthism or discrimination on the basis of health status is something that heart transplant recipients must be alert to, as their chronic illness may be regarded by an employer as so incapacitating to make it impossible for them to return to gainful employment (Roberts: 2015). Ivarsson *et al* (2012: 404) found that recipients often experienced fatigue or had to deal with managers who lacked understanding of their situation, including their sensitivity to infections. However, closer to home, the heart recipient may find that family members may have different expectations about their recovery, envisaging "a faster recovery and that everything would return to normal" (Almgren 2018: 27).

### *3.8 Biographical identity and culture - and their disruption*

The common adage is that death and taxes are the only two certainties in life. It is possible that illness before death may now be regarded as another one of life's certainties. Bury (1997: 2) offers an analogy from the textile manufacturing process to express the integral connectedness of health and illness in society. Just as the longitudinal and transversal lines of thread are strung across in connected rows to create a piece of fabric, he suggests that "health and illness are part of the warp and weft of everyday reality" (Bury 1997: 2). While, historically, humanity has been beset by disease and illness, the possibilities and hazards of modernity are "nowhere more obvious than in illness, health and medicine" (Bury 1997: 13).

For Charmaz (1982: 2), dealing with serious illness requires effort and time, while overcoming stigmatising judgements, intrusive questions and feelings of diminished worth. She further states that people who live with a serious chronic illness oscillate “between being immersed in the illness and keeping it contained” (Charmaz, 1982: 4). Turner’s (1992: 37) suggestion that it is difficult to consider personal identity without reference to a specific body, that “who I am rests crucially on having a specific body”, may have crucial significance in respect to biotechnology such as organ transplantation, where an organ from one body is placed in another body. However, as Habermas (2003: 23) warned, the reality of advances in bioscience means that “more and more of what we are ‘by nature’ is coming within the reach of biotechnological intervention”. Organ transplantation impacts on a recipient’s sense of self as reflected in a healthy body. The transplantation represents a radical bodily and biographical disruption (Bury, 1982; Charmaz, 1983; Turner, 1992).

The effect of such bodily and biographical disruption through transplantation, and the recipient’s efforts to hold onto the received organ and continue to live, also requires consideration in a South African context (see Cormier *et al* 2017; Nilsson *et al* 2008; Svenaeus 2012). For example, how do recipients make sense of losing a part of themselves and taking on a body part – if not an identity part - of another, especially when that ‘other’ part was harvested from a donor with a different psycho-socio biography? Karmakar & Parui (2018) explore this theme in Jodi Picoult’s novel *Changing Heart*, where a heart recipient’s sense-making is challenged by the receipt of the heart of an inmate on death row. In some instances, recipients relate vivid stories that suggest a merging of their own and their organ donor’s lives (see Neukom *et al* 2012).

Chisaka and Coetzee (2009) have shown how, in South Africa, stories of chronic illness and chronic poverty are intricately linked, with poverty cushioning the chronically ill individual’s selfhood. These researchers also raise the prospect of “the ultimate biographical disruption: suicide” as a real prospect of chronic illness (2009: 124).

Sanal (2011) has written an account of transplant recipients who believe that their body incorporates a transplanted organ and all that the organ embodies or represents. This includes *the life history of the donor*, the metaphorical or cultural significance of the organ itself, and “the varieties of transplantation policy and politics” (Sanal, 2011: 13). He further reports that recipients experience “a heightened attention to the truth or falsity of the imaginary one inhabits”, a “change in consciousness” suggestive of a new, “altered state designed by some other who has taken over the divine unknowable realm” (Sanal, 2011: 13).

Bury's (1982: 169) approach is to view chronic illness as "a major kind of disruptive experience". In explaining chronic illness, he relates this deeply personal, individual event to a wider, social context such as war or imprisonment, similar to what Giddens (1979: 124, 126) described as a "critical situation... a set of circumstances which – for whatever reason – radically disrupts accustomed routines of daily life" and which inaugurate "a new process of identification". As Bury (1982: 169) asserts that:

Illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. It brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal roles of reciprocity and mutual support. The growing dependency involved in chronic illness is a major issue here. Further, the expectations and plans that individuals hold for the future have to be re-examined.

Furthermore, the recipient's reaction to the experience of receiving a donor heart may reflect an altered sense of physical, psychological, even biographical wellbeing (Bury, 1982), as "a new consciousness" and "schizophrenic conditions" (Sanal, 2011: 13). Based on a similar methodology as the current study, Mauthner *et al* (2014) theorised that transplant recipients experienced a common disruption to their own identity and bodily integrity.

There may even be an understanding that part of the donor's personhood has been transplanted with the organ (Fox & Swazey, 1992: 36). Pearsall *et al* (2000: 66) have suggested that cellular memory is a plausible explanation for parallel changes in heart recipients following their transplantation and the histories of their respective donors. They argue that such parallels cannot merely be explained in terms of the effects of the surgery or immunosuppressant drugs or statistical coincidence.

Sharp (2006: 107-108) particularly examines the impact on the recipient of long-term chronic illness before and after transplantation, the cost of the drug regime, and inability of many to carry out daily activities. In her view, a transplant recipient simply swops out one set of debilitating life factors for another. The prospect of a second life is thus, pitted against a lifelong regime of anti-rejection medication, lifestyle precautions and socio-economic concerns. She also questions transplantation for being "a lifesaving technique that nevertheless relies on donors' deaths" (Sharp, 2006: 15). Sharp (2006: 26) notes how communication about transplantation renders hazy the reality of body commodification. She also considers the ideas of transplantation that recipients and healthcare providers share about

the organ donor and death, and where these ideas might converge, especially whether death resides in the brain, body, soul, or a combination of these or other sites (Sharp, 2006: 7).

Like Williams (2005: 25), I understand the sociology of health and illness' concern with "the social taking cognizance of the individual". In the context of heart transplantation, this concern is not about asking why a person is sick but "what set of structures has influenced, and continues to influence, the life chances of members of the group to which she / he belongs" (Williams, 2005: 23). Recently, the American Medical Association (2019) has highlighted the importance of health professionals gathering information on the social determinants of their patients' health, including economic stability, education, health insurance, literacy and access to healthcare; community environment, including workplace conditions, civic participation and cohesion; and physical conditions in the neighbourhood. Williams (2005: 38), citing Archer (1995) among others, argues that structure in this context "serves to enable or constrain, but not to determine human action". Heart transplantation, therefore, enables an election of treatment by a heart failure patient, but the availability of that treatment is not determinant. The same holds true for the non-availability of transplant treatment in the state sector for indigent patients, which represents a constraint, or one's membership of a medical aid scheme, which makes the possibility of treatment easier to achieve. However, these factors do not act as determinants in the process.

Mattingly (2006: 567) warns that protracted illness offers the sufferer no hope of being 'normal', of returning to the person one once was. Instead, personal identity "becomes intimately tied to the pain, uncertainty, and stigma that comes with an afflicted body". Identity questioning by the chronically ill, according to Charmaz (2012: 101), involves wondering whether the current ill patient's identity will become permanent and override any other identity marker, past or present, and whether that will be the only identity one is able to lay claim to in the future.

### *3.9 Miracle or medicalisation*

Religious sense-making has become a key part of the narrative which organ transplant recipients apply to an experience of illness - which brings them close to death - and then the receipt of a donor organ - which revitalises their life. Macdonald (2006: 64) reports that recipients in her study describe this as the "spiritual component of transplant". Sharp (2006: 8-9, 26) regards the *aura of the miraculous* as a key but fatally flawed premise of *transplant ideology*, the euphemism of a miracle hiding the extent to which the treatment draws on an

*elaborate array of sophisticated* and expensive medical technologies. She defines the biomedical paradigm of disease theory as a progression from diagnosis of human health problems, to treatment and cure. In its more current iteration, the paradigm emphasises technological solutions, presenting healed patients who “emerge as little more than medically manipulated cyborgs” (Sharp, 2006: 9). Transplantation of human, especially cadaveric body parts, represents the zenith of biomedicine, offering “interchangeable parts, as precious gifts” which harbour “the transmigrated souls of the dead” (Sharp, 2006: 14). This transfer of human parts between disparate bodies is conceived of as “a natural progression within medicine”, even as it draws heavily on “monstrous imagery such as ‘Frankenstein syndrome’” (Sharp, 2006: 23). She further regards organ transfer as a site of lucrative medical practice sustained by an ever-expanding demand for technological expertise, yet hidden behind, even outright denied by the euphemistic veil of *the gift* (Sharp, 2006: 23).

However, spiritual or religious sense-making, as shown by Macdonald (2006), Sanal (2011), Kamran and Ghazal (2017), and Sheikhalipour *et al* (2018), play a significant role in the journeys of organ transplantation recipients, both before and after surgery. In the post-transplant phase, such constructions may aid coping mechanisms – for example, through a reimagining of the broken self or adherence to immunosuppressant medication regimes (Harris *et al* 1996: 24). Shildrick (2015: 21) reaffirms the historical importance of the heart as the biological and metaphorical seat of life. For a recipient of a donor heart, *living on* is fraught with emotion “not only about the self and the now dead other, but about the persistence of the other within the self” (Shildrick 2015: 22).

### 3.10 *The gift of life and a sense of appreciation to the donor or the donor’s family*

As indicated earlier, Fox and Swazey (1992: 31) regard the gift exchange that happens in human organ transplantation as a symbolically powerful and intricate event. Since the first human transplantation was performed in the 1950s, the medical profession and society at large have defined transplantation as a “gift of life” (Fox and Swazey 1992: 32). The metaphor of *the gift* reflects “entwined obligations to offer and give, to receive and accept, and to see and find an appropriate way to repay” (Fox and Swazey 1992: 32). Many other authors have used the gift exchange as a lens through which to view organ transplantation (Ben-David 2005; Galasiński and Sque 2016; Gerrand 1994; Shaw 2015). For example, Galasiński and Sque (2016: 1151) trace organ donation’s association with the notion of a *gift of life*, and how it establishes “the obligation to give, the obligation to receive, and the

obligation to repay” involving donor and recipient, with subtle pressures at every stage. Examining organ donation from the perspective of what the donor has done, Fox and Swazey(1992) show how the live donor’s offering of a part of their body constitutes an inestimably precious gift. The same may be true of the family of a deceased donor who agree to donate their loved one’s organs to others in need of a donation. On the other side of the transplantation transaction, “the acutely ill patient who receives the organ accepts a priceless gift. Fox and Swazey suggest that these “gift of life” aspects of seeking, giving and receiving a human organ “remain intrinsic to the dynamics and meaning of transplantation” (Fox & Swazey, 1992: 31). They attribute to the organ recipient a deep appreciation of the *gift of life*, while also recognising animistic feelings from the recipient towards their donated organ, especially in the case of heart transplantation. While on the surface, they say recipients regard the heart they have received as *just an organ*, albeit crucial to their ongoing life, and that “on deeper levels many respond to it as if it were a repository and emanation of the donor’s quintessence” (Fox & Swazey, 1992: 36).

Recipients in Ben-David’s (2005) study identified the heart they received as *the greatest of all gifts*, for which they must make a form of recompense. In another study, heart recipients were aware of “a distinct sense of obligation and a need for reciprocity. Society had given to them, so they had an obligation to give something back” (Galasiński & Sque 2016: 1352). Ben-David (2005: 50) points out that the gift-exchange narrative – the notion of the donor family agreeing to an organ transplant and somebody giving a present, free of charge, is a widely accepted sociological explanation of organ transplantation.

However, it is not clear in the reviewed studies that all recipients necessarily always are comfortable with the ‘gift of life’ narrative. Shildrick (2015) suggests that heart recipients must reconcile within themselves conflicting narratives about the transplantation procedure. First, they must view it as a purely technical procedure “with few consequences for their sense of self” and, second, that it is “a point of connection to *an other*, whose very death has given them life, and with whom they are expected to be emotionally engaged” (Shildrick 2015: 26). Referencing the work of Marcel Mauss (2002), she writes that “the bond of reciprocity between giver and receiver mobilises a complex cycle of obligation and indebtedness” (Shildrick 2015: 30). And that:

In the case of heart transplantation, the gift circulates between the living and the dead and sets up an economy of exchange in which the obligation of reciprocity, and its affective correlates, shifts endlessly between donors and their proxies and recipients.

Once recipients have written to donor families, for example, they usually want a response, and the desire for kinship goes in both directions (Shildrick 2015: 31).

Shaw (2015) suggests that “gift terminology” is an important part of the professional clinicians’ lexicon, impressing on recipients “how lucky they are to receive a second lease of life, given the short supply of organs”. By having the significance of the gift highlighted, recipients are encouraged “to take ownership of their new organ” and to show gratitude to the donor by being responsible for the post-transplant regime of medication and care.

## **Chapter 4: Research design, methods and procedures**

### *4.1 Introduction*

This is a qualitative study that investigated the experience of receiving and living with a donor heart, and the meanings that recipients attach to this. In-depth interviews were conducted with heart transplant recipients, healthcare professionals and programme co-ordinators associated with private heart transplantation programmes in the Western Cape, Gauteng and Kwazulu-Natal Province in South Africa.

### *4.2 The research field*

There are five heart transplant programmes in South Africa. Four of those are based in private hospitals and the fifth is based at GSH in Cape Town (Organ Donor Foundation 2019). Netcare, which is South Africa's biggest private hospital group, also runs the biggest organ transplant programme in the country, covering all organ and tissue types. Its heart transplant programme was started in 1994 (Netcare 2019; SAPA 2014). Two of the cardiothoracic surgeons engaged in heart transplantation at CBMH, previously worked in a joint practice but now operate separate transplantation programmes. In terms of patient treatment protocols, there appear to be key differences between the two surgeons' respective programmes, warranting treating them as separate programmes within the same hospital group. The same distinction is made between CBMH's heart transplant programmes and the Netcare transplant programme at Milpark Hospital in Gauteng. Milpark currently performs more heart transplant procedures than CBMH annually. In Durban, Busamed Gateway Private Hospital currently manages the country's fourth private heart transplantation programme which was previously associated with Entabeni hospital in the city (Cole 2018).

Initially, I intended to interview transplant recipients, clinicians and co-ordinators associated with the public sector heart transplant programme centred on the GSH and University of Cape Town complex. This approach was regarded as valuable to identify similarities and differences in protocols and approaches between the private and public sector programmes. However, despite numerous formal interactions with officials over a period of two months, I encountered numerous instances of non-responsiveness. This culminated in the administrative hurdles proving too onerous to obtain ethical and gatekeeper permissions within the timeframe allocated, to conduct my fieldwork. The approach of the GSH-UCT complex towards providing ethical permissions for this research appear to flout the provisions of the

National Health Act No. 61 (2003) and the subsidiary regulations drafted thereunder. I was unable to deal with my concerns about the GSH-UCT complex approach within the ambit of this research project. Reluctantly, I had to withdraw my intention to conduct interviews in the public sector.

#### *4.3 Sampling*

Participants were drawn from healthcare professionals and transplant co-ordinators working in four private sector heart transplant programmes, and recipients who have received organ transplants in those centres.

My initial contact with heart recipient participants was through the social networks (e.g. social media support group) that I belong to. Purposive sampling was used to recruit additional participants. I contacted the various clinicians associated with the respective programmes directly as they operate as independent practitioners. I also obtained permissions from the two private hospital groups to interview members of their respective staffs who work as transplant co-ordinators. All participants signed consent forms and were guaranteed confidentiality in terms of all aspects of this research project and the thesis write-up.

#### *4.4 In-depth interviews*

I contacted each potential participant and arranged to meet with them at places convenient to them. Nineteen recipients were interviewed in the Eastern and Western Cape, Gauteng and Kwazulu-Natal, from August 19 to 31, 2019. Eight were associated with the CBMH programmes in Cape Town, four were drawn from the Gauteng programme at Milpark Hospital and six from the hospitals in Durban, Kwazulu-Natal (see Appendix 1: Interview question schedule: Heart recipients). Among the recipients, the earliest person transplanted was in 1999 and the most recent in 2018. The ages of all the recipients at the time of their transplant ranged from 20 to 66. The ages of all the recipients at the time of the interviews ranged from 22 to 76. Three women and 16 men respondents were interviewed. Eleven recipients identified themselves as Christian, one identified as a “nominal Christian”, three as Hindu and two as Muslim. One individual is an atheist and another identified only as someone who did not pray. The recipients’ work profiles included academic, teacher, religious minister, printer, retailer, entrepreneur, engineer, beautician, plumber, hairdresser, business owner, warehouse supervisor. Race did not feature at all in identifying recipients, although references to race by recipients during interviews are included in the case study discussion where relevant.

I also interviewed five clinicians - four cardiothoracic surgeons from the above four transplant programmes and one cardiologist from one transplant programme. I interviewed three transplant co-ordinators associated with two of the programmes (See Appendix 2: Interview question schedule: Clinicians & co-ordinators). The interviews with the clinicians and co-ordinators were intended to triangulate some of the information obtained from the heart recipients. However, given the space constraints of the mini thesis format, I was not able to include the responses of co-ordinators and it was possible to only reflect limited responses from clinicians. Where I have referred to clinicians, I have completely anonymised the responses, referring to “one surgeon” or “another clinician”, to avoid the risk of exposing the identity of individuals in a very small pool of professional participants.

#### *4.5 Questionnaire*

I used a semi-structured questionnaire, seeking “thick descriptions” from heart recipient respondents of their perspectives of the transplant process both pre- and post-surgery, their experiences and understandings, and the cultural significance of some behaviour (Punch 2006: 46, 157). My own experience and knowledge of the clinical work-up - the diagnosis and preparation for treatment (The Free Dictionary 2019) - surgery, post-transplant treatment and recovery enabled me to delve deep into the experiences of the recipient respondents. Shorter, targeted questionnaires were administered with the transplant clinicians and co-ordinators.

#### *4.6 A dilemma in autoethnography*

The title of this research project is no mere rhetorical question – it demands an answer. Of all those who could provide an answer, I am the best placed to do so for myself. Of course, I understand that my engagement as a sociological researcher with heart transplantation research can never be a distanced, stoic study. Try as I might, I remain implicated in every aspect of this research. Mauthner *et al* (2014: 4) show how transplantation is neither “a neutral” nor an “inconsequential” experience for recipients. I also interviewed members of the transplant unit who performed my own transplant surgery for purposes of this research. Commentators might suggest that I am unable to take an objective perspective of my experience at the hands of this team. However, it is spurious to suggest that, because they participated in my transplantation, I am incapable of critiquing their professional actions either in relation to myself or other recipients.

Williams (2005: 2) warned himself of the risk of inserting his own account of heart transplantation into an academic thesis. I note his warning but suggest that my approach here is fundamentally about presenting an understanding – my own and that of others – of these topics. Muncey (2010) has shown how a personal story can be included effectively, valuably and unproblematically in an academic research study using participant observation. Autoethnography, she says, “emerges out of the process of doing research while engaging in the process of living a life” (2010: 2). This is a fair assessment of the donor heart recipient researching transplantation.

#### *4.7 Breaking bread and sharing tears - the impact of hearing others' stories*

I have found my interaction with fellow heart transplant recipients infinitely more than a mere research project. As we met, tentatively opened a discussion, there was the almost immediate realisation that we had a deep experience in common, seeped in brokenness, pain, struggle, but also since we were, incredibly, alive. In coming to a decision to focus on the stories of heart transplant recipients, I had not considered the emotional impact on me of going through this process, of hearing their stories and reliving my own, each time. It was impossible for me to be disaffected. These times of intimate sharing triggered my own memories of the experiences I had during heart failure, intense moments of secondary trauma. I wept many times as recipients recounted their stories of how sick they were, recounted the minute details of their physical and emotional battles, told of the struggle to keep breathing, the repeated hospitalisations, the lives disrupted, halted for a period or forever. But then there were the tears of joy when they spoke about the moment of the call, being told over a cell phone connection that a donor heart was available. These reflections brought back my own experience, of a world having just stopped for a solitary individual to catch up, the manic activity alongside total calm, the act of desperately remembering the logistics – worked out months, even years ago but needed at the moment that one received *the call* – for getting to the hospital on time and in one piece, the rush of relaying news updates to loved ones, and confronted by the absolute state of being gobsmacked which the entire journey brought on and which was exacerbated by *the call*.

## **Chapter 5: South African stories of heart transplantation**

### *5.1 Introduction*

In this chapter detailing the case study undertaken, I start with a synopsis of my own experience of heart failure and transplantation. Thereafter, I examine the experiences and understandings of other heart recipients in South Africa against the theoretical discussion and the broad themes discerned in the literature review. My own experience of heart failure and transplantation accords in almost all respects with the shared experiences of other recipients included here. Uncertainty is a theme which permeates all aspects of this discussion. I also draw in the comments of clinicians where appropriate. Interviewees' statements are quoted directly or paraphrased where necessary for narrative style or space constraints.

### *5.2 My own story*

In March 2007, I was diagnosed with ischemic idiopathic dilated cardiomyopathy, a cardiac condition which reduces the heart's ability to pump oxygenated blood to the rest of the body. The doctors were unable to determine exactly what caused my condition but suggested either a heart attack or a viral infection. At that stage I was diagnosed with an ejection fraction (EF) of about 38%. This placed me in a heart failure category according to the guidelines of the Heart Failure Society of South Africa (2013) but doctors never stated emphatically that I was experiencing heart failure. (My diagnosis and treatment were complicated by the fact that simultaneously, my small intestine was gangrenous due to poor blood flow and required resection). I understood that my life trajectory in respect of my heart condition would continue with minimal disruption and in similar vein as before my diagnosis, albeit requiring medication.

Beginning in about June 2015, I was repeatedly ill with symptoms of flu and colds, shortness of breath, and fatigue – the latter after ordinary daily activities like showering. It was not immediately clear to me that heart failure was causing my symptoms and I was concerned that my poorly diagnosed illness could be misconstrued as malingering (see section 3.3 for a discussion of the validation of professional diagnosis). Doctors eventually diagnosed that due to heart failure, my body was retaining liquids which surrounded my lungs, caused bloatedness, and weight gain. Doctors who treated my symptoms in general practice or physicians' consulting rooms stated that, in their view, I was not a suitable candidate for a heart transplant because of comorbidities such as diabetes. (I recognise with hindsight that the lack of transparent protocols which are widely communicated, means that most clinicians

outside of transplant units are likely to be unfamiliar with current practice on comorbidities or similar issues within South Africa generally or within specific transplantation units.)

In August 2016, I was diagnosed with end stage heart failure, with an EF of between 10-12% (Heart Failure Society of South African 2013; Yancy *et al* 2013: e246; Mayo Clinic, 2017). In the absence or failure of alternative treatment options, I was referred to CBMH for assessment for heart transplantation treatment and was subsequently accepted as a candidate for such treatment. I was admitted semi-permanently to hospital to receive intravenous inotrope medication to minimise some of the more debilitating effects of heart failure until I received a donor heart. On Monday, October 10, 2016, I was informed by the cardiothoracic surgeon that a donor heart had become available. I was to be transplanted the next day, October 11.

I was neither anxious nor afraid. There had been opportunities for me to come to terms with my mortality and I was at peace now. I had even provided a funeral script for my family, as Poole *et al* (2014: s222-s223) found in their study to be common and as others report in this study, should I not receive a donor heart or not recover from transplant surgery. As I waited through that day until the next morning when I was wheeled into theatre, I was in a state of awe. Emotional. Incapable of appreciating the immensity of what I was about to experience. I would be in an unconscious state, incapable of controlling anything that would happen. I was prepared for the possibility that anything could prevent the surgery from happening up to the last moment, including a final decision by the transplant team that the donor and I were not an optimal match, in which case the heart would be allocated to another recipient.

I wondered what it would feel like to wake up from this life-giving surgery. My recovery was nothing short of outstanding, as many others report (Lund *et al* 2013); while I was extremely ill before transplant, once I was over the immediate post-surgery period, my life improved radically for the better. With each recovery milestone that I experienced in my body, I was galvanised to greater positivity and looking ahead to the next milestone. My spouse was not as fortunate. She was still caught up in our life experience before transplantation, re-living the minute details of illness, anxious that I would relapse into end-stage illness.

Throughout my period of illness and after receiving a heart transplant, I constantly considered the question “Why me?”. In the context of my own Anglo-Catholic Christian faith, I have understood the process of my transplantation as nothing less than a miracle, one of the great mysteries of life, generally, and of my life, especially. And yet, I realised acutely that access

to first-class healthcare, medical aid benefits which covered the cost of treatment, a family support system, made it possible for me to receive this treatment, over others who were as ill or worse than I.

Until recently, I have not had a spiritual kinship to my donor. But my Christian faith provides for a deep spiritual relationship with those of my loved ones who have already died. Whenever my family is in crisis, I evoke the memory of my forebears, who protected, comforted and sustained us. That was also my attitude as heart failure bore down on me. I regard my donor in a similar context now.

### *5.3 The epidemiology of heart transplantation*

#### *5.3.1 Introduction*

In this section, recipients give their understandings of the underlying structural causes of their heart failure. Clinicians and recipients comment on protocols that apply to transplantation treatment. Recipients also comment on the availability, accessibility and costs of heart transplantation treatment.

#### *5.3.2 Tracing heart disease*

This study affirms the need for coherent, deeper research into population aetiology for heart failure in African communities, as the Mayosi (2007: 1182) study highlighted, and for correlating this to heart transplant treatment. Many recipients here - Theo, Rafael, Gavin, Henry, Ethan, Logan & Calvin - reported prior instances of heart disease in their families. For example, some spoke about fathers who had “a few” heart attacks and who later died from the condition. Another participant spoke of a mother with angina, older siblings who underwent bypasses, and a brother who died in theatre during a bypass procedure. Theo’s cousin was an early heart transplant recipient in the 1970s, while Ethan said his father’s “whole family has heart disease – it’s hereditary”. Rafael’s mother used to joke that “we are not a cancer family; we’re a heart family”.

One recipient, who identifies as an Indian South African, agrees that some groups of people are more susceptible to heart disease. “It’s in the genes,” he says. Both his parents had heart disease and received bypasses.

However, despite the instances of illness in his family, another recipient, Logan, understands that cardiac disease is caused by lifestyle choices. Shane agrees with Logan as he attributes the rise in heart disease to “the stressful lives we live”.

#### *5.3.3 Transparent protocols*

##### *5.3.3.1 Recipient perspectives on protocols*

Nowhere does the challenge of transplantation in South Africa seem more acute than in the absence of clear protocols, both in terms of donation and receipt of organs.

A few recipients expressed concerns about the opacity of the processes which led to their own transplantation. For example, Felix gave an emphatic “no”, when asked if transplant protocols and procedures are sufficiently transparent. Born in another country, Felix is a naturalised South African based on residency, he regards himself as blessed to have the heart

of a South African. However, he wondered if the state could put non-citizens ahead of citizens. He argues that the process of selecting a recipient must not be “too mechanical” or completely evidence-based; there must be space for a “doctor’s discretion”.

Logan initially was comfortable expressing a view that age, geographic location and comorbidities are among factors which are considered in deciding which recipient should get a donor heart. However, when he was asked a follow-up question to confirm his understanding, he hesitated, stating that he would also like to obtain clarity from the transplant co-ordinators on what criteria they applied in selecting recipients.

Shane and Gavin believed that being admitted to hospital improved one’s chances of being allocated a donor heart, suggesting that the adage “out of sight, out of mind”, applied. Both participants also believe that the heart procurement system favours patients in private hospitals and that being forced to receive treatment from a public hospital would have compromised their chances of survival. In a government hospital, a donor might not receive a donor heart quickly, they suggest. Dawid, who was forced to get heart failure treatment from public hospitals because he did not have medical insurance, said that his experience was “very, very difficult because some of those government hospitals don’t have good heart specialists”.

The idea that, as Neuberger (2011: 2-4) proposed, younger potential recipients were more likely to obtain a transplant than older patients, played a role in Gavin’s decision to opt for a transplant at age 55, as he said: “The doctor said to me that they are very hesitant to do a transplant after say 62 because... the younger you are, the more successful their prediction is that you going to survive.”

Age limits would have prevented 65-year-old Rafael from getting a heart transplant in England. He regards himself as fortunate for returning to South Africa where he received a transplant. Even though he matched the donor, there was a much younger patient also on the waiting list. He said: “It wasn’t an automatic thing.” The transplant unit took a decision to offer the donor heart to him, rather than the younger patient. The literature suggests that it is not an open-and-shut case that younger patients would be preferred to receive a donor heart. Stehlik and Lindenfeld (2016: 258) show that “patients transplanted in their 40s and early 50s are at lowest risk while both younger and older recipients have a higher risk of mortality”. They suggest that a more responsive immune system resulting in a higher risk of rejection, and higher rates of medical non-compliance may be responsible for higher

mortality in younger patients. They also point out that sometimes older recipients receive higher-risk donor hearts, which could explain the excess mortality attributed to age (Stehlik and Lindenfeld 2016: 264).

As indicated in section 3.3, Pepper (2019) and Thompson (2019) confirm that no protocols defining and regulating all aspects of organ donation and transplantation in South Africa have ever been published in terms of the National Health Act. As a result, it is difficult for heart failure patients to have any criteria against which to gauge the diagnosis they receive from clinicians and the expectations they have about how a donor heart might be allocated to them. The recipients in this study showed that they neither knew nor understood the procedures they would be subjected to once referred to a heart transplant programme for assessment. They also had little appreciation for what the likely outcomes would be and how those would be implemented by clinical professionals. Ivarsson *et al* (2012) showed how information and support from healthcare professionals could be improved to avoid patients feeling discouraged (see section 3.5) when outcomes did not meet their expectations. The lack of protocols must also impact prospects for intra heart transplant unit auditing of outcomes as well as inter-unit audits, as highlighted in section 3.3 above in the discussion of Neuberger's (2011: 3) minimum policy standards. The Organ Donor Foundation (2019c) provides basic information on numbers of transplants performed each year but offers no outcome statistics to gauge the efficacy or safety of a unit's approach. As Keogh (2000: 7) points out, cardiac surgery "with its potentially profound adverse outcomes" requires effective quality control.

#### *5.3.3.2 Surgeon perspectives on protocols*

Matching blood and tissue types, and organ and body sizes of donor and recipient, are paramount, said one surgeon interviewed in this study. "All donors are allocated as fairly as possible," said another, but added that transplantation units must prioritise the best overall outcome.

Currently, there is a list of awaiting-transplant patients which is shared among transplant coordinators. When a patient is listed as an emergency case, they will be offered the first suitable donor heart available. One surgeon did not support this approach, as these patients usually represented "the worst risk and the worst outcomes".

The transplant units also focus on ethical and societal concerns, which can trump a clinical consideration, a surgeon said. A concern for transplant units was whether a patient – even one on medical aid - was so financially compromised that they should not be transplanted because

they did not have access to a clean home environment or to money for transport to get to hospital for a check-up.

Clinicians insisted that they have firm protocols in place for this “rather difficult-to-understand decision-making process”, as one surgeon put it. After some prodding, they acknowledged that, at best, there are “guidelines” which have been adopted *inter alia* from Europe and Canada. These guidelines reflect to a greater or lesser extent how issues of age, the extent of heart failure, comorbidities, geographic location, the length of time the patient has been on the waiting list, are implicated in a decision to award a donor heart to a waiting transplant patient.

One surgeon acknowledged that he resorted to “gut feel” in his assessment of how well a patient might do after transplantation. He stated: “My gut feel has never let me down and I trust my gut.... The protocols are there as guidelines and then sometimes you must just use your clinical acumen and things that you have seen in your career.” The result of the lack of protocol transparency coupled to using gut instinct, as this surgeon said, was that patients accessed information on the Internet which suggested either that they were not eligible for transplantation or that they must not be refused transplantation. However, resorting to gut instinct is not necessarily an inappropriate response for a transplant surgeon. Pfeffer *et al* (2016: 7) acknowledge that the absence of an absolute and uniform definition of end stage heart failure may demand greater subjectivity in its diagnosis and treatment.

It was not always clear that a surgeon would tell a patient if they were being overlooked in favour of another recipient because of age, comorbidities or social status. As one surgeon explained, circumstances such as time, place, tissue match and even the presence of infection might militate against a waiting recipient receiving a donor organ. In that situation, an older patient might be the only one able to benefit from the donor organ. Another surgeon acknowledged it was unethical to exclude somebody based on age, when he noted: “The decisions that we make are ethically very, very fraught.”

This series of comments by clinicians expose the serious challenges faced within the South African heart transplant environment in respect of ethical processes that are fair and are seen to be fair by all, including recipients. As shown in section 3.3, Neuberger (2011) has highlighted this challenge of fair decision-making in the context of a scarce national resource. However, as Stehlik and Lindenfeld (2016: 255) suggest and based on research into characteristics such as age and comorbidities among a cohort of 17, 868 heart recipients

transplanted between 2006 and 2011, protocols need not be onerously applied to exclude certain groups of recipients. But protocols do need to exist and, as Thompson (2019) has pointed out, fair and transparent decision-making on who gets a donor organ requires sensitive consideration in democratic South Africa.

#### *5.3.4 Hearts are free, transplants cost an arm and a leg*

All organ donation in South Africa is done based on a ‘gift’. Donors and their families do not pay for the cost of the donation (Organ Donor Foundation 2019b). But the recipient is responsible – either directly or through their medical aid - for the costs of the transplant procedure if it takes place in a private hospital. Indigent recipients may receive transplant treatment at GSH (University of Cape Town 2019).

Despite the significant cost of the treatment, most recipients – by their own admission - did not have an accurate idea of what their own transplantation cost, although some were spot on. Their responses to the question of how much their procedure cost, ranged across an increasing order of magnitude, from R350,000 to R2 million. The average cost among recipients was about R1.57 million. A reason for the wide range of costs put forward by recipients might be the impact of heart failure on cognition and memory, resulting in an inability to clearly recall the details of the information communicated to them by the transplant team (see section 5.6.3 below).

However, recipient experience also points to a greater need for transplant units to provide accurate information about the costs of treatment at the time of assessment for treatment as Almgren (2018) and Kittredge (1989) have shown in section 3.5. Shane related his first interaction with a surgeon on his transplant team. “I said I just need to know: ‘What am I going to pay for a heart transplant?’ His answer to that was ‘do I look like a [financial] broker? - I’m a doctor’.” This response “put more stress onto me”, says Shane. If, as some clinicians indicate, they do take account of socio-economic status during the assessment, the need to provide reliable information about the costs of transplantation should be clearly indicated. See the discussion in section 3.8 of Sharpe’s (2006: 15) critique of the socio-economic consequences of transplantation’s disruption of the recipient’s life.

Shane also believes that the private hospitals are about “extracting money from the medical aid schemes”. One surgeon concurred with this view that certain groups of private hospitals tried to secure as many lucrative procedures as they could, stating: “As soon as there is money involved... [a hospital group will] want all the transplants to happen in [their

hospitals]. As shown in section 3.9, Sharp (2006: 23) referred to this as the “site of lucrative medical practice” which is hidden by the veil of *the gift*.

Information provided by some clinicians and transplant co-ordinators also point to clear disparities in expenses between the various transplant units. One surgeon said the cost of heart transplantation on their programme was about R650,000. This could not be explored further in the context of this research.

### 5.3.5 *Congenital conditions and transplantation*

A recipient, Bev, had a congenital heart condition, ebstein anomaly, which relates to the displacement of the tricuspid valve (The Free Dictionary, 2019). She had struggled from birth, and her condition deteriorated rapidly in her mid-twenties. Her body was massively swollen and was placed on a high dose of diuretics and was permanently on oxygen. Her mother said that “her body started shutting down.” In addition, Bev faced difficulties in transitioning from a paediatric cardiology programme to an adult one. She said that nobody would take her case because it was so rare and required much investigation, so she stayed with a paediatric cardiologist. For this reason, when her cardiologist referred her for transplantation, the cardiologists associated with the transplantation unit would not examine her. As her mother explains: “It actually made good sense to me, [the cardiologist] was polite.” Given that she was being treated by a paediatric cardiologist until her transplantation, Bev did not have the benefit of a work-up by the transplantation unit before her transplantation. As a result, her mother said: “We had no idea what the cost would involve, the medication she would have to take.”

Given advances in medical treatment, more children born with congenital heart disease are surviving into adulthood, resulting in an increase in grown-ups with congenital heart (GUCH) disease who are presenting with severe heart failure that may require transplantation (British Cardiac Society Working Group 2002: i1). Complex congenital conditions and the effects of previous surgeries to correct a birth condition constitute a “specialist problem” (British Cardiac Society Working Group 2002: i10). One cardiothoracic surgeon interviewed in this study said that specialist clinical services were required for GUCH patients in South Africa, like the experience with GUCH patients in the United Kingdom.

## *5.4 Diagnosis of heart disease*

### *5.4.1 Introduction*

This section on the diagnosis leading to transplantation includes recipients' comments on the substance of the diagnosis process as well as how the healthcare professionals communicated the diagnosis.

### *5.4.2 The first diagnosis*

Recipients readily acknowledged that when the first signs of heart failure emerged, they realised they were ill, but had no idea how serious their condition was. Bury (1982: 172) and Charmaz (1991: 24) have shown (see section 3.5) that a physician's validation of an illness is very important for a patient, presenting the possibility that they will be effectively treated. In this regard, Theo was diagnosed with cardiomyopathy in 2010 by his local cardiologist, who treated him effectively with medication for five years.

Barker (2010: 156) has theorised how, in the context of the "contested illness", patients learnt of their condition through self-diagnosis, from a friend, by searching the Internet, or through illness support communities. Heart disease is not a contested illness, but it is telling that, in this study, not one recipient came to a diagnosis through an alternative method, given the challenges facing communication on health issues in South Africa. Instead, it is noticeable that in all instances in this study, recipients learnt of their diagnosis from either a GP, physician, cardiologist or cardiothoracic surgeon. However, Calvin and Felix, among others, point out that, while at first they knew no other heart recipient, they were assisted in accepting the treatment through the counselling of other recipients.

Interviewees reported that the Internet played a significant role as a repository of information for a further understanding of their condition and the proposed treatment after they had been diagnosed by a healthcare provider. Even when a firm diagnosis was provided, some recipients remained in denial of the implications of their illness, according to a heart transplant surgeon interviewed in this study.

Some recipients such as Shane, Rafael and Logan suffered heart attacks without realising it. In 2009, fifty-nine-year old Ethan was feeling unwell and went to hospital where he suffered three successive heart attacks. Calvin suffered a heart attack in 1994 at the age of 34, which resulted in him losing 50% of heart muscle mass. In 2014, his cardiologist told him his heart was failing and the only option was a heart transplant, he "went into a tailspin immediately" but realised that he had "been given a lifeline". A cardiologist diagnosed Johan with arterial

heart disease in 1990. Over the next 20 years, he had stents inserted and five bypass operations. In 2010, his cardiologist recommended a transplant.

One Monday morning in 2000, Gavin, a successful manager in the “very strenuous” retail and property sectors, felt like a bus had hit him. Doctors diagnosed an irregular heartbeat and, subsequently, cardiomyopathy and an enlarged heart. He said that “it was like somebody giving me a death sentence” when his cardiologist told him he needed a transplant.

In 1973, Isak discovered he had a leaking mitral valve which was replaced. By 2007, he was in chronic heart failure. He faced critical life events: the death of his wife, to breast cancer, and his daughter, to meningitis; contracting chronic myelogenous leukaemia (cancer of the blood); having his infected gall bladder removed. He received a donor heart in 2018.

Rheumatic fever which was never properly treated when he was young is what Felix, 67, believes was the underlying cause of his heart disease. After he collapsed in 2012 while on an international business trip, his cardiologist warned him to consider going onto the transplant list. He hesitated initially; his limited understanding was that heart transplantation was a ‘magical’, short-term treatment, and as he said “and then, eventually, I think you go”.

Anita reported that she had been exercising while experiencing flu symptoms. She noted how “the flu virus from my throat area” caused inflammation of the heart muscle or myocarditis (The Free Dictionary 2019). A family friend in the medical fraternity put her in touch with a cardiologist who, coincidentally, was associated with a heart transplant programme, and he raised the possibility of a heart transplant.

Coincidental contact with a cardiologist in a transplant unit also played a role for James, 55, a passionate sports person who attributes his heart condition to continued training while he was sick. After he had a heart attack on the rugby field at the age of 26, he continued to have heart ‘events’ such as passing out at work, and a stroke in his home. In 2014, he was assessed by a transplant unit and waited over two years for a donor heart.

#### *5.4.3 Communication – the good, the bad and the ugly*

Recipients like Shane, Nasir and Tinus reflect what Almgren (2018: 36) describes as a failure by the clinician to establish credibility and trust with the patient. This lack of person-centred care exacerbated the uncertainty as theorised by Mishel, leading to the patient feeling abandoned and not being taken seriously (Almgren 2018: 36).

The message that Henry got from a cardiologist in 2011 was even more stark. He was told: “*Daai ding is fucked up, hy moet uit*” (that thing is fucked up, he must get out). The diagnosis was made when his heart failure deteriorated four years after a virus damaged his heart. He waited until 2013 for a donor heart because of his rare AB blood type.

A doctor with “no bedside manner” told Shane he must prepare to die because his body was shutting down. When later he was referred to the transplant unit, Shane felt “no one is even listening or caring”. The transplant surgeon berated him for constantly communicating: “Have you seen the size of your folder? This is from all your communication.” His response that it was because nobody was answering his communication, led to an argument with the “irate and snappish” surgeon.

Nasir reported repeated negative encounters with treating doctors. He admits having “*moered*” (hit) a trainee doctor at one hospital who hurt him as he tried to find a vein for a drip. Another time, he threatened to call police after a stand-off ensued because an “Afrikaner doctor” would not authorise his release from hospital until further tests were done which Nasir believed were unnecessary and which a nurse had warned him against.

Tinus was treated in a hospital emergency room in his post-matric year after starting to cough blood. A congenital condition, limb-girdle muscular dystrophy, which also affects the heart and respiratory system, was the underlying cause of Tinus’s illness. A doctor whom he had consulted as a teenager had wrongly assessed that the condition would not affect his heart and encouraged him to look after his muscles. He started intense exercising to build muscle which affected his heart. Now, a 19-year-old rural youth and alone in a city hospital, an ER doctor told him: “If you don’t get a transplant, you will die.” His EF deteriorated quite rapidly to 18% and he received a donor heart in January 2017.

As heart failure intensified, recipients were increasingly too weak or disoriented to deal with doctors, relying on family members for the interaction (see discussion in section 3.7 of Vogels *et al* 2007). Ivarsson *et al* (2012: 404) also found that patients’ recall of having been given information fluctuated as they waited for a transplant due to their cognitive ability being impeded by heart failure. Gavin was in a wheelchair when he consulted the heart transplant unit. “I didn’t even have the energy to look up at somebody and speak to them.” Isak remembers that his transplant team was constantly in contact with him and his family, providing information about medication and rejection.

However, James said that the information the transplant unit promised him and what they provided were “two totally different things”, although “things have changed subsequently”. He also noted how the unit has “come a long way” with information booklets. Ethan and Calvin talk highly of their respective transplant co-ordinators, describing them as an “angel” or “guardian angel”.

Dawid was 24 and “a good rugby player”, with a professional side, when he was diagnosed with heart disease. He had been boosting his performance with steroids. Despite flu which developed into pneumonia in 2006, he continued to play rugby. Doctors did not recognise his descent into heart failure, until one doctor saw from his x-rays that he had fluid on the lungs and referred him to a cardiologist, who diagnosed an enlarged heart and told him about transplantation. “I was a young lad... and he tried everything medically possible for 9-10 years to give me a life.” Then he met the transplant unit cardiologist, who immediately put him on the heart transplant list.

Almgren (2018: 17) has noted the uncertainty occasioned by unpredictability. Sometimes the information communicated to patients by the transplant unit is accurate, but individual circumstances can change very rapidly, confounding the best efforts of a transplant unit to communicate accurate information. Johan was told that he would spend just three days in the ICU after surgery, but he spent over a month due to his weak condition at the time of transplantation. He also had to return to theatre to re-stitch his chest after he picked up a virus and was coughing so badly that the stitching of the sternum broke.

As discussed in section 3.5, Williams (2005) indicated the contrast in his experiences from one doctor, who avoided diagnosing a heart condition, to other doctors associated with the transplant unit, who adopted a team approach, communicated fully, and included the patient in all decisions. Many recipients like Dawid, Ethan, Felix and Theo had the benefit of good cardiologists who took the time to explain what was wrong with their heart, and what the treatment options were, including transplantation. But Ethan, Felix and Gavin also reported that other cardiologists who treated them were, as Felix stated “not as informative”. Gavin said his doctor was “fantastic, he kept me alive for a long time”, but he said his doctor never told him what was wrong with him. The impact of this lack of communication on uncertainty has been identified in various studies (for example, Almgren 2018: 17) leading to positive intervention studies to reduce or manage uncertainty.

Ivarsson *et al* (2012: 402) showed how patients experienced a lack of coherence and information transfer in the communication from the transplant unit. They found that patients wanted more information on the risks of mental and physical complications, including rejection. Patients especially lacked coherent information about the new diet they should follow (Ivarsson *et al* 2012: 403). Patients also expressed their disappointment that their closest relatives had not been adequately supported during the transplantation process (Ivarsson *et al* 2012: 403).

## 5.5 Call waiting

### 5.5.1 Introduction

The call represents a significant moment or series of moments that a potential heart recipient experiences, when a transplant unit informs them that a donor heart is available. Until now, potential recipients may still have hesitated over whether they will accept a donor heart. They can spend significant time anticipating the call, wondering if it will come, fearing that it might never come. Sometimes, the call comes but the recipient misses it. Or, the recipient receives the call and responds, but the transplant cannot proceed for clinical reasons over which neither the recipient nor the transplant unit has control. In circumstances of severe illness and medication in hospital, the recipient may not be fully aware of the news that has been brought by a doctor or nurse.

### 5.5.2 The call

There is no confirmed timeframe for the process of waiting for a donor heart, adding to the uncertainty of the heart patient, who is incapable of reducing this uncertainty in any way, as Almgren (2018: 17) pointed out.

As indicated in discussing my own story, transplant units routinely call in a back-up or standby transplant candidate in case the preferred recipient is found at the last moment not to be an optimal match or may be incurred an infection. This represents a further area of stress for the potential recipient.

Both Kittredge (1989) and Neuberger (2011) have reviewed the critical importance of matching an ideal donor heart with an ideal recipient in order to minimise organ rejection and not waste a limited resource. All the surgeons who participated in this study concurred with this approach in the literature.

Since the beginning of 2010, Ethan had been on three ‘standbys’. James got his first call a year after being placed on the transplant list. However, they phoned again to let him know that there was something wrong with the donor heart. He waited for two years before he received another call, which he missed as he had switched his phone off during the night. His condition deteriorated and he was placed on a national emergency list. Two months later he got a donor heart from Johannesburg.

Three months after being placed on the transplant list, Dawid was called but, *en route* to the hospital, he was called again to be told that another person would receive the heart. He said

the following on this incident: “That was bittersweet - I was happy another guy is gonna get a transplant, but I had to wait. That broke me for a while.” The thought crossed his mind then that his chance had come and gone – that another heart would not become available.

Nasir had two cancelled calls that a heart was available. He felt he had no choice: “What you gonna do? You just wait.” He is typically nonchalant in explaining his emotional state after the third, positive, call: “They said I am going for the op, that’s all,” prompting an interjection from his daughter: “He is understating this. I will tell you - that is the first time in my life that I ever saw my daddy cry.”

After initial concerns about transplantation, Shane was excited about the prospect of getting a heart transplant. But he realised many people died without getting one because of the shortage of donors. As he noted: “It made me realise very quickly my own mortality and at that stage I had already made my peace with death and dying. He was also called in after a donor heart became available but, at the last moment, it was discovered that it was not a match. He was happy that the surgeon did not transplant a mismatched heart. When he got a second call that a donor heart had become available, he was too weak to be excited, as he said: “I was tired man”. However, he was also “scared to get too excited”.

Logan received three conflicting calls in rapid succession about the same donor heart. He learnt later that another patient was scheduled to receive a donor heart but this patient’s new medical aid had not been finalised at the time of the call and he was delisted. This patient tried to visit Logan to see “the patient that stole his heart”. Logan said: “I think he was angry.”

After he received the call one Sunday evening in 2017, Tinus and his family drove through the night to get to the transplant centre. On the drive, his father broached a ‘difficult’ issue, and said: “If it’s not a success what then, what’s your wishes, where do you want to get buried, what would you like to happen?” Once they *got that out of the way*, the family just drove again in silence. As Tinus said: “No one knew what to say, what to expect. I could see they were scared but I wasn’t - that’s the first time in my life that I wasn’t scared at all because I knew it couldn’t get any worse, even if it was a failure, I tried. Everyone tried.”

Henry attended events at the hospital with recipients who said they had waited a few months. He said: “And I thought to myself, why am I waiting so long?” The main reason for his wait was his rare AB blood type. When he finally got the call after 20 months, he was petrified: “I went as cold as you can get. That was the scariest time of my life because now I know it’s

gonna happen.” He was also concerned that the donor would be dead, asking himself: “Why must somebody else come and die for me so I can go on?”

Theo said he was very fearful of having to undergo this major surgery. He would tell family members that if a heart became available, they must “give it to the next guy... I had almost made peace that I wasn’t going to be around... I almost knew that I was on my death bed” But when the call came, his cardiologist said to him that “there is no choice; it is now or never”.

Waiting for a donor heart, Gavin was ‘almost comatose’, and had been placed in an isolation ward in the transplant hospital. One day, he thought that he was not going to make it through the night, even telling his wife that he could not go further. As he said, “that night, I made my peace with God.” At 4am, a nurse came in and told him a donor heart had been found for him.

### *5.5.3 Getting ready to die*

During this period of waiting, thoughts of death can become most acute for the recipient. They may “make peace” with dying after considering that the call will not come, and even consider not accepting a donor heart if the call eventually comes. A major aspect of uncertainty for the heart recipient resides in human ignorance about death. In not knowing what death means, until we are confronted by issues of mortality. This confrontation can occur either vicariously through the death of someone close to us, or at the point where, due to a sudden turn of events such as a diagnosis of serious illness, we are confronted by the reality that our death is more imminent than we had thought.

Many recipients reported that they had made peace with dying, because of their faith, although being weighed down with illness also played a role as Charlton (2005) found. Often, a recipient who is admitted to an ICU because of heart failure, is exposed to the death of a fellow patient, which affects them. The night a stabbing victim died across from him in the hospital, Tinus said that he made peace with dying. It was 4am, he had just been woken up for early morning coffee and “everything just stopped - they stopped, the machine stopped, he stopped, and he passed away... And when I tasted that coffee I was like ‘shit’ and it’s been with me ever since”. He said that whenever he drinks coffee, he can “taste that silence”.

Theo said that during his heart failure, “if I was to be called home, I was quite ready to go”. He had made peace with dying to the extent that he told a church worship leader “what songs

to sing at my funeral. I knew there was no way out, because you feel the life leaving your body at that stage”. Shane and Nasir concurred that they had also made peace with dying. Felix said that despite being raised in a Dutch Reformed Church, he only had a half-hearted belief in an after-life. Because he is “a believer”, Andre was not afraid of dying. “I was ready. I know I am blessed”. James, on the other hand, was distraught and ‘cut up’ because of fear of the unknown.

Being a burden to his family, featured big as Henry approached death. At times he feared dying, at other times, he felt it would be better to die, as he considered the impact of his illness on his family.

## *5.6 Functional status before and after transplantation*

### *5.6.1 Introduction*

Heart recipients report significant, even radical differences in their quality of life and functional status before and after transplantation.

### *5.6.2 Words that matter*

Recipients use evocative descriptive words for the experiences of heart failure and transplantation.

Their descriptions of heart failure, as their blood is unable to bring oxygen to the rest of the body, as organs shut down and excess fluid cannot be excreted, include words like:

unfair; fatigue; paradox; bad; stress; difficult; lasting; hell; agony; death sentence; uncomfortable; blank; changed; non-existence; uninspired; favoured; changed; challenges.

For the aftermath of their transplantation, they use words such as:

alive; grateful; gratitude; mercy; amazing; life; heaven; disbelief; favoured; new; inspired; relief; favoured.

The word “when” was used by one recipient to describe the acts of waiting both before and after transplantation.

### *5.6.3 Quality of life before transplantation*

The symptoms outlined very briefly here cover the gamut of conditions evident in heart failure as discussed in section 1.3 (Pfeffer *et al* 2016; Yancy *et al* 2013). Pfeffer *et al* (2016: 7) describe end stage heart failure patients as a “most challenging and fragile group”, enduring disproportionately “the greatest healthcare burden on individual, familial and societal levels”.

As a child growing up with a serious congenital heart condition, Bev had to deal with many challenges. Deprived of oxygen when she was born, she had learning disabilities and had to attend a special school. She was forced to sit out most physical activities at home and school. In the years before her transplant, she was barely functioning. Bev and Theo had major organ failure. Theo described a feeling that his heart was ‘panicking’. Bev’s mother said that “her body was shutting down”. Maria was also close to death, describing her condition as “very non compos mentis”, unable to breathe.

Logan, Shane and Theo experienced extreme shortness of breath and extreme lethargy, with Logan remembering being very tired after doing simple things like having a shower. Calvin felt like “a flat tyre” as life “slowed down a bit”.

Shane experienced tachycardia and bradycardia (alternating slow and rapid heart rates), and diverticulitis (inflammation of the colon) (The Free Dictionary 2019). Once, his EF dropped to 12% and he felt he was “knocking on heaven’s door”. Medically boarded from work in 2011, he considered that “I am just waiting for my chance to die.” Shane’s experience of praying for God to end his life - clinically termed suicidal ideation (The Free Dictionary 2019) – anticipated what Chisaka and Coetzee (2009: 124) termed the “ultimate biographical disruption” of suicide.

Fluid retention forced patients to restrict their intake of liquids. Theo felt his body was at the point of ‘almost exploding’ due to fluid build up. Gavin remembers living on ice blocks because of restrictions on fluid intake.

Dawid would nap in a *bakkie* on his construction site during the day. By 2017 he was admitted to hospital almost semi-permanently for a year, being in an induced coma for six weeks so that his heart could rest. Anita was also confined to bed at home for a year, waiting for a donor heart, because she had a rare blood type. She could barely walk. As Johan got weaker, he regretted the fact that: “everything that a man should do, I couldn’t do”. Eventually, he sat in his armchair for 30 months, waiting for a transplant.

Wave after wave of distressing news about his physical condition caused Tinus to wonder “why me?” Later, evoking a sense of *c’est la vie*, he asked: “why not me?”

#### 5.6.4 *Post-transplant regimes*

The post-transplant regimes vary from programme to programme. All programmes require a few months, sometimes up to six months, of complete isolation, and most programmes require an annual check-up. Some programmes require annual biopsies to test for rejection, bone density scans and consultations with members of the unit, while other transplant units adopt an attitude at least in respect of biopsies that “what is not broken does not require fixing”, as Ethan expressed it.

Recipients must get used to challenging daily medication regimes, taking up to 20 tablets a day at times. There is a vast number of side-effects of immunosuppressant and other medication. Stiefel *et al* (2012: 688) found that heart recipients most often reported tiredness,

lack of energy, nervousness, muscle cramps, mood swings, bruises and decreased interest in sex, among about 30 symptom experiences. They stated that patient perceptions of symptoms represent a critical post-transplant outcome which must be “actively addressed by clinicians” (2012: 689). However, they cautioned that a limitation of their study was that it presented data from only one transplant centre, ignoring the effect of varying immunosuppressant regimens across transplant programmes (2012: 689). Given the absence of formal transplant protocols in South Africa, the requirement to audit the impact on outcomes of respective regimes is not possible.

Gavin regards the medication as “worse than the transplant”. However, compliance with the post-transplant treatment regimen as set out by their respective transplant unit is paramount for recipients, despite the difficulty of complying acknowledged by Isak.

Anita, Gavin and Wikus reported having memory lapses. Unable to even sign his name, Johan has had to develop his fine motor movement (small muscles) with jigsaw puzzles aimed at three-year-olds. While recipients refer to medication as the cause of their cognitive – including memory lapses - and muscular issues, the studies by Almedia and Flicker (2001) and Vogels *et al* (2007) show how heart failure may be an underlying cause of such challenges.

Maria, 68, has had “quite a bit of skin cancer”. She struggled to keep fit walking, following degeneration in her hips and knees. However, she feels younger than she is. Theo’s concern about skin cancer has affected his ability to engage in outdoor sporting activities.

Henry and Logan have struggled with extreme blood sugar levels post-transplant, which they also attribute to their medication. “In fact, I am more concerned about the diabetes than my heart,” said Logan. Calvin has had his gall bladder removed since the transplant. Recipients also experience weight-gain and rapid hair and nail growth as a result of steroid medication.

Gavin says that he has had to reconfigure what normal is, as pre-transplant, “sick was normal”. He struggled initially with little energy, had headaches and other side effects of cyclosporin. Shane said it was a profoundly “beautiful feeling to breathe without mechanical assistance. Dawid describes his quality of life as “200% better”.

Bev had to learn that it was okay to drink normally, a common theme among recipients. Importantly, she is very happy that she no longer requires an oxygen pump to breathe, can make her own decisions, drives her car. Her mother says: “She’s got life, she’s got a life.”

But it wasn't all plain sailing. Bev also suffered PTSD, as she said: "I actually didn't know my place, I was totally confused." Now, she is "a lot more aware of what's going on".

All recipients avoid situations that might expose them to germ infection because of their impaired immune systems – even a handshake or exposure to the sun's ultra-violet rays. James reports his new lifestyle is geared to avoiding infection and Isak finds himself constantly asking "is it germfree?" Despite such preventive measures, Tinus contracted a fungal skin infection, *Alternaria alternata*, which occurs very rarely in humans (The Free Dictionary 2019). He noted that "only 256 people have had it in the world." The fungal infection required aggressive and expensive medication which had not yet been registered for use in South Africa. Gavin also experienced skin itching for three months, stiffness in his joints and gout from immunosuppressants.

Few patients in this study have had episodes of organ rejection, for which they acknowledge full compliance with the medication regimen. Responding to a question about whether he had experienced rejection, Rafael responded: "I'm very strict." Meanwhile, Gavin's surgeon told him: "If you follow my instructions and do what I tell you to do, you will start feeling better and better and better." And, Gavin says, "of course I did". Another surgeon said in response to a question in this study about compliance: "The patient should do what you tell them to do." These shared perceptions of clinicians and recipients reflect a Parsonian concept of the *sick role*, that the rights and obligations of a sick person are to limit the disruptive effect of an episode of sickness (Barker 2010: 148) and that clinicians will intervene to the extent necessary to send people back to their regular societal roles after a temporary illness (Bradby 2012: 24).

Unusually, Ethan has continued to use cyclosporin, which is primarily used in the initial post-transplant period because it has significant side-effects. Of all recipients in this study, he consumes the least number of tablets per day. His experience may reflect what Stehlik and Lindenfeld (2016: 256) point out as attempts by surgeons to reduce mortality as a result of under-dosage or excessive immunosuppression resulting in death, by individualising the level of immunosuppression.

After years of being unable to have children while she was ill, one interviewee gave birth to a child after her transplant, one of the most life-affirming experiences of the recipients interviewed in this study.

### 5.6.5 *Working life*

While 12 out of 19 recipients were still working at the time of their interview, six of those were working in their own or family-owned businesses. Recipients spoke about the challenges of working, as the review in section 3.7 of studies including on healthism by Charmaz (2012), Ivarsson (2012) and Roberts (2015) found. For example, one recipient, Dawid, stated that he was unable to find work outside of his brother's construction company, because other employers had concerns that his transplantation would make him a liability. The construction site involves "really hard, hard work", such as picking up cement bags, but his physical strength is very good.

Theo said his business took strain while he was ill. But he has gone back and picked up the pieces. "I just run from morning until night, it's a rat race and it's amazing just to be able to be there and to do it." James returned to work six weeks after his transplant. His business customers wanted to know "when is this guy getting back to work". Isak started slowly, ramping up his hours until he was fulltime. Initially he had a lot of energy because of high cortisone dosage. Now he feels the effort of working.

Henry works a 10-hour shift four out of five days a week, and eight hours on the fifth day. He acknowledges that he is more aggressive now than before transplant with his colleagues.

Formally retired, Felix believes he is busier now than he was before retirement, and he goes on extensive international trips. He manages 'physical dips' by ensuring that he has a day's break before meetings. Rafael said that "some of my best work" had been produced since his transplant.

Gavin noted that his medical boarding from work was partly due to the medication side effects. Almgren (2018: 37) has suggested that reduced ability to work could be the result of a cycle of uncertainty which leads to stress that in turn reduces cognitive capacity.

## 5.7 Identity and its disruption

### 5.7.1 Introduction

Recipients had radical and diverse experiences and perceptions of disruption – or its absence - in their lives as a result both of their chronic heart disease and of their subsequent heart transplant. In this, their experiences accord fully with the examples from the studies done by Bury (1982) and Charmaz (2012). At times during the interviews, recipients would make a comment about their attitude towards disruption, which was contradicted later by another comment without any acknowledgement of the contradiction or a change in their attitude, perhaps a function of cognitive impairment (see Vogels *et al* 2007: 440 in section 3.7) or of their medication side-effects.

### 5.7.2 *The disrupted body, personality, life*

Rather than having a sense of disruption in his body, Rafael regards his body as “honoured. How lucky can I be? Because I wouldn’t be doing what I’m doing. I’m like a sort of old car. I’ve got a new engine, but the body parts are shit.” Bev also experiences the difference in her life as positive. “I have always been sick. So having a normal heart, it is very different.” Theo agrees that he feels ‘very positive’ towards his body in the post-transplant period. Ethan said that he is: “the same person I used to be”. He simply: “can’t go back to football”. James concurs: “to me I just seem like I am the same person you know. I’d like to think I still am.”

However, Gavin would readily take his old, healthy heart back, if that option was offered to him. This reflects what Turner (1992: 37) described as identity resting crucially on a specific body and what Mattingly (2006: 567) showed was the impossibility of a heart transplant recipient returning to ‘normalcy’. Gavin snapped at someone who suggested that he was very lucky to be medically boarded, sitting at home, and not needing to work. Gavin said to him: “I’m not lucky my friend. Do you understand the price that I had to pay? I’m still paying the price; I will never be like you are.”

### 5.7.3 *The birth heart*

Giving up their birth heart meant different things to different recipients. Some have residual positive or negative emotions towards their birth heart. Others neither mourn, nor have a feeling of nostalgia for their birth heart. For example, Bev wanted to see her birth heart but the cardiologist was “mortified and they wouldn’t let me”. Theo had a cavalier attitude, saying “it has given up on me and landed on the dump”, while Gavin told the anaesthetist to

“throw it in the bin... discard it. I was [disgusted]. I couldn't wait to get rid of that heart”. Similarly, said Shane: “I was actually glad to get rid of my heart. I know that might sound callous.”

Shane, Henry, Dawid, Andre, James and Logan agree that their birth heart did not fail them. Instead, as Henry remarks, “it was my own fault because when I was sick, I didn't look after myself”, like consulting a doctor. Dawid felt like he brought it on himself by “using steroids” to achieve great heights in sport. He had positive connotations about his birth heart “up to a time”, but then changed his attitude towards his birth heart “because it gave me so much hard times”. Andre ‘hammered’ his heart during exercise, while enduring the flu. His heart just decided that “no shit, I can't take this punishment anymore”. For James, everything was “self-inflicted. I blame myself, you know”. Isak said that his heart was so enlarged that it had filled the chest cavity and had to be cut away from the septum and the lung. When his surgeon told him this, he said that: “I realised that I had no nostalgia to see the thing or not... the thing was really done”.

Felix has no thoughts about his birth heart, because he was “overwhelmed with the sense of rebirth”. He recognises and acknowledges the importance of the ancestors in terms of an African religiosity. He reflected that when someone dies without their birth heart the ancestors receive you with “displeasure”. Anita also acknowledges the concept of ancestors, as she said that she prayed to her donor as she considered her/him as one of her ancestors.

Initially Tinus suggests he has no feelings towards his birth heart but afterwards, affirms his respect “for that heart. That's a tough heart; it's been broken, kicked, stamped upon, dragged and who knows what, but it survived”.

#### 5.7.4 *The donor heart*

Turner's (1992: 37) theorising that identity requires a specific body is not necessarily reflected in the views of the recipients in this study. Their configured bodies with a different heart have not given them an altered identity, they maintain. Rather it is the illness which led to the failure of their birth heart which affected their sense of self. The responses of recipients in this study show that there is little basis for Sharp's (2006: 14) shrill critique outlined in section 3.9 of heart recipients as “medically manipulated cyborgs” or as harbouring “the transmigrated souls of the dead”.

Isak believes the genetic makeup of the donor heart can have an impact on the body of a recipient. In his case, he accepts that the trauma of his donor's passing may have impacted his

body. This aligns with the suggestion by Pearsall *et al* (2000) raised above that cellular memory is a plausible explanation for the changes in heart recipients following their transplantation which coincide with the histories of their respective donors.

Dawid got baptised “with this heart” in his church after his first-year anniversary. In stating how he feels about his new heart, Tinus re-tells a story from an elderly Christian in his hometown, who said that the donor heart was “always your heart in another body”.

#### 5.7.5 *The post-transplant self-image*

Despite the challenges of uncertainty throughout their transplantation experience, many recipients were able to make sense of their life change, finding positive meaning in the changes. This supports Mishel’s (1990: 256) theory that if a patient infers that the uncertainty is positive, coping strategies and the support of social resources or health care providers can ensure a positive outcome.

Andre said that as a heart recipient, it’s okay to accept that “something happened which does not happen normally. It makes you special.” That realisation may affect the personality and the lifestyle of the recipient: “I have no stress, no worry, I worry about nothing, what will be, will be”.

When he attended his first transplant clinic, Isak said that he was “surprised to see how good many of the people looked who had been transplanted. I thought, ‘you had a heart transplant, look at you now!’ That struck me.” He does not experience bodily disruption within himself, but recognises that he has gone from being the “least conflictual” person to being “much more assertive”. He said: “Suddenly I am a more black and white chap.”

Other recipients (Johan, Isak, Gavin, Henry & Tinus) remark on their own new assertiveness, even ‘hot-headedness’ or aggressive mood swings. Mostly, recipients implicate their new medication regime as the reason for their mood changes. Contrarily, Tinus believes his new quickness to anger and irritability is the result of the transplantation rather than post-transplant medication.

The chest scar from the surgery features big in the considerations of some recipients. Bev, who has had other operations, is “proud” of her scars, admitting that “sometimes... I just cry” when she looks in the mirror. Henry believes the chest scar from the transplant is like his tattoo, “It’s there to show me what good life can do to you”.

Cockiness is a trait attributed to Tinus by those who know him, as he confirms: “I know I am capable. If I walk into a room, I know that I’m the smartest guy in the room.” But the muscular dystrophy which was at the root of his heart disease caused him to regard his body negatively, as a disadvantage. Heart transplantation presented Tinus with a chance to feel more positive about his body.

Felix admits struggling psychologically with the differences in his body, asking: “Lord, Lord, why me?” He wishes people would appreciate that he has his ‘own demons’ despite the miracle he has experienced.

#### *5.7.6 The significance of donor characteristics*

I asked Dawid if it would have bothered him to receive the heart of a donor who was anti-Christian, considering his strong Christian faith, his response was: “that went through my mind even about another racial group – if that man was black and I’m white”. I immediately regretted my question. I really enjoyed meeting and listening to all the recipients I met. And I had developed an affinity with Dawid. Given our racialised South African context, I assumed that, because he is a white South African, he might venture into expressing an ethnocentric view, that he was unhappy to receive the heart of a black person. I wanted to protect him from himself, protect our nascent relationship by stopping him from exposing what I presumed would be a racist attitude. Before I could stop him, Dawid forged ahead and said that it would not have bothered him. He would have assimilated the cultural and religious identity of his donor, whatever that may be, willing to learn another language, and understand the religion. As he said: “Ja no, I would have done anything [for] the second chance,” even learning and understanding the Muslim or Jewish faiths, or learning an African language so that he could communicate with rural Africans how he had received a donor heart from a black person. He had already started learning isiXhosa phrases from the ward sisters before his transplant. I learnt a sobering lesson about my own racial prejudice.

When somebody asked him if he knew the race of his donor, Rafael said he “just felt an anger that came literally from my stomach. I said, ‘How dare you fucking ask me that question?’ I never even thought of that.” Some people have asked him if he felt “any strange changes in your personality, and do you think you’ve taken on something of your donor? I think that’s bullshit because it’s just a pump. Emotions are from here,” he said, pointing to his head.

The first question Isak asked his wife when he gained consciousness, was if the man who donated his heart was a Christian believer. He doesn’t mind anymore, as he said: “Now that

all my faculties are working properly, I think it's really not so important, because it is actually just an organ, it has nothing [to do] with your personality or testimony". While he never worried at any time if his donor "was white or black or pink or yellow", he acknowledges now that it would bother him if his donor had a different sexual orientation to his. "But I would make peace with the fact that I am in control of my heart," he said.

Being 'in control' is repeated by Tinus who said that despite his birth family's characteristics: "I identify as my own person". Similarly, regardless of the demographic background of his donor "I control who I am".

While Gavin is adamant that he is "still the same person - I didn't have a brain transplant" – he looks at old photographs of himself and thinks "you were living with cardiomyopathy there and even there you look normal but you weren't".

Shane jokes that while his donor was a champion dancer, he cannot dance. "I have still got two left feet. I don't know how to dance," he said. He won't argue with those who say their donor's characteristics have also transferred, "but I don't believe that I have changed".

#### *5.7.7 Replacing one chronic condition with another*

Shane said that his surgeon warned him that he would be changing end stage heart failure and all its physical implications, for a regime of immunosuppressant medication and a susceptibility to infections. This is in line with the concerns reflected in section 2.2 as raised by Almgren (2018: 12), Kittredge (1989: 47) and Sharp (2006: 107-108) about swapping one chronic condition for another. According to Shane, the doctor said: "If we stop our anti-rejection drugs they say within three to four days we could be dead. I can't believe that."

#### *5.7.8 Disruption of family*

Sadala *et al* (2012) have shown how the loved ones of a heart recipient must confront their own anxiety and uncertainty, caring for and sharing in the suffering of the patient. Concern for family was repeated frequently among recipients in this study. As their conditions deteriorated, recipients worried about what may happen to their loved ones once they died. After transplantation, they remained alert to the ongoing challenges and anxiety that their own loved ones' experience as a result of the disruption by their chronic illness.

Heart recipients sometimes under-value their partners and need to remind themselves of the support they receive from partners, suggests Gavin: "If it wasn't for my wife, I wouldn't be sitting here because the support that I received from her was just amazing." Wondering if he

would see his family again was the “biggest concern” for Henry, as he was wheeled into theatre. A year after getting his donor heart, Henry and his wife realised that his daughter needed PTSD counselling because of living through his transplantation.

Theo said he fought “very hard to hide his diagnosis away from my family because I did not want to be the sick dad or the sick husband.” His spouse remains “extremely anxious all the time. One does not realize how much your spouse goes through... sitting on the outskirts just watching you fade away”.

His wife “walked all the way” with Johan for 29 years. “Nobody realises that the person who supports you has even a harder time than you have,” he said. Felix stated that what drives him nowadays is ‘seeking redemption’ by making up to his family. He said: “I wish I had more time to make up to family, to my children.” He is concerned that too much attention is given to the patient and not the caregivers.

## *5.8 Miracle or Medicalisation*

### *5.8.1 Introduction*

As I have indicated earlier, most of my interviewees self-identify as part of a major religion, being either Christian, Muslim or Hindu. These religious recipients report that their faith played a significant role in coming to terms with illness, making firm decisions about transplant treatment and post-transplant recovery. They also regard the availability of a donor heart as a miraculous, Godly intervention. The belief in God or a spiritual power (Macdonld 2006) outside themselves was reflected in a generally positive outlook about the post-transplant life.

### *5.8.2 Of gods and doctors*

There was “no such thing as luck” in the allocation of the donor heart to Johan, who stated firmly: “No, no, this was in God’s plan that this should happen, and it’s changed me.” Tinus agreed: “I don’t believe in luck, everything happens for a reason,” adding that his religion gives him hope. This is also his attitude towards the incorrect diagnosis of a specialist who said that he could exercise despite suffering from limb-girdle muscular dystrophy, which attacks the heart muscle and respiratory system. He believes that his rigorous exercise routine brought the problems in his heart to the surface much sooner.

Bev said she “always knew that God had a plan”. But, as she deteriorated in hospital, her mother considered that she would not get a donor heart. Her mother noted that: “I was cross at the world. I was so cross with God and I was shouting at him, how can he do this and I was crying when I was by myself.” Her mother spoke with a counsellor who suggested that she was already in a state of mourning as her daughter was dying.

Isak is a firm Christian whose faith is a big, fundamental part of his life and outlook. He made peace “with the fact that my illness was not really God’s punishment as I thought in the beginning. I allowed stress to threaten and destroy my health”. Getting a heart was “simply” as a result of God’s “grace”. Theo answered, “very much so” when asked if his faith had played a role in his decision to proceed with transplantation, while Shane said: “My strength comes from a higher power and I call him God.” Transplantation was part of God’s plan for him to live longer, said Henry.

Dawid said the availability of a donor heart was God giving him a second chance. But it was ‘bitter-sweet’, someone had to die so that he could get a new life. Andre believes that God made a way for him both in the opportunity to get an LVAD and when the technology was

problematic, to provide a donor heart. “It is the Lord, it isn’t us.” When Logan regained consciousness after the transplant, he realised that the nurse caring for him in the ICU was a Christian. “This is just the way God operates, send me somebody to guide me and to pray with me.” He was in hospital for 19 days and every night the nurses would gather around him and pray with him.

“Getting my heart was like a miracle,” says Anita. “I call it a miracle. A second lease in life was a miracle because I could feel how ill I was.” A Hindu who describes himself as religious, Calvin said he used meditation techniques – “every time I was put into hospital I said this is my temple, this is my place of healing”. He credits his mindset for the fact that he continued to live with an EF of 4%.

There are aspects of recipients’ experiences which do not fall under a rubric of the miraculous. However, these events also befuddle interpretation, such as misdiagnoses which facilitate a better outcome (Tinus, James), or chance encounters with individuals who play a role in treatment (James, Anita), suggesting to the recipient that the only appropriate understanding must resort under the miraculous.

### *5.8.3 Faith as an impediment to receiving or donating a heart*

Perhaps understandably, interviewees’ religious outlook did not gainsay transplantation treatment. Some, like Nasir, checked with religious leaders if there was any conflict between the faith and transplantation. There was none. However, his wife and a Muslim imam, a cleric, arranged to receive his birth heart and buried it in a private ceremony, as is required by the tenets of his faith.

Some, however, held back on transplantation treatment in the hope that God would heal them without medical intervention. This was based on the Christian biblical story of God healing Lazarus and bringing him back from the dead. Johan said that he battled at first over whether to choose proposed medical treatment, and he concluded that “God also uses doctors” and told his transplant surgeon “I’ll go for it”. Isak delayed proceeding with the transplantation process because he believed that “God would do a miracle” and heal him. He hoped there would be a ‘back door’ to escape surgery, however, “When that did not happen, I said, ok, now we must do the necessary to change things.”

Rafael and James expressed disgust with those who claim that their religion or culture precludes them from donating their body organs, yet they have no qualms about accepting another’s organ donation. Rafael, who describes himself as a devout Jewish Atheist, said:

“That really pisses me off because people are prepared to accept an organ on any grounds, but are not prepared to donate it because of religion.”

## 5.9 *The gift of the donor*

### 5.9.1 *Introduction*

All recipients were appreciative of what they generally described as their donor's gift of generosity (see Fox & Swazey 1992; Shaw 2015). Some recognised the significance in Christian theology of one person giving up their life for another, but the importance of "the gift" in their minds transcended religious denomination and even the absence of any religious identity.

### 5.9.2 *The gift of life*

Recipients clearly do recognise, as Shildrick (2015: 24) has pointed out (see sections 3.4 and 5.2), that our lives depend on the death of another, and that "in willing the availability of a suitable organ, someone else must die". I have not encountered any heart recipient who consciously or subconsciously disregards this essential aspect of heart transplantation. But it is not clear that recipients see themselves as a repository of their "donor's quintessence" as Fox & Swazey (1992: 36) suggest.

Bev's mother said that while they waited for a donor heart to become available, she felt awful considering that during the holiday season there might be more people on the road, resulting in more vehicle accidents and raising the possibility of a donor heart becoming available. After they received the call and arrived at the hospital, waiting in the early hours of the morning, a nearby patient passed away. This triggered "anticipatory grief" (see Poole *et al* 2014: s222-s223), a realisation in Bev that somebody had died "to give her a heart", said her mother. "That upset her terribly... she was crying *snot and trane*. So, we had to get the psychologist – to come and talk to her."

After his transplant, Shane said he would sit at home "and the tears would just roll down my cheeks" as he felt immense pain for his donor's loss. He would pray to his donor, committing to honouring his donor's heart "as best as I can, live as good a life and be as good a man as I can in honour of your life-saving gift that you gave me" (Shildrick 2019: 24). Because of his own experience of bereavement, Isak wrote to his donor's stating that he understood what they had endured. "But I hoped they would have some joy and consolation knowing that something of their son lives in me."

"There can't be a greater gift, than a donor giving you an organ, it's extraordinary," declared Rafael. It wasn't like getting a headache table at the corner shop, because "you can't buy a heart there... It doesn't mean anything to me, other than a repair, a fantastic repair".

“The less you know, sometimes the better,” is the principle which Ethan applies to knowledge about his donor. All he knows are the gender and age of his donor. He does not want to know more. “It’s for your sake, for your mind and your body because you don’t want to disrupt something that is working for you now.” But every year he writes personal letters to his donor’s family. Theo also says he does not want to know more than the bare minimum. He feels no connection to the donor, neither any obligation to the donor or the donor’s family. He acknowledged feeling “a little bit sorry for them too... it’s an act of God that somebody has to go for somebody else to live.

Felix knows the gender of his donor because “the nurses talk, they think you are not listening”. Later, in order to reassure him that there was no substance to a recurring dream he was having about his supposed donor dying in a car accident, a member of the transplant unit told him about his donor’s demographics. “I don’t mind not knowing at all,” he says. He writes a letter to the donor family every anniversary of his transplant. “I pay my homage to their generosity and the blessings that they have given me.”

Gavin did not write a letter to his donor family, believing they had closed a chapter on their lives, as he too had done. “I don’t know if I will ever write it... It took me a while to get used to having somebody else’s heart in me, although the heart never bothered me.” Neither has he consciously tried to find out anything about his donor. He will look after “this gift... irrespective” of the “life they lived”.

Andre believes passionately in knowing the identity of his donor and meeting his donor’s family but has been unsuccessful in his efforts to uncover information about them. It is unfair that living organ recipients can know who their donors are but not recipients of deceased donors, he said. It will not matter if his donor’s demographic traits were different from his own. He also does not feel any obligation towards his donor.

Because of media publicity surrounding James’s transplant, his donor’s family contacted his wife to ask how he was doing. “It’s a tiny, tiny world,” he says. “I am not embarrassed to tell you I was extremely emotional [post transplant]. I couldn’t string a sentence together without crying whenever I talked about my donor.”

Logan has very little information about his donor but is vividly aware that “somebody had to lose a loved one, to give me this second chance”.

Anita found out the identity of her donor just a short time before our interview. She had always wanted to know the identity but her spouse told her “you don’t need to know”.

Calvin appears to have more information about the identity of his donor than other recipients, but has avoided making contact with the donor family. He feels “maybe not knowing, is better than knowing... because you are not under pressure to meet the expectations of the donor family”. He does have a sense of obligation towards his donor family. “I just feel I am grateful. It was a time and a place where somebody made a decision and that decision has given me a life.”.

Johan knows his donor was a 23-year-old foreigner living in SA. This highlights the conflicted status of foreigners in South Africa – they may be donors but generally may not be recipients of organs (National Health Act No. 61 of 2003).

Henry understands that the attitude against disclosing donor details to a recipient is to avoid people being “a nuisance” to each other.

The attitudes of some recipients here are contrary to Shildrick’s (2015: 22) finding that life after heart transplantation is fraught with emotion about “the dead other” now living within the recipient.

## **Chapter 6: Conclusions**

### *6.1 Researcher impressions*

This study has provided rich insights into recipients' understanding of their heart disease and transplantation. Clinicians associated with heart transplant units and those working outside such units must consider to what extent the understandings of recipients accurately reflect existing knowledge and communication excellence within the respective transplantation programmes.

### *6.2 Assessing the research goals*

#### *6.2.1 The medical experience*

The medical experience during heart failure and the post-transplant treatment are virtually identical across all heart recipients. Most recipients have very positive recollections of how they were treated at the level of general practitioners and cardiologists outside of the heart transplant unit. The diagnosis was effective and communicated well. However, some recipients had experiences with doctors who either had a poor bedside manner, were grossly insensitive in how they communicated that a patient was in heart failure, or did not communicate at all that the diagnosis was serious and had severe implications, including requiring heart transplant treatment. Some doctors exposed incompetence or unprofessional, even unethical behaviours.

By the time they were consulting with clinicians in a transplant unit, the medical experience for most patients was excellent. However, there were instances of poor performance and inadequate communication. It is appreciated that the clinical circumstances for a very ill person can change very quickly. It is also appreciated that a patient in heart failure can only receive transplant treatment once a donor heart is available. However, some recipients did not have the benefit of any or ongoing counselling from transplant unit members on what they would experience while waiting for a transplant, nor on the detail of the transplant procedure itself.

Serious concerns were raised about the standard of communication from healthcare professionals about a range of questions that recipients had at the time of their illness or as they prepared for transplantation. Some recipients also expressed concern about the costs of treatment, including post-transplant check-ups, especially in instances where travel and subsistence costs had to be considered.

### 6.2.2 *Internalising disruption and the imminence of death*

Heart recipients acknowledge that the moment when they were first told that they were dying of heart failure and required a transplantation in order to continue to live, represented a huge blow to their sense of self, the ego, their appreciation of their body, their understanding of their place in the family or the world. However, they realise that transplantation represents an opportunity to continue to live, even if it means swapping one form of chronic illness for another, and regardless of the negative implications of the new chronic illness. Many recipients have continued to conduct their personal, professional and social lives in a manner approximating their lifestyle before heart illness emerged. Some excel in work roles.

### 6.2.3 *Culture, identity and spirituality in sense-making of disease and transplantation*

Culture, individual identity and faith each play a significant role in the sense-making of heart transplant recipients. They place great value in their birth or socialised culture and identity, but not at the expense of the value of transplantation generally, or their own donor heart specifically. On the contrary, they allow their birth identity and donor heart to meld into a body and persona which is at once *the same* and *different* from the individual's attributes before transplantation. They are willing to receive and fully accept a donor heart regardless of the identity markers of the donor, asserting where necessary their own sense of being able to control their whole body.

### 6.2.4 *Miraculous gift or luck-of-the-draw?*

Heart transplant recipients mostly attribute their transplantation to a miraculous gift, reflecting their own faith or the faith of their family and loved ones, regardless of any religious or denominational affiliation. Only one recipient entirely eschewed any belief in a miraculous event. Heart recipients also place significant reliance on their families for support during chronic illness before and after transplantation. The unanimous view of those interviewed in this study is that the life after transplantation is a radical improvement on the quality of life during heart failure.

## 6.3 *Further research*

While this research project was intended to be a comprehensive study of some aspects of heart transplantation in South Africa, it has shown the need for a deeper exploration of the research questions raised at the start and also pointed to a raft of further questions warranting research attention.

The major shortcoming of this study is the failure to follow through on the intention to research the perceptions of recipients who were treated in South Africa's only public sector heart transplant programme, based at Groote Schuur Hospital in association with the University of Cape Town. This failure was due to the administrative hurdles inherent in and the non-responsiveness of officials responsible for the GSH-UCT's ethical and gatekeeper permissions processes. As a result, comments about that programme are purely speculative, from heart recipients who were transplanted in private hospital programmes but who considered what might have occurred if financial circumstances forced their referral to the state sector for transplantation. The opportunity remains to engage with heart recipients from Groote Schuur and clinicians associated with that programme in respect of the original research questions and especially in respect of transplantation guidelines and protocols, costs, post transplantation treatment regimes, and government policy on transplantation.

This study highlights also the need for further research in the following areas:

- From an epidemiological point of view, further work must be done to ascertain the extent to which recipients trace heart failure causation to their genealogy, and the extent to which this understanding assists diagnosis and treatment (see section 5.3.2).
- The communication of organ donation and transplantation guidelines and protocols to heart recipients, especially protocols in respect of age, co-morbidities and socio-economic status (see 5.3.3).
- The clear disparities in expenses related to heart harvesting and transplantation between the various transplant units (see 5.3.4).
- The experiences of other GUCH patients of end stage heart failure and transplantation (see 5.3.6).
- Patient perceptions of symptoms resulting from immunosuppressant regimes within heart transplant units and comparisons with other South African units (see 5.6.4).

#### 6.4 *Why me?*

This thesis has shown that heart recipients offer rich understandings of their experience of heart disease and transplantation. Uncertainty – prompted by various internal and external factors - is identified as a significant contributor to the recipient's experience. In the context of uncertainty and in response to the question *why me?* recipients resort to religious, cultural and psycho-social sense-making regarding their condition before and after transplant. They

explain most aspects of their transplantation – including the illness which led to the treatment and the availability of a donor heart – in terms of religious, cultural and psycho-social factors. They regard the success they have experienced through the treatment as a function of these factors. Once they accepted the need for transplant treatment, they regard the changed, transplanted self as the best outcome, and as the only means of resolving their illness. However, recipients also acknowledge that structures, especially the nature and implications of South Africa’s bifurcated healthcare system – split as it is between public and private sectors – play a significant role.

My own experience largely aligns with the general experiences of heart recipients indicated here. *Why was I transplanted?* Because I was very ill and had reached the measure of heart failure for which transplantation is clinically indicated. Because I had access to medical aid which allowed me to consult with healthcare practitioners in the private sector. Because I was able to consult a cardiologist who was knowledgeable about transplantation and had established a process for referral of end stage heart failure patients to a private sector transplant unit. Because no factors were identified which made me clinically unsuitable to receive a donor heart. Because my condition deteriorated to the point where I was admitted semi-permanently to a hospital. Because a donor who was a good match for me became available within a relatively short period of time. Because of access to good medical care before, during and after transplantation. Because I had the economic means and social support system to comply with the post-transplant medication regime and its implications. Because of what I understand to be the grace of God.

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## **APPENDIX 1: INTERVIEW QUESTION SCHEDULE: HEART RECIPIENTS**

This schedule of questions for heart recipients covers a range of issues which might be relevant in the research.

1. When did you receive a donor heart?	
2. At which hospital did you undergo your heart transplantation?	
3. When were you diagnosed with a heart condition?	
4. Where were you diagnosed - the name of the hospital (if it was at a hospital) and the physical location of the hospital or the treating doctor?	
5. What was the initial condition or diagnosis?	
6. What was your first understanding of your illness?	
7. Could you (following your doctor) attribute your illness to a specific reason or cause?	
8. How did you respond to this knowledge?	
9. Did you presume or did the doctor suggest that your lifestyle was the cause of your illness?	
10. Indicate if the doctor who referred you to the heart transplant unit was in public or private practice? Attached in a general practice or as a specialist?	
11. What prior knowledge did you have about heart transplantation?	
12. Had you met with or known anybody who was a heart recipient?	
13. What do you know about the prevalence of heart disease in South Africa? And especially the prevalence of end stage heart failure?	
14. In your view, are South Africa's heart transplantation programmes meeting the need that might exist for transplantation?	
15. Are you generally someone who takes a keen interest in their health?	
16. What did you understand would happen after you were referred to the heart transplant team?	
17. Explain to me what happened or what was communicated to you during your first and subsequent interactions with members of the heart transplant team?	
18. What was your attitude to the possibility of being the recipient of a donor heart?	
19. How do you think was this attitude developed?	
20. Did you consider the possibility that the transplant team might consider you not to be a suitable candidate? How did that make you feel?	
21. Do you know how much your heart transplant cost?	
22. Did you know that heart transplants happened in both the public sector and the private sector?	
23.	
24. Were you ever concerned about the lifetime consequences associated with your heart transplantation <ul style="list-style-type: none"> <li>- having to take immunosuppressant medication,</li> <li>- possible side-effects,</li> <li>- regular biopsies,</li> <li>- the costs of the procedure itself,</li> </ul>	
25. the cost of post TX medication?	
26. At what point did you decide that you wanted to proceed with a heart transplant if a donor heart became available?	
27. Did you consider that you had a choice to say that you did not want to proceed with the transplant?	
28. How did doctors and other healthcare staff regard your views of your illness and	

potential for transplantation? Did you feel that your views were considered or taken into account throughout the process?	
29. What was your quality of life while you waited for a donor heart to become available?	
30. How long did you wait for a donor heart and where were you during that period?	
31. Did you consider that you might not get the call and what the consequences of that might be?	
32. Were you concerned about dying?	
33. Why do you think some people wait so long for a heart transplant? Or never get the call?	
34. Did you consider that you might die during the transplantation surgery?	
35. How does your cultural, including (if any) religious identity, influence your views on organ transplantation generally or your own heart transplantation specifically?	
36. How do members of your family or the community with which you identify, feel about heart transplantation generally and your transplantation specifically?	
37. When you were informed that a donor heart had become available, how did you respond?	
38. Why do you think this donor heart was allocated to you?	
39. Did you know if anyone else was in hospital waiting for a heart at that time?	
40. What factors did you think had played a part in you being considered for that heart?	
41. Did you consider yourself at that moment to just be very lucky?	
42. How easy or difficult was it to get to the transplant centre from your permanent place of residence?	
43. What most defined the post-transplantation recovery period for you?	
44. How long were you in hospital post-transplantation?	
45. Did you experience rejection that required lengthy periods of hospitalisation?	
46. How did your experiences in the post-transplantation phase line up with what had been communicated to you before your heart transplant?	
47. Did your transplantation lead to any changes in your outlook towards issues of life or death?	
48. What aspect of your personality, your family relationships, your social environment or any other factor do you believe most contributed to your wellbeing post-transplantation?	
49. What aspects of you – for example, your body, personality, intellectual abilities - have stayed the same despite the heart transplant?	
50. Do you consider that your personal identity or your bodily make-up might be different because you have received a donor heart?	
51. Do you sometimes consider that there might be a greater purpose to you receiving a donor heart?	
52. Have you tried to find out the identity or other personal information of your donor? Why or why not?	
53. How does it matter to you – if at all - what are the identity or personal characteristics of your donor?	
54. Do you experience any sense of affinity with the donor of your transplanted heart?	
55. Do you experience any sense of obligation towards the donor or the donor family?	
56. Have you tried to communicate in any way with your donor family through the transplant co-ordinator?	
57. Do you know your heart numbers – such as blood pressure, cholesterol, ejection fraction, rejection?	
58. How often do you go for blood tests?	

59. How often do you undergo biopsies?	
60. How often do you attend a transplant clinic or examination?	
61. Are you part of a recipient support group? Why or why not?	
62. In what ways do you think your experience of transplantation might have been different if you had no access to medical aid?	
63. Would you have considered going through a government hospital like Groote Schuur Hospital?	
64. What are the do's or don'ts of your post-transplant medication or lifestyle?	
65. How easy or difficult has it been to comply with your doctor or team's protocol requirements?	
66. Were you able to continue to work for an employer through your illness and following your heart transplantation?	
67. Which of your previous family, social or extra-mural pursuits have been disrupted to the extent that you have not been able to take them up again?	
68. Do you regard your transplantation, the removal of your birth heart and the insertion of a donor heart, as diminishing your sense of self in any way or as a sense of loss?	
69. What words would you use to describe your heart disease and transplantation?	
70. How do you feel about your birth heart which became diseased?	
71. Describe your feelings towards your body today – good, positive, let down	
72. How do you feel about ceremonies that happen in some transplantation centres to honour the donor whose organ has just been removed or to humanise the donated heart?	
73. In your view, what is the one thing that government may do to facilitate heart transplantation for others experiencing end stage heart failure?	
74. Do you feel special or privileged that you have been able to receive transplantation treatment?	

## **APPENDIX 2:**

‘WHY ME, LORD?’ SOME SOCIAL FACTORS ASSOCIATED WITH THE RECEIPT OF A DONOR HEART IN SOUTH AFRICA

### **INTERVIEW QUESTION SCHEDULE: CLINICIANS AND CO-ORDINATORS**

This schedule of questions covers a range of issues which might be relevant in the research and which are directed at heart transplant clinicians and co-ordinators.

<b><u>Questions for heart transplantation clinical and related professionals and co-ordinators</u></b>	
75. How long have you been working in the heart transplantation programme?	
76. How many heart transplants have you directly been involved in during this time?	
77. What prompted you to work in this field?	
78. What protocols guide the work of the heart transplantation team in relation to accepting suitable heart recipients?	
79. Explain to me the diagnostic process which is applied in assessing potential heart transplant recipients.	
80. Have aspects of these processes been developed by the team itself?	
81. Have you played a role in the development of any aspect of the protocol process?	
82. Do you know if they are like the protocols used by other heart transplantation teams around the country?	
83. Do you regard heart transplantation as still being the “gold standard” treatment for patients with end stage heart failure?	
84. Does South Africa’s overall heart transplant programme meet the need for such treatment in relation to the epidemiology of heart disease?	
85. In your view, is the protocol for allocating a donor heart within the overall heart transplantation programme in South Africa applied objectively and effectively so that the “neediest” potential recipient is identified and benefited?	
86. How are competing demands for a donor heart to be transplanted into a particular recipient mediated in South Africa’s transplantation sector generally or in the programme you care associated with specifically?	
87. How important is the recipient patient’s view of their illness and the proposed transplantation treatment?	
88. In your experience, what role does the potential heart recipient’s personality play in a decision to proceed with a transplant?	
89. And social or group identity?	
90. And cultural, including religious, association?	
91. In your opinion, what role does any of these factors play in the post-recovery phase of a heart transplantation?	
92. What is the biggest challenge you face in your work in heart transplantation?	
93. What knowledge do you have about the work of other heart transplantation teams?	
94. Does government have a role to play in the organ transplantation field in South Africa?	

95. What role might government play in facilitating your work in heart transplantation?	
96. What proportion of your transplant procedures are done through private medical aid, private funds or State funds?	
97. Have you ever had to decline patients for heart transplantation treatment on non-clinical grounds, for example, such as their legal status or inability to afford the treatment? And how did you manage their further treatment, if at all?	
98. In your opinion or in terms of your team's protocols, what factors impact on the presumed longevity of a heart transplant recipient?	
99. How easy is it to get heart recipients to comply with your protocols, whether before or post-transplantation?	
100. In your experience, what aspect of their post-transplant treatment do recipients most struggle with?	
101. Any other comments you might wish to offer?	

