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"HEY SISTER! WHERE'S MY KIDNEY?"

EXPLORING ETHICS AND COMMUNICATION IN ORGAN TRANSPLANTATION IN GAUTENG, SOUTH AFRICA

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A thesis submitted to the Faculty of Humanities, University of the Witwatersrand, Johannesburg in fulfilment of the requirements for the degree of Doctor of Philosophy

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Abstract

Introduction

South Africa is characterised by numerous dichotomies and diversities, within which its two-tier healthcare system operates. An under-resourced state sector serves a majority of the population and a resource-intensive private sector serves a small minority. Within the constitutional framework of human rights and distributive justice there are nevertheless expectations of fair and equal access to healthcare services. There is furthermore an expectation of quality care across the health system, in spite of a number of systemic challenges related to staff and equipment shortages, unrealistic working hours and poor working conditions.

Organ transplant is available to different degrees within the South African healthcare sector. Whilst transplant programmes are burgeoning internationally, cadaver transplant numbers in South Africa have decreased over recent years as donor organs have become increasingly scarce. Current research suggests that these challenges to transplant in South Africa arise from aspects of personal and cultural beliefs, illegal transplant practices and resource constraints - which all serve to compromise the ethical implementation of transplant services in the two-tier healthcare system.

The impact of interprofessional communication and transplant professional–patient communication has not been previously researched in South Africa. However, research into other healthcare issues has shown that communication is vital to the ethical provision of healthcare services, especially those which involve patient-centeredness and multidisciplinary interaction. Transplant involves a significant amount of communication within a particularly large network of recipients and their families, cadaver donor families, living donors and a range of transplant professionals. This communication seems a vital part of the transplant process, disseminating information which role-players need in order to promote favourable outcomes. Given the extensive networks involved in the transplant process, communication would seem to be a fertile area for research.

This study aimed to explore communication in organ transplant in Gauteng province, South Africa. It considered both interprofessional communication and communication with patients as this took place within the hierarchical healthcare system and throughout the transplant process. An ethics of care framework was utilised in order to account for the expectations of care which South Africans confer upon their health system.

Methods

The study took place in the Gauteng province of South Africa across six healthcare institutions. Both the state and the private sector were equally represented. Altogether, thirty in-depth interviews with transplant professionals, two focus groups with transplant coordinators, two interviews with cadaver donor families, and one focus group with living kidney donors, were conducted. Thematic analysis and triangulation of the data utilising Braun and Clarke's (2006) principles revealed three main themes relating to context, communication with patients, and interprofessional communication

Findings

The South African transplant context is complex and multifaceted, shaped by both the patients' expectations of care and the transplant professionals' perceptions of care. These expectations and perceptions are influenced by personal beliefs, suspicions of biomedicine, the media, and resource inequalities which pose challenges to accessing transplant services. The transplant context is characterised by ethical dilemmas relating to distributive justice, as questions about resource distribution and allocation of donor organs are raised.

Transplant communication is influenced by context and varies depending upon role-players in transplant and the different phases of transplant. Demands for care by those hoping to receive an organ had a noticeable influence on transplant professional-potential recipient communication in the pre-transplant phase, a period when emotions of desperation and uncertainty were prominent. By the time recipients had received their organ and entered the more stable post-transplant phase, a relationship of trust developed in which communication was

regular and caring roles seemed fulfilled. The opposite trend was evident in communication between transplant professionals and donor families. This was characterised by notions of care in the pre-transplant phase, contrasting with a perception amongst donor families that care was sometimes overlooked in the post-transplant phase - a time often imbued with chronic uncertainty. Even in the pre-transplant phase numerous ethical issues surrounding autonomy, decision-making and informed consent proved to complicate and challenge transplant communication.

Interprofessional communication was shaped by hierarchical institutional organisation, a lack of continuity of care, and resource constraints, all of which challenged transplant professionals seeking to provide care, and sometimes resulted in aggressive interchanges. The pressure to procure an organ timeously – which could result in patient care and professional respect being somewhat disregarded – could so compromise interprofessional communications that moral distress was created. Furthermore, as a result of miscommunications, an ethical vacuum where the best interests of patients in the transplant process were not, apparently, a foremost consideration, was identified.

Conclusion

Transplant is a highly complex process requiring a number of different communication styles and skills and accompanied by intricate ethical challenges. Although transplant professionals seemed cognisant of the need for careful communication, inequalities, resource scarcity and conflict intervened to create a space for moral distress and uncertainty in which communication was affected, and the provision of care was the casualty.

Appraising results within an ethics of care framework suggests that transplant in Gauteng cannot be considered to be a process fully informed by the imperative of care. The ethics of care proved to be a helpful framework for understanding transplant communication in Gauteng because of the way it accounts for interpersonal relationships - fundamental to the transplant process - whilst also emphasising the importance of resources necessary to provide good care. It was

concluded that in the current environment, where there is little legal direction or political buy-in, transplant in Gauteng will be unable to reach its full potential.

Declaration

I declare that this thesis is my own, unaided work. It is submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or for examination at any other university.

Harriet Rosanne Etheredge

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Glossary of Terms and Acronyms

KEY TERMS

Allied professionals – Health and transplant professionals including nurses, physical and psychological support professionals and technical assistants

Biomedicine – Allopathic, evidence-based health care.

Health communication - Communication associated with the process of seeking and providing health care in general.

Health professional – An individual who has obtained a degree in health sciences, or one which feeds into health sciences (such as social work or psychology).

Health system – The larger context within which health institutions are nested and the overarching trends which link these institutions together.

Interprofessional communication– The interactions which take place between health care and/or transplant professionals.

Living-donor – A living individual who has donated an organ to another person.

Medical professionals – Health and transplant professionals with a medical degree. These include surgeons, specialised medical personnel, and anesthetists.

Organ allocation – The process by which transplant professionals decide which of the potential recipient(s) on the waiting list will receive a donor organ.

Organ procurement – The pre-transplant phase during which transplant coordinators locate potential donors and obtain relevant consents.

Post-donation – Any time after the point where a family or living donor has consented to donate organ(s).

Post-transplant – Any time after transplant recipients have undergone surgery during which a donor organ was implanted.

Potential recipient – An individual with end stage organ failure whose name has been added to the transplant waiting list for that particular organ, but who has not yet received a transplant.

Pre-transplant – The phase before the surgical procedures (retrieval and implantation) begin.

Recipient – An individual who has undergone surgery in which a donor organ was implanted into his or her body.

Surgical phase – The phase during which organs are removed from the body of the donor and implanted into the body of the recipient.

Transplant / transplantation – The overall theme of my research; these two words are used interchangeably and encompass the concept of organ donation as a whole.

Transplant centre - Transplant centres are generally based in hospitals. They house transplant coordinators and recipient follow-up facilities. When a donor is identified, the organ harvest may take place at the referring hospital, and the donor organs will be transported to the transplant centre for implantation into a recipient.

Transplant communication – Communication incidental specifically to the transplant process. Differs from 'health communication' in that it focuses on the transplant rather than health in general.

Transplant coordinator – Generally a health professional with a nursing background who has specialised in the facilitation of an organ transplant. The role involves both coordination of transplant professionals and a number of aspects of medical management of donor and recipients. This role should been seen as distinct from 'transplant professional' for the purposes of this thesis.

Transplant professional – A medical or allied healthcare professional who is involved in transplant, either as a member of staff in a transplant unit, or as an employee of a health institution.

Transplant process – The phases in which key role-players or end-users (transplant professionals, recipients, donors and their respective families) necessarily participate over a period of time in order for a transplant to occur. Includes post-transplant care.

ACRONYMS

DFG – Living donor focus group

DFI – Donor family interview

ICU('s) – Intensive Care Unit(s)

MAC – Ministerial Advisory Committee

NHI – National health Insurance

ODF – Organ Donor Foundation

TCFG – Transplant coordinator focus group

CHAPTER 1

Introduction

In this thesis I will argue that the context in which organ transplant takes place in Gauteng is complex and multifaceted. I will go on to demonstrate that transplant communication is influenced by this context, and varies depending upon roles and the different phases of transplant. I will show that there are ethical issues at three levels of transplant which influence care, perceptions, and outcomes. I will argue that care is sometimes compromised despite access to first-world medical expertise, and to relatively well established systems and protocols in Gauteng. I will do this is by taking a unique look at transplant, communication and ethics using a qualitative approach, which has not been done before in South Africa.

1.1. OVERVIEW

Transplantation is internationally accepted as the gold standard for patients with end-stage organ failure. Organ transplant occurs worldwide across different contexts and within different frameworks. However, transplant practice is almost universally hindered by the supply of organs failing to meet the demand.[1] Because transplant takes place at the boundary between life and death, with its attendant grief and desperation, this undersupply of organs has a number of far-reaching implications which compound transplant complexities. Given the nature of transplant it is a field which lends itself to research which spans countries and embraces a number of different disciplines.

This chapter aims to introduce my research project and provide some context relevant to the research setting. It begins with an overview of the research and an explanation of my motives in undertaking the study. It continues with a brief sketch of South Africa, which shapes the context for this study, and the Gauteng province in particular, concentrating on aspects which are relevant to this research.

[1] The only place where the supply of organs meets demand appears to be Iran, which has a paid living kidney donor programme; here the waiting time for a kidney is less than two weeks (Pourmand, 2008).

The South African healthcare system is then covered in more depth in order to give the reader a sense of some of the complexities which shaped the project. The chapter will then address health communication, the discipline within which my research is grounded and an exploration of which is vital for developing the argument of this thesis. Finally, the structure of this dissertation and choices of writing style are detailed.

As a developing country, the challenges which shape transplant in South Africa are different from those found in wealthier first-world settings. Transplant programmes in South Africa are significantly smaller than their first-world counterparts, yet South Africa carries a burden of disease which lends itself to transplant. Transplant may be indicated for end-stage organ failure resulting from hypertension, diabetes and cardiovascular disease, the incidences of which are all high in South Africa (Myers, 2015). In common with international experience, the number of individuals awaiting a transplant in South Africa significantly outstrips the supply of organs. Transplant in South Africa is further complicated by disparities in access to healthcare which are a function of the structure of the healthcare system and the country's political history.

This is the first qualitative transplant communication study of its kind in Gauteng province. As there was little previous literature on transplant communication in this setting the study was seen as explorative. It was decided to cast a wide net in research sampling and to obtain a diverse study population, where a number of viewpoints were represented. As such, this research only starts to outline and explain transplant communication in Gauteng. It is not definitive and it is not all-inclusive. It has nevertheless yielded potentially useful results and identified a number of research areas which may benefit from further investigation.

1.2. WHY I DID THIS STUDY

I undertook this study because through my work in bioethics I became acutely aware that communication and ethics both appeared to pose challenges for transplant practice, and I had conducted my own transplant research studies which

enhanced my belief that this was a subject the investigation of which was long overdue.

I first became interested in organ transplant when studying bioethics and health law at the University of the Witwatersrand Faculty of Health Science. Here I noticed that potential donors were not always referred into the transplant system. Although there was substantial literature suggesting that religious and cultural beliefs may prevent referrals, I was surprised that the communication essential in the referral process – such as picking up the phone or going to see a transplant coordinator – was not considered more critically. My interest in transplant was further piqued in interactions with a number of individuals who highlighted the ethical issues inherent in transplant practice in South Africa. However, many of these individuals also seemed at a loss to explain how and why organ donations appeared to be on the decline.

As I started reading transplant literature, it became apparent that the issue of communication in transplant in Gauteng had not been researched to any substantial extent. Furthermore, international studies suggested that effective communication was essential to successful transplant programmes. A large body of South African health communication research also suggested that communication was vital for ethical healthcare practice, though this literature had not been extended to organ transplantation. I decided to pursue this study, based on the need to fill this gap in academic literature, with the hope of highlighting transplant communication as a phenomenon worthy of rigorous academic and ethical inquiry.

Through the data collection and analysis process I became aware that a notion and expectation of care – and experiences of poor care - permeated the data. The type of care encompassed both that which health practitioners render to patients and their families, and that where the donating of an organ to another person was seen as an act of caring. This is exemplified in the title of this research, where a potential recipient enquires about the whereabouts of a donor kidney, wondering where the care he or she expects is.

Framing my research within ethical constructs could be seen as a result of my own bias, as a bioethicist, to continually seek out and engage the ethical aspects of healthcare. There may be a number of other theoretical frameworks within which the findings could have been presented. However, issues of access to healthcare, quality of care and the context within which these interactions take place are important to many South Africans. Hence making use of a bioethical approach seems relevant, and indeed necessary, in order to provide different perspectives from which transplant practice may be examined.

I hoped that the outcomes of my research project would be to inform policy and practice, and to add to the debate about the ethics of care.

1.3. SOUTH AFRICA – CONTEXTUAL BACKGROUND

This section aims to introduce South Africa and the South African health system. It will show that South Africa is a country of inequality, and that although the system of justice and governance in South Africa has changed, the legacy of Apartheid still shapes access to vital services and the realisation of human rights in the country. It will show that inequalities in South African society, which translate into inequalities in access to health services, also influence transplant. Finally, this chapter will also introduce health communication and give the reader a sense of the number of individuals who interact during the transplant process.

South Africa, with a population of approximately 53.15 million people (World Bank, 2015) living across nine provinces, is a highly complex and diverse country. Data from the 2011 National Census states that the majority of the South African population is aged between 15 and 64, with slightly more females than males. Individuals in South Africa represent six racial groupings, with 79.2% of the population identifying themselves as belonging to the Black African group[2] (STATSSA, 2012a). Adding to this diversity, South Africa has eleven official languages, spoken in varying degrees throughout the country (Mesthrie, 2002).

[2] Writing about race requires sensitivity and an awareness of grouping people together based on certain observable traits or attributing certain characteristics to these groups. Given South Africa's history of segregation along racial lines during Apartheid, it is imperative to be cautious. For the purposes of this dissertation I will make use of the terminology employed in the 2011 National Census when referring to race.

This multilingual aspect of South Africa poses challenges for communication, because very few people in this country can speak all eleven official languages, and there is no single language which is spoken by everyone (Mesthrie, 2002). Interestingly, the 2011 National Census did not capture the religious affiliation of South Africans, as this was not considered a priority in terms of the Census objectives (STATSSA, n.d.). However the 2001 National Census portrays South Africa as a religiously diverse nation of eight distinctive religious groups with approximately 80% of the population identifying themselves as Christian (STATSSA, 2004).

Furthermore, South Africa is a country of inequality, with a GINI coefficient estimated between 0.65 (World Bank, 2011) and 0.70 (Hvistendahl, 2014)[3] and an acknowledged continuum from the very poor to the very wealthy. Intersections between these inequalities further complicate the South African context. For instance, the 2011 National Census reported average household incomes ranging from R 60 613 to R 365 134 per annum and explicitly noted trends between wealth and race, stating that Black African households earned the least whilst White households earned the most (STATSSA, 2012a). Similar inequalities were found in other sectors of South Africa, with the Census (STATSSA, 2012a) noting that 35% of the White population over the age of 20 had benefitted from tertiary education, compared to 9% of the Black African population. Educational discrepancies were considered to feed into employment statistics, with approximately 65% of the Black African working age population employed, compared to approximately 91% employment in the White population, who also reported larger income.

1.3.1. Inequality and injustice in South Africa

Prior to 1990, South Africa was a country governed by a system of racial segregation known as Apartheid. Apartheid legislation mandated the separation of people based on race with the aim of creating a state founded on the notion of white supremacy. To this end, a vast number of Black Africans were displaced,

[3] A GINI coefficient is one of the standard measures of inequality in a country. A GINI coefficient of 0 indicates absolute equality whereas a coefficient of 1 indicates absolute inequality (Hvistendahl, 2014).

abused, cruelly treated, separated from their families and unable to access facilities to the same extent as White South Africans (Cameron, 2014). Black South Africans were often denied access to secondary and tertiary education and this meant there was a large Black African workforce who were only able to take unskilled jobs, often in sectors such as mining and manufacturing, for minimal, inadequate compensation. As a result of Apartheid segregation, the country inherited by Nelson Mandela in 1994 was vastly unequal. For instance, the majority of tertiary healthcare institutions were located in urban areas typically occupied by White people, and therefore not easily accessible to Black African people. Hence, the social welfare system in South Africa at the end of Apartheid was almost non-existent, and the majority of the population was highly disadvantaged and living, in many cases, in extreme poverty (Cameron, 2014).

The South African Constitution which was implemented after democracy, and its accompanying justice system, advocates the realisation of basic human rights for all, based on a concept of redistribution of wealth and the enhancement of social systems. The Constitution acknowledges that this realisation of rights is a long-term process, and state that the rights to access health care, education, basic housing and other amenities should be realised in a progressive manner, depending on the availability of resources (Western Cape Government, 2014).

South Africa is generally considered to be a politically just country. This is evidenced by the existence of political rights, such as the freedom to vote and freedom of speech. However, social justice is still a pressing issue. Handmaker and Berkhout (2010) argue that 'social justice' is a term frequently invoked in South African discourse, by, amongst others, political entities and social lobbying or rights groups. It compels us to redress systemic socio-economic inequalities such as those in healthcare (which will be explored in Section 2.5.3) by considering context, living standards and population discrepancies as well as resource distribution. In legislative terms, social justice is mandated through the normative human rights enshrined in the Constitution (Western Cape Government, 2014). Michelman (2010) argues that the South African government has failed to address these issues

and these rights have not been realised to any substantive extent, indicating constitutional failure.

In his 2014 book Edwin Cameron traces the South African Constitution and its implications for justice. He addresses notions such as forgiveness and redistribution, arguing that the law in South Africa is both a help and a hindrance when it comes to promoting a just society. Cameron (2014) argues particularly strongly in favour of the South African Constitution and the role of the Constitutional Court in mandating access to anti-retroviral medication. As Section 1.4.4 will show, antiretroviral provision has faced challenges in light of AIDS denialism amongst the most prominent leaders in the country. Cameron (2014) argues that the South African justice system, through the mandate of human rights, grants and social welfare has provided at least a modicum of dignity to even the poorest of people. However, he rightly notes that serious discrepancies are still evident, that debate along racial lines is still prevalent and that South Africans do not appear to have much faith in their democracy or justice system. Rightly, Cameron (2014) recognises the Constitution as idealised, though he argues that it will prove a useful beacon in time to come. Most interestingly, Cameron (2014) notes that service delivery protests are twice as common today as they were twenty years ago at the start of democracy. Healthcare delivery is one of the services which has attracted its own fair share of these protests (Dhai, Etheredge, Vorster & Veriava, 2011).

1.3.2. Gauteng Province

Figure F1 is a map showing South Africa and its nine provinces.[4] Geographically, Gauteng province is the smallest, covering a landmass of approximately 1.4% of South Africa's total area. However, Gauteng is densely populated and is home to the majority of South Africa's major industries, including mining, banking, infrastructure, development and investment. Over 33% of South African gross domestic product emanates from Gauteng, making it the wealthiest and most financially productive province in the country (South Africa Info, 2012).

[4] Eastern Cape, Free State, Gauteng, KwaZulu-Natal, Limpopo, Mpumalanga, North West, Northern Cape and Western Cape.

Gauteng province has a population of 12.28 million people and of the eleven official languages IsiZulu is spoken by 19.8% of the population, followed by English (13.3%), Afrikaans (12%) and Sesotho (11.6%). According to the 2011 National Census, educational disparities in Gauteng have improved over the past 19 years, with 34.7% of the adult population holding a matric certificate – a rise from 22.8% in 1996 (STATSSA, 2012b). Housing in Gauteng has also improved, with the overwhelming majority living in formal dwellings with piped water and electricity (STATSSA, 2012b). However, the unemployment rate in Gauteng Province remains high at 26.3%.

Figure F1.1 – The nine provinces of South Africa (Map from South Africa Info, 2012)

This map depicts the nine provinces of South Africa. Gauteng province is indicated by a solid black circle. It is the smallest of the nine provinces, yet it is considered the financial capital of the country.



1.4. THE SOUTH AFRICAN HEALTH SYSTEM

1.4.1. Overview

The inherent inequalities and discrepancies which permeate South Africa undoubtedly influence the South African healthcare system. The Bill of Rights of the South African Constitution mandates that all residents have the right to access healthcare services, and that the South African government is obliged to facilitate such access (Hassim, Heywood & Burger, 2007). However, South African academic literature exploring this topic appears unanimous in agreeing that the two-tier healthcare system is fragmented and permeated by extreme inequalities (McIntyre, Gilson, Wadee, Thiede, & Okarafor, 2006; Price, 1998). These are often related to post-Apartheid economic policies which favoured a maxim of economic growth over redistribution (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009).

Baldwin-Ragavan, de Gruchy and London (1999) argue that many of the challenges and injustices facing the health system today result from Apartheid policies which play out within different socio-economic contexts. With the end of Apartheid, they note, not only came the laudable South African Constitution, but also a policy of economic growth which did not recognise redistribution as a major priority. Rather, those who were already wealthy at the end of Apartheid – generally White South Africans – benefitted from investment and infrastructure opportunities and became wealthier. Those who were impoverished were not able to access the market. This policy permeated healthcare and the expansionist mandate led to market-driven fee-for-service health provision and the phenomenal growth of the private sector (Mayosi & Benetar, 2014).

Thus, in spite of health policies which are geared towards universal coverage and equality in the provision of health services, there are still vast discrepancies in access for different areas of the population. For instance, the Apartheid legacy of tertiary medicine primarily for White people has led to the location of most tertiary and specialised health services in major metropolitan areas (Hassim, Heywood & Burger, 2007). Given significant resource constraints, the government has not been able to deliver such services outside these areas, nor has it been able to increase

these services in the major metropolitan areas on a welfare based system. Hence, the healthcare needs of many of the population – those who were most affected by Apartheid – remain unmet (Dhai, 2012).

In his work on access to antiretroviral treatment and HIV in South Africa, Steinberg (2008) furthers the argument about inequality in access to healthcare facilities. He documents the progress of a Médecins Sans Frontières (MSF) programme to roll out antiretroviral therapy which was deemed reasonably successful in the Khayelitsha Township based in Cape Town. However, it was pointed out that Cape Town is relatively well resourced, and the MSF was encouraged to attempt a similar rollout in a rural area where little health infrastructure was available. When infrastructure was available in these settings, posts were unstaffed and drug delivery took many months.

Dhai (2012) in an editorial for the South African Journal of Bioethics and Law argues particularly strongly that the South African health system is highly unjust - that the right to access health care has not been realised, that wasteful expenditure has been rife and that health service delivery is unacceptable. The following quote aptly illustrates Dhai's (2012, p.2) point:

> *No doubt the state has the resources to provide better services, but our democracy fails to do so because it is plagued with inefficiencies, incompetent management, corruption and lack of accountability. And sadly it is the indigent, and black groups in the main, that are victims once more.*

1.4.2. The two-tier system of South African healthcare

The private sector in South Africa provides healthcare services at a fee. However, this fee is not necessarily market-related, and there have been allegations of collusion and price-fixing in private healthcare. The private sector is generally characterised by well-resourced hospitals concentrated in metropolitan areas (Hassim et al., 2007). Access to private medicine depends on the ability to pay. This in turn depends on factors such as financial status and, given that many companies provide access to medical schemes for their employees, on employment. The private sector serves only a fraction of the population, and

enjoys the majority of medical spending, as indicated in Table T1.2 and Figure F1.3. Although there have been attempts to consolidate private healthcare, this is still viewed as unnecessarily expensive due to uncompetitive business practices such as benefits-based pricing (McIntyre et al., 2008).

The state sector provides healthcare through public funding mechanisms and those who cannot afford private medical cover are obliged to seek government funded care (Hassim et al., 2007). Policies directing healthcare provision in the state sector determine the packages of healthcare services available to state patients. South African healthcare policy is based on the utilitarian premise that individuals will benefit most from reasonably priced primary and preventative care that can be rolled out on a population level (Kautzkyi & Tollman, 2008; Peterson, 2000). This often comes at the expense of those individuals who require more costly interventions such as dialysis (Etheredge & Paget, 2014).

Both health sectors in South Africa are criticised for systemic failings. McIntyre, Goudge, Harris, Nxumalo and Nkosi (2009) reported dissatisfaction with healthcare services. In the private sector, respondents criticised the quality of care provided, felt that unnecessary interventions were undertaken in order to make money and that private medical schemes were too expensive. In the state sector, respondents expressed dissatisfaction with the quality of health professional-patient communication, cleanliness of facilities and the availability of drugs (McIntyre et al., 2009). I was involved in a 2011 quantitative research study which reported on the views of 600 participants towards strike action in the South African state sector. A surprising finding of this study was the perception of poor conditions in state hospitals. Participants who had experienced state healthcare felt that this was inadequate and were particularly critical of the quality of care provided by nurses (Dhai et al., 2011). Clearly, expectations of quality healthcare, the promise of which forms the cornerstone of South Africa's health system and legislation, have not been met (National Health Act No. 61 of 2003).

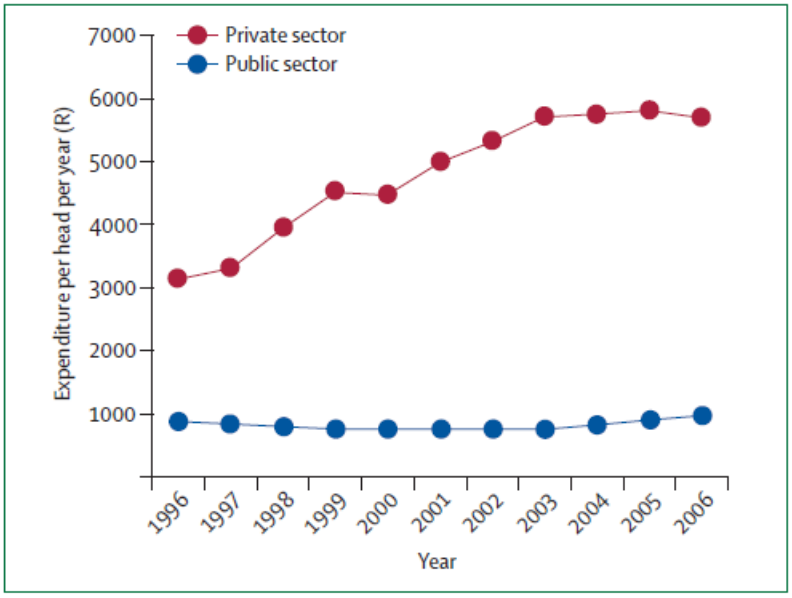
Table T1.2: Disparities between the state healthcare sector and the private healthcare sector in South Africa (Hassim et al., 2007, p.165)

This table illustrates financial discrepancies between the state and private healthcare sectors in South Africa in 2007. Of interest is the annual expenditure in the private sector which is much greater than that in the public sector. Yet only about 10% of the population benefit from this expenditure. Also of note is the difference in per capita annual expenditure.

	Total annual expenditure	% total national expenditure on health	Number of people covered	Annual per capita expenditure	Monthly per capita expenditure
Public sector	33.2 bn	39%	37.9 m	R 875.98	R 72.99
Private Sector	43 bn	60%	3.9 m	R 6,231.88	R 519.32

Figure F1.3: Healthcare expenditure per capita in South Africa's public and private sectors. 1996 – 2006 (Coovadia et al., 2009, p.828).

The figure below depicts annual per capita expenditure in the South African state and private sectors over ten years from 1996 – 2006. The figures have been adjusted for inflation and are expressed in prices at the year 2000. The figure shows growth in private medical expenditure as compared to state expenditure. It is evident that private healthcare expenditure has been increasing, whilst state expenditure has remained relatively static, and much lower than private spending.



1.4.3. Remedying health inequalities - National Health Insurance (NHI)

In an attempt to remedy some inequalities in the South African healthcare system a National Health Insurance scheme is being piloted by the government. Ataguba and Akazili (2010) provide an overview, arguing that details of the exact policy are still vague, though there have been some indications as to the structure of the system. The NHI will aim to provide quality healthcare for all South African residents, primarily funded through general taxation such as VAT and excise duties. Furthermore, those in formal employment will be required to pay a regular levy, structured progressively to account for income level. These funds will be pooled and then drawn upon to supply healthcare interventions countrywide. As yet, these interventions have not been precisely outlined, however it is noted that primary, secondary, tertiary and quaternary services should be provided (National Department of Health, 2011; Matsoso & Fryatt, 2013).

The majority of South African academic literature seems cautious about the NHI, emphasising that careful consideration of several factors is required in implementing the scheme (McIntyre et al., 2008; McIntyre et al., 2009; Weimann & Stuttaford, 2014). Opponents of the NHI argue that the financial mechanism dictating it is unrealistic, that there is substantial scope for corruption, that it would be more appropriate to improve the current public healthcare system and that inequalities will be further permeated, whilst the benefits will be minimal (Bateman, 2009; Ncayiyana, 2009; Van der Heever, 2010).

1.4.4. Some public perceptions of the South African biomedical healthcare system

With the disparities in access and inequalities discussed above, it is apt to now discuss people's perceptions of the South African health system. In her 1991 book *Curing Their Ills: Colonial Power and African Illness,* Megan Vaughn traces the colonial construction of identity in biomedicine, arguing that the objectification of individuals according to racial grouping led to asymmetrical power relationships which facilitated abusive medical practices and may have perpetuated distrust in

biomedicine as a construct of colonialism. The previous sections have clearly demonstrated that healthcare services in South Africa still bear some resemblance to colonial paradigms, with disparities in access between racial groups. Thus, it is unsurprising that biomedicine is still viewed with suspicion in Africa.

Perhaps the most recent example of this distrust can be found in responses to the Ebola outbreak of 2014. Academic literature suggests that perceptions of poor healthcare in Ebola settings, including the failure to respect the dignity and life-world of those in affected areas, has perpetuated suspicions of biomedicine (Boozary, Farmer & Jha, 2014) and that decades of conflict in the affected African countries has led to a suspicion of authority figures such as health professionals (Fauci, 2014).

Two other aspects of biomedicine which may propagate this distrust, and have been more substantially explored in academic literature, are the HIV and AIDS epidemics (Dickinson, 2013; Liverpool et al., 2004) and clinical trials (Kempf, 1996; Kingori, Muchimba, Sikateyo, Amadi & Kelly, 2010). Perceptions of poor service delivery, inequality in access to healthcare services and adverse events appear at the root of the situation. Furthermore, there is a historical legacy of 'medical experiments' in South Africa. An example of this was the collaboration between Roodeplaat Research Laboratories headed by Dr. Wouter Basson, and Delta G, which, amongst other programmes, aimed to develop an anti-fertility vaccination and then administer it to Black African women without their knowledge (Gould & Folb, 2002). However, it is also argued that distrust can be perpetuated by political leaders. A notable example of this in South Africa was seen when President Thabo Mbeki and then-Minister of Health Manto Tshabalala-Msimang, created friction amongst South Africa's biomedical health system and civil society through their systematic AIDS denialism (Campbell, 2004).

Suspicion of biomedicine may be perpetuated through media coverage of adverse events; this will be discussed in more detail in Section 2.6.3. Some recent South African headlines include: "Baby falls during mom's birthing hell" (Mooki, 2014), "Public hospitals, a mother's worst nightmare" (Moeti, 2012) and "Corpses sold at

Gauteng Hospital" (Bernard, 2013). Given the sensational nature of these writings it is perhaps unsurprising that such distrust exists.

1.5. HEALTH COMMUNICATION

This thesis will demonstrate that the complex transplant context impacts on both ethics and communication. These present different challenges at different phases of the transplant process. However, the finding that care is compromised came about through specifically exploring communication in transplant

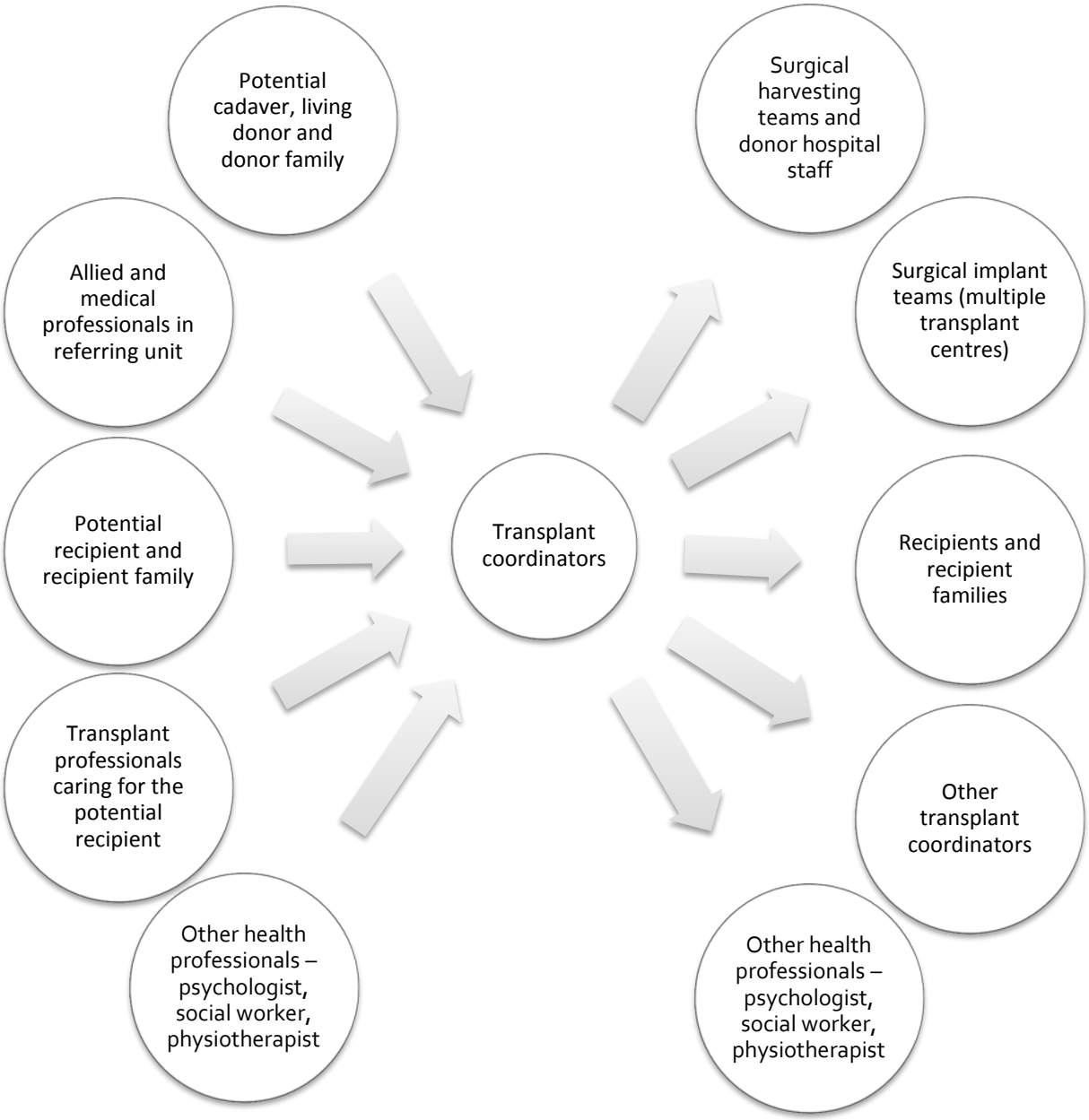
In order to give context to the following discussion of communication in organ transplant, I must first introduce the main role-players in the process. Transplant involves a large number of individuals, patients and their families as well as a number of health professionals. Figure F1.4 shows a basic schema of transplant communication. It is important that this is foregrounded here to enhance the forthcoming chapters. Communication between medical professionals, allied professionals and patients (potential recipients, recipients and their families, cadaver donor families and living donors) as it relates to the transplant process formed the foundation upon which research questions were formulated. It was by exploring these communicative pathways that results of a varied and unexpected nature emerged. It was by specifically examining communication that all the results of this research emerged.

Health communication is a relatively young field which lends itself to multidisciplinary academic inquiry because of the nature and variety of interactions that take place in the health context (Hannawa et al., 2014). These interactions happen across a range of settings, are relevant to a wide assortment of health interventions and involve varying numbers of role-players. The Picker Institute (2011, p.6-7) described health communication as follows:

> *Communication encompasses the exchange and sharing of information among several key players of the healthcare team, including communications between patients/families and providers, as well as among providers collectively responsible for a patient's care. Communication is a*

Figure F1.4 – Transplant interactions

The figure depicts transplant interactions. It shows the coordinator at the centre of the process as the person in charge of facilitating the transplant. The left-hand side of the figure shows pre-transplant processes, whilst the right-hand side shows the surgical and post-transplant processes. All these processes and the role-players involved will be discussed in greater detail in Chapter 4.



> *foundation of effective patient–provider partnerships. It is a theme constant in any interaction a patient may have with the healthcare system.*

Ruben (2014) argues that communication in the health setting is both a barrier to and a facilitator of care. When it is appropriate, communication can transcend cultural and language divides, resulting in understanding and establishment of fiduciary relationships. However when communication in the health setting is misdirected or lacking, it can negatively influence care (Ruben, 2014).

The quote from the Picker Institute illustrates that health communication is fundamentally about the sharing of information, both among health professionals and also with patients. Constancy of communication as an aspect of health provision is emphasised. Because of the diverse South African context, which has been discussed previously, health communication here involves a number of individuals from different backgrounds, with different world-views and belief systems and different education and literacy levels (Watermeyer & Penn, 2009). Thus, health communication in South Africa is a process of negotiation, where skills and strategies are continuously evolving to account for differing patient life-world's (Watermeyer & Penn, 2012). Furthermore, in the South African context the notion of commercialised care – with the concept of a health 'provider' (Ruben, 2014) – could shape communication in the private sector.

1.6. THESIS STRUCTURE

This thesis aims to guide the reader through my research project and is structured in order to highlight my argument. Because my research project explored a process (transplant) from a variety of perspectives (transplant professionals, donor families, living donors) across a number of settings, the data set was very large, diverse, at times contradictory and complicated.

In order to adequately make sense of my research findings, I have had to consider a number of theories from the literature. I have chosen to present the literature review chapters in a particular way in order to promote cogency (Figure F1.5). However, the fact that a theory or concept is only mentioned in the final review

chapter does not mean it is less important or relevant for this research than those which were mentioned beforehand.

The chapter reviewing health communication and health communication research, which is critical for this thesis, is presented in the middle of the literature review. The reason for this is that health communication in South Africa is shown to be substantially influenced by the healthcare hierarchy. The healthcare hierarchy forms part of an institutional structure and I felt it was essential to explain this structure in detail before considering communication.

Figure F1.5: Overview of the literature review



Throughout the literature review, barriers to and facilitators of transplant in Gauteng will be identified. The whole transplant process is considered, but judgements about its outcomes are mainly based on its impact upon the end users (potential and actual recipients, donors and their families). Impacts on transplant professionals are also important because they have an effect upon the efficiency of the transplant process and hence on the end users. For the purposes of my thesis, a phenomenon is considered a facilitator of transplant if it appears to positively affect the transplant process – from the referral of potential donors, through the management of a potential recipient, to the recipient follow-up. Barriers to transplant are identified as those aspects which appear to hinder the transplant process, and are considered the opposite of facilitators in their consequences.

Chapter 2 considers organ transplant, first internationally and then within a South African setting, highlighting some of the challenges which South Africa faces and which are not as problematic in developed countries. Chapter 3 explores the health hierarchy and the concept of moral distress, integral factors influencing health institutions. Chapter 4 describes the transplant process. Chapter 5 considers communication research and demonstrates the underpinnings and vital relationship between communication and ethics in healthcare. Chapter 6 considers literature related to the main ethical theory underpinning this research – the ethics of care. It presents a theoretical model based on the literature review. Chapter 7 presents a detailed explanation of the research methodology.

Chapter 8 presents my results under the first main theme of context. It is in this chapter that I illustrate how complex the Gauteng transplant context is, and how a number of multifaceted considerations influence the process of transplant as it is played-out in actuality, often with implications for ethics and communication. My data in this chapter speaks especially to the ethical issue of distributive justice and the allocation of both health and transplant resources in Gauteng – which is a primary ethical issue in terms of transplant context. In Chapter 9 I present my results relating to transplant professional – patient communication and ethics, showing that different phases in the transplant process are accompanied by ethics and communication issues which influence perceptions of care. Factors like

uncertainty management will be explored, in order to further highlight the varying nature of communication at different transplant phases. The main ethical issues which appear in this chapter are informed consent, autonomy and decision making, which influence communication and perceptions of care, especially for cadaver donor families. Chapter 10 will present my findings related to interprofessional communication and ethics. There results will show how systems influence communication and ethics, having implications for care. The data suggests that interprofessional communication is fractured by an organisation's structures, such as hierarchy, and that ethically, the notion of acting in the best interests of the patient can be lost when communication is ineffective or lacking.

Each of these chapters deals with one of the main themes identified in analysis. Chapter 11 presents a discussion of key findings. Its overall argument is that the ethics of care cannot be realised where organ transplant poses unresolved challenges to communication resulting in moral distress and a fractured transplant system. Chapter 12 considers implications for theory and literature and makes recommendations for practice and research.

1.7. WRITING STYLE

Writing this dissertation has given me significant pause for thought. Transplant is a complex procedure, which requires lengthy surgery and can involve the opening up of large areas of the body, resection or removal of bones and removal of body parts. Of utmost importance ethically is respect for the dignity and bodily integrity of the donor, in a situation which could be considered as a sanctioned physical assault. Respect for this right to dignity should also be foremost in the mind of an author when writing about a process where it is (necessarily) violated to some extent. The challenge for me was portraying an awareness of the need for sensitivity in this thesis, versus brevity in describing a complex technical process with sufficient detail to contextualise the research results. In light of this, I opted for an objective and factual description of the process, but am acutely aware of the sensitivities pervading such a discussion.

This thesis spans a number of academic disciplines. The project is rooted in the Health Communication Research Unit at the University of the Witwatersrand where the Faculty uses humanities and psychology writing conventions. However, the project also involves aspects of bioethics and philosophy where my own voice has been important in drawing and justifying conclusions utilising philosophical argument and this is typically presented in the first person. Hence, I have made the decision to write this thesis in the first person because I feel it is more accessible and better allows for expression of my overall argument.

Chapter 2
Literature review – overview, international and local transplant, setting the scene

2.1. INTRODUCTION

This chapter aims to set the scene for the research which will be presented in my thesis. The chapter will start by considering the fundamental premises of organ procurement, and it will then consider the procurement practices of a number of different countries. Next, the chapter will narrow its scope to consider organ procurement and allocation in South Africa, following which a section of South African literature relevant to this chapter will be critically discussed. This discussion will compare South African research findings to those from other countries, and it will attempt to show that some of the most commonly invoked barriers towards organ donation in South Africa have been overcome on an international level. The chapter argues that whilst these barriers are highly relevant, the fact that they can be overcome suggests that research should focus on the situation 'on the ground' (ie as transplant currently takes place in hospitals and transplant centres in South Africa), which is what my thesis proposes to do.

2.2. ORGAN TRANSPLANT

At present, there are two sources of human organs for transplantation - cadaveric donors and living donors (Truog, 2005). Each type of donor presents its own challenges, however the essential argument in organ transplant is that a donor organ is a scarce resource. Like other scarce resources, ethical debate arises primarily around the ways in which they can be procured and how they should be distributed. Unique about organ donation ethics, and what distinguishes it from the distribution of other scarce resources such as crude oil or platinum, is that at present an organ can only be obtained from another human being. It requires either a death (cadaver donation) or that a living person undergo a potentially risky

surgical procedure. This complicates ethical argument by introducing human factors such as grief, greed, desperation, expectation and uncertainty, all of which are pivotal to this research and will be explored in my thesis.

2.2.1. Organ procurement

Traditionally the premise of altruistic organ donation has a strong base in transplant literature and history. The notion of altruism in 'giving' another the 'gift of life' without any expectation of reward or compensation is regularly evoked (Caplan & Virnig, 1990; Titmuss, 1971). Although altruism in organ donation is laudable, a parallel body of transplant literature recognises other aspects of human nature such as greed, desperation and power and the role these play in decisions to give organs (Barnett, Blair & Kaserman, 1992; Biller-Andorno, 2002; Schweda & Schicktanz, 2009; Siminoff & Leonard, 1999).

Over the last fifteen years notions of incentivising cadaver organ donation have become more dominant in academic literature as the international supply of organs struggles to meet the demand for them (Arnold et al., 2002; Board, 2002; Chouhan & Draper, 2003; Gill et al., 2014). Incentivising organ donation may more realistically take account of the factors of human nature that influence it.

However, the transplant community is polarised when it comes to paying individuals who give an organ. Delmonico et al. (2015) argue that organ donation should be financially neutral. They posit that paying an individual for an organ may either leave a person better off or worse off in the long run. In order to avoid this, and still to encourage people to become donors, it is suggested that conventional barriers to donation be compensated. For instance, loss of income and lodging expenses during a transplant work-up for living donors could be refunded, as could funeral expenses for the families of cadaver donors (Delmonico et al., 2015).

2.2.1.1. Cadaver organ procurement: opt-in vs opt-out

A number of strategies to procure organs are considered in academic literature. Essentially, these run according to two systems, explicit consent or presumed consent (Gevers, Janssen & Friele, 2004). Within both explicit and presumed consent strategies, opt-in and opt-out are the most popular paradigms, and they

are used internationally. There are a number of other procurement policies[5] which have been suggested, however only opt-in and opt-out will be dealt with here as these are the most relevant to my research.

2.2.1.2. Opt-in procurement systems

The primary requirement of an opt-in system is that an individual has recorded an express wish during his lifetime to become an organ donor. The way in which this preference is stated depends on the legal procurement system of the country in question (Gevers et al., 2004). Some of these are explored in the following sections. However, Gevers et al. (2004) argue that the notion of opting-in is not so simple in practice, with transplant legislation often mandating the involvement of family members who can consent on behalf of a deceased person. This deference to the family when it comes to donating organs of a loved one is known as weak express consent. A strong form of express consent would consider only the previously stated wishes of the potential donor and pay no heed to the wishes of the donor's family. A weak express consent considers the preferences of the potential donor's family in balance with those of the donor (Rens, 2008). South Africa makes use of the opt-in system based on weak express consent, considered in more detail in Section 2.5.1.

2.2.1.3. Opt-out procurement systems

Sometimes all individuals in a country are presumed to be organ donors unless they have explicitly stated otherwise. This type of presumed consent is generally termed an opt-out approach to organ procurement. There are various ways to opt-out. One can lodge an objection to organ donation on a central, computerised registry or one can verbally lodge the objection before a designated civil servant. There is also sometimes the option of objecting on one's driver's licence (Rens, 2008).

[5] Giles (2005) advocates a system of reciprocal altruism where those who make an explicit, 'altruistic' commitment to donate their own organs at time of death ought to receive priority should they require a transplant during their lifetime. Chouhan and Draper (2003) favour a more regulated system of mandated choice. This policy would legally require every individual residing in a country to actively make a decision about organ donation and its respective components (i.e. which organs to donate). They argue that this system could be induced through political incentives like withholding tax refunds until a decision has been made.

2.2.2. Living organ procurement

There are three main categories of living organ donation. The first is directed donation to a family member, the second is directed donation to a non-related but known individual and the third is directed donation to a stranger, where the organ is given to a specified individual who is not personally known to the donor[6] (Truog, 2005). Living individuals are limited in what organs they are able to donate - a kidney, a lobe of liver, a lobe of lung or a segment of pancreas to another person[7], but not a vital organ such as a heart (Donate Life America, 2015). In South Africa, only living donor kidney and liver lobe transplants take place.

2.2.2.1. Altruism in living organ donation

All of these living donations are premised on altruism, however Truog (2005) argues that, in reality, directed donation to a family member or friend can be complicated by an environment of coercion, in which a compatible individual feels pressurised to undertake an action which they would not have otherwise considered. Furthermore, Fellner and Schwartz (1971) noted that medical professionals were suspicious of altruistic motives in living organ donation. In related donation coercive familial factors were thought to prevail and in non-related donation there was the suspicion of financial incentives.

Erin and Harris (2003) and Friedman and Friedman (2006) are proponents of financial incentives and compensation, going so far as to advocate a 'market for organs'. They suggest a highly regulated procurement service which will pay donors for their organs and either sell these on to willing recipients – placing the

[6] Purely altruistic living donation to an unknown person is also possible, though thought to be rare (Troug, 2005)

[7] Practically, recipient outcomes with living kidney transplantation appear to be good (Gjertson & Cecka, 2000). Furthermore, the risk of living kidney donor morbidity and mortality is minimal and thus living kidney donation has become routine procedure internationally (Segev et al., 2010). Recipient outcomes with living liver transplant are also encouraging, however morbidity and mortality factors like small-for-size syndrome means that paediatric recipients experience better graft survival than adult recipients (Kiuchi, 2003; Renz & Roberts, 2000). Furthermore, living donor hepatectomy carries a higher rate of donor morbidity and mortality than living donor nephrectomy (Lo, 2003). In spite of these risks, living liver donation is becoming routine practice internationally. Outcomes from the more novel lung lobe and pancreas segment appear promising though lung lobe transplant is considered secondary to receiving an entire set of lungs and is usually only utilised in emergency cases where a set of cadaver lungs is not available (Mohite, Popov, Yacoub & Simon, 2013). Lobar lung transplantation also carries substantial risks for the donor(s) (Barr et al., 2006).

burden of cost on the public – or allocate them in an equitable manner – placing the burden of cost on the state. Whilst providing financial compensation and incentives for organ donation is illegal in most countries (and generally also considered unethical) there is still an extensive global black-market where the organ trade is said to flourish (Friedman & Friedman, 2006).

Kerstein (2009, p.573) found that legalised kidney sales in Iran have negative psychological effects on the vendors, who liken themselves to "prostitutes". In an ethical analysis of payment-related procurement systems, Smith (2015) argues that even the most ethically sensitive structure poses challenges when it is not compatible with the religious practices of the country in which it is implemented.

2.3. INTERNATIONAL CADAVER DONOR TRANSPLANT PRACTICE

The majority of countries worldwide make use of either an opt-in system or an opt-out system of cadaver organ procurement. Each country has varying legislation on the mode of consent and involvement of the family. Table T2.1 illustrates transplant data from a number of different countries.

Table T2.1 – Organ transplants from deceased donors by country

This table illustrates transplant data from a number of different countries. Further detail is given on some of these countries if they have chosen to implement an opt-in or opt-out system in a particularly interesting manner. The table details the number of solid organ transplants, per million of population per annum (pmp), in each country for the years 2011 and 2013 in order to show trends in transplant growth. In some cases 2011 data is not available, and then the earliest year of available data is used. For more information regarding the rationale for this table please see Appendix 1.[8]

Country Name	Policy	2011 (pmp)	2013 (pmp)	Source
Austria	Opt-out	80.1	86.4	IRiODT*
Belgium	Opt-out	91.1	79.3	IRiODT
Brazil	Opt-out	26.8	31.7	IRiODT
Croatia	Opt-out	93	83.4	IRiODT
Denmark	Opt-in	43.9	34.7	IRiODT
Germany	Opt-in	43.2	40.3	IRiODT
Great Britain	Opt-in	48.9	57.52	IRiODT
Malaysia	Opt-in	2009 – 1.5	0.06	IRiODT
Singapore	Opt-out	2009 – 12.8	12.1	IRiODT
South Africa	Opt-in	4.1	3.9	Appendix 1
South Korea	Opt-in	23.5	27.3	IRiODT
Spain	Opt-out	81.7	82	IRiODT
Tunisia[9]	Opt-in	2012 – 0.3	2.06	IRiODT
United States of America	Opt-in	71.7	71.5	IRiODT

* International Registry in Organ Donation and Transplantation

[8] Transplant statistics per country are not always available or up-to-date in the public domain. In the cases where statistics are not up-to-date, the year which numbers refer to is recorded. In some cases I had to calculate transplants per million of population by making inferences from the data available; the equation and calculations which this entailed are detailed in Appendix 1.

[9] Tunisia is the only African country which is mentioned in the IRiODT statistics related to deceased donors.

2.3.1. Countries with an opt-in system of organ procurement

2.3.1.1. United States of America (USA)

The USA has a sophisticated system for organ procurement based on the opt-in model (Organ Procurement and Transplantation Network, 2015) and coordinated by the United Network for Organ Sharing (UNOS). UNOS is a nationwide computerised transplant coordination and organ matching programme. Because the USA has a large number of willing organ donors and sufficient resources, much organ allocation is decided on UNOS. This removes some elements of human communication and possible human error in organ allocation (Chouhan & Draper, 2003). In theory a strong express consent system is utilised, whereby if a person has consented to being a donor, their organs will be harvested in the event of their death and no other consent will be sought (US Government, 2015). In practice, however, it appears that families are given the opportunity to veto the previous consent of a loved one to be a donor (Vastag, 2002).

2.3.1.2. Great Britain

Organ donation in Great Britain was affected by the Alder Hay Hospital Scandal in 2001. A pathologist at the hospital was, (amongst numerous other incidents of malpractice), retaining organs of children following post-mortem examination, without consent from the family, and using these organs for research (Hunter, 2001). Following the scandal, the British Medical Association (BMA) and the British Government rejected proposals for presumed consent legislation because of negative public sentiment towards organ retrieval and distrust in the medical system, exacerbated by media reporting of the scandal (Chouhan & Draper, 2003). At present Britain uses a weak express consent opt-in system (Chouhan & Draper, 2003). Opt-out is being reconsidered, however, the issue is still being debated and no decision has yet been made (British Medical Association, 2015).

2.3.1.3. South Korea

South Korea experiences severe organ shortages (Min et al., 2010) and makes use of an opt-in system of organ donation, with the premise of weak consent (Kim,

Elliot & Hyde, 2004). Religious and cultural beliefs seem to hinder consent for organ donation. Many South Koreans practice Confucianism, where there is an ingrained belief that the deceased person will be 'mocked' by the transplant team (Kim et al., 2004). It has been argued that better tools for raising awareness of organ donation could assist in mitigating the apparently negative influence of religion on donation decisions (Lee, Park, Myung-Il & Kim, 2012).

2.3.1.4. Denmark

In the 1980s, proposed changes to the Danish opt-out policy prompted public discussions about organ donation. It is interesting to note that these discussions actually led to an increase in the Danish donation rate (Matesanz, 1998). Following public debate, an opt-in policy was introduced. However, this has had serious negative consequences with donation rates falling by 50% (Chouhan & Draper, 2003). Birkeland, Christensen, Kosteljanetz and Svarre (1997) note that the change in the law necessitated the implementation of programmes which aid transplant professionals in communication, especially asking relatives for consent. These programmes promote holistic management of relatives – focussing on empathy and sensitivity. One of the foundations of these programmes is a theatrical element, where professional actors portray grief-stricken potential donor families and transplant professionals interact within these situations. Birkeland et al. (1997) argue that these programmes have had a significant impact, increasing the number of organ transplants taking place in Denmark by sensitising transplant professionals to the importance of tailored, careful communication.

2.3.1.5. Germany

Germany makes use of a strong express consent opt-in policy (Deutsche Stiftung Organtransplantation (DSO), 2015). Illegal activities related to organ transplant took place across Germany in 2013, where medical doctors are said to have falsified patient records in order to improve their chances of obtaining a donor organ. According to Pondrom (2013) sensational media reporting of the incident is believed to have significantly diminished trust in the German transplant system and this has negatively affected the number of organs donated in that country.

2.3.2. Countries with an opt-out system of organ procurement

2.3.2.1. Brazil

An opt-out policy with strong consent was abolished in 1997 because, in practice, most doctors were unwilling to remove organs without the consent of the donor's family. Furthermore, under the opt-out system many Brazilian people feared that their organs may be removed before they were clinically dead – this led to a large number of individuals choosing to opt-out. Another flaw of the opt-out system in Brazil was that the country did not have sufficient infrastructure to maintain a list of those who were unwilling to donate organs, posing challenges for trust in the medical system (Csillag, 1998).

Observation of such realities on the ground prompted the government to introduce a weak presumed consent system, where the preferences of the family would be sought before organ removal (Csillag, 1998). A notable provision of the weak consent process entails that the will of the father of the deceased should prevail. If the father is not available, then the will of other family members will be considered in the following order: mother, son or daughter, and finally, spouse (Csillag, 1998).

2.3.2.2. Singapore

Singapore adopted an opt-out policy, with a strong consent imperative, in 1987. The Muslim population was exempt, based on their religious opposition to organ donation (Kwek, Lew, Tan & Kong, 2009). This meant that there were relatively few organs harvested from Muslim patients and affected the Malay population in Singapore, most of whom are Muslim, and who have a high burden of renal disease (Singaporean Ministry of Health, 2007).

In 2008 the policy was extended to include the Muslim population (Kwek et al., 2009). The rationale behind the extension was in order to try and improve access to donor organs for Muslim people (Singaporean Ministry of Health, 2007). It is interesting to note that the public debate, which preceded legalisation of presumed consent in Singapore, led to a rise in the number of organ donors under

the then opt-in system. Chouhan and Draper (2003) argue that this demonstrated the important role that adequate publicity campaigns for organ donation can play.

2.3.2.3. Belgium

Belgium has adopted an opt-out policy for organ donation which makes use of strong presumed consent. The only instance in which the wishes of family members are taken into account is when they actively oppose organ retrieval after a patient is declared brain dead. However, there is no obligation for Belgium physicians to reveal intentions to remove organs to family members (Michielsen, 1996). The central registry, which carries records of those who have opted-out, is accessible to all transplant coordinators.

2.3.2.4. Spain

Spain has a weak consent opt-out system based on the premise that organ shortage was not due to a lack of willing donors, but rather, to a failure to convert willingness to donate into actual organ donation (Miranda et al., 1999). One aspect of Spanish organ procurement involves transplant coordinators actively seeking out potential donors in relevant intensive care units (ICUs) – rather than waiting for referrals (Min et al., 2010; Miranda et al., 1999). Moreover, when a potential donor is identified, the transplant coordinator must try to persuade the family to give consent, as opposed to merely asking whether they would consider donating organs (Chouhan & Draper, 2003). This system relies on good communication between its relevant stakeholders, and prides itself on providing balanced information about organ donation to the public, through careful media coordination (Chouhan & Draper, 2003).

2.3.2.5. Croatia

Croatia has a system of presumed consent, but family members are always consulted about organ donation decisions. Croatia has also taken steps to integrate their transplant programme by appointing hospital-based and national coordinators (Živčić-Ćosić, 2013). Furthermore, when a person signs up as an organ

donor in Croatia, they will be given priority on the transplant waiting list should they ever require an organ (Muller, 2015).

2.3.3. Some conclusions about international cadaver organ procurement systems

It is evident from the appraisal of procurement systems above that neither opt-in, nor opt-out is obviously superior. Both have their merits and their limitations, and the efficacy of either seems to depend more upon its specific implementation than the macro-considerations of the policy. Those countries that have had the most success (Croatia, Spain, Brazil) appear to rely heavily on communication, coordination and effective national policy.

Communication interventions to improve transplant numbers often took place at two levels simultaneously. The first level was improving public awareness and the second was providing transplant professionals with the communication skills to undertake donation conversations in the hospital setting, as was the case in Spain and Denmark. The policies discussed above suggest that effective transplant communication needs to consider the general public and the role of health workers if it is to promote donation and lead to an increase in transplant numbers.

2.4. INTERNATIONAL CHALLENGES IN ORGAN TRAFFICKING AND COMMERCIALISATION OF ORGANS

Internationally, organ trafficking, transplant tourism and the commercialisation of body parts poses serious challenges to ethical organ transplantation. One of the most common forms of trafficking is transplant tourism, where individuals who are ineligible to receive an organ in their country of residence, or who are likely to die before receiving a donor organ, travel to other countries in order to receive a transplant (Lundin, 2015). These individuals are generally wealthy, and can afford to pay brokerage and medical fees in the transplanting country (Scheper-Hughes, 2014). Organ sellers, and those who have been victims of trafficking often come from impoverished backgrounds, and are promised some type of financial compensation. However, the compensation is not always forthcoming (Lundin, 2015). Because selling organs is illegal in the majority of countries, and because

the vendors are highly vulnerable, those who are exploited have little recourse to legal action (Lundin, 2015).

Manzano, Monaghan, Potrata and Clayton (2014) highlight the complexities of human trafficking for the purpose of removal of organs and organ trafficking. They state that although the Declaration of Istanbul on Organ Trafficking and Transplant Tourism has provided some international guidelines, loopholes in legislation of individual countries allow for trafficked organs to enter the formal healthcare system. This can be through compensation from health insurers and the provision of follow-up treatment. In this way, Manzano et al. (2014) argue that organs are 'laundered', and that it is the guise of legitimacy, which the practice of trafficking takes on, that hinders efforts to identify and reliably report on trafficking cases.

2.5. ORGAN TRANSPLANT IN SOUTH AFRICA

Currently, transplant in South Africa is based on the notion of an altruistic donor (cadaver or living). However, it is poorly regulated and there is no legally mandated oversight body to set norms and standards for transplant practice (Muller, 2015). Each transplant centre in a province has its own operating guidelines, and these may be different across provinces. Furthermore, there is no national or provincial waiting list or donor register. Unlike Belgium, Austria and other countries which are register-dependent, South African waiting lists are maintained at individual transplant centres. Muller, Thomson and McCurdie (2015) argue that the South African cadaver transplant rate is so low due to the impact of religious beliefs, lack of education, lack of transplant coordinators to facilitate the procedure (there are currently 22 transplant coordinators in South Africa) and cultural practices.

2.5.1. Cadaver organ donation in South Africa

Currently South Africa utilises a weak express consent opt-in system for cadaver donation. The South African transplant rate, presented in Table T2.1, suggests that the country is well below the curve when it comes to transplant numbers. The stagnating 4 cadaver transplants per million of population falls far short of numbers boasted by other developing countries with similar weak express consent opt-in policies, like Malaysia, which is considered a developing country. South Africa

performs even worse when compared to developing countries such as Brazil, which have adopted opt-out systems.

If a person in South Africa wishes to be an organ donor they may make this preference known during their lifetime by signing up through the Organ Donor Foundation of South Africa's (ODF) website. Legally, a stated preference to donate organs during one's lifetime is sufficient in South Africa, however Labuschagne (2013) argues that the wishes of a donor family will still be considered for two main reasons. Firstly, common law provides certain rights to a family in terms of the remains of a deceased relative. Secondly, transplant professionals are hesitant to proceed without family consent for emotional reasons.

This highlights one of the anomalies of a weak express consent system. Even if one has signed up as a potential donor, the actual donation must ultimately be authorised by the next-of-kin, who may override the donation preferences of the individual in question (Labuschagne, 2013; National Health Act No. 61 of 2003, Section 62). In a 2013 paper, Etheredge, Turner and Kahn argued that it would be more prudent to ensure that one's next-of-kin are familiar with donation preferences rather than to sign up as an organ donor, because it is the next-of-kin who ultimately make the decision. In a 2005 Brazilian study Barcellos, Araujo and Da Costa found that only one third of study participants would donate the organs of a loved one if they were unaware of their preferences.

Making use of extensive ethical and legal analysis of the South African transplant system, Labuschagne (2013) argues that required response may be the most appropriate cadaver donor procurement system for South Africa. Labuschagne (2013) recommends that required response should take the form of a questionnaire which would be filled out when individuals apply for their driver's licences, passports, identity documents and other official documents. This questionnaire should require that individuals specify whether or not they wish to be a donor and Labuschagne (2013) argues that applications for official documents cannot be lodged until the questionnaire has been completed.

2.5.2. Living organ donation in South Africa

In South Africa, directed donations between family members (blood relatives) are permitted. Directed donations, where individuals are not blood relatives, must be authorised by the Ministerial Advisory Committee (MAC) appointed to oversee organ donation (Veriava & Swanepoel, 2011). One of the main functions of the MAC is to ensure ethical and legal best practice in transplantation. This includes identifying possible coercive or illegal relationships between role-players, preventing trafficking or sale of organs and ensuring altruistic motives (Barday, 2011; Veriava & Swanepoel, 2011). The concept of a team like the MAC is not unique to South Africa, suggesting that coercive forces in transplant are an international problem. In the USA, transplant centres often host a donor advisory team. The main function of this team is to safeguard the best interests of the donor (Choudhury, Jotterand, Casenave & Smith-Morris, 2014).

Slabbert (2009, 2010) and Slabbert and Oosthuizen (2005, 2007a, b) advance compelling arguments for establishing a market for human organs in South Africa. They claim that a regulated market would serve to decrease the incidence of organ trafficking and increase the supply of organs through appropriate donor compensation.

2.5.3. Access to transplant in South Africa

Organ transplant is available to different degrees within the South African healthcare system. According to the ODF (2013a) there are eighteen transplant centres in the country. Of these, eight are state-based and the other ten are private. At face value these numbers do not seem cause for alarm, however when one considers the types of transplant each centre offers, the inequalities in access become clearer (Muller et al., 2015). Of the eight state transplant centres, only one offers adult heart and liver transplant services, and this is based in the Western Cape. This implies that state patients are generally unable to access these services anywhere else in the country. However, adult heart and liver transplant services are provided at four private transplant centres spread across South African metropolitan areas. Similarly, the only state run paediatric heart and liver

transplant centre is based in the Western Cape, posing similar challenges for access (ODF, 2013a).

In 2012 Davids, Marais and Jacobs published the first report of the grant-funded South African Renal Registry. Although related only to renal replacement therapy (RRT) (haemodialysis, peritoneal dialysis and transplant) the report illustrates several injustices in access to such health services, particularly those related to resource constraints. It is clear that these disparities in access are along those lines elucidated in Baldwin-Ragavan, de Gruchy and London (1999). The 2012 report of Davids, Marais and Jacobs illustrates population growth in South Africa, comparing it to the number of facilities providing RRT in the state and private sectors, and also considering the race of individuals who have access to RRT. It becomes very clear that the previously disadvantaged Black African population are still, in the majority, served by the state healthcare sector and that facilities for RRT are greatly limited in this setting. Tables T2.2. T2.3. and Figure F2.4 are taken from Davids, Marais and Jacobs (2012) and illustrate this inequality. This information on RRT is very useful when examining distributive justice in transplant.

Table T2.2 – Population data by ethnic[10] group (Davids, Marais & Jacobs, 2012, p. 11)

This table illustrates South African population data, by ethnic group, during the first eighteen years of democracy. It is interesting to note that the population in all ethnicities has increased, except for people of White ethnicity. This observation is important to enhance the argument that RRT is still substantially more available to White people in the post-Apartheid era than it is to Black African people.

	1994	2012
Black African	30.746	41.625
Coloured	3.461	4.716
Indian / Asian	1.038	1.311
White	5.191	4.622
Total	40.436	52.274

Table T 2.3 – Treatment Centres for dialysis and transplantation in South Africa (Davids, Marais & Jacobs, 2012, p. 11)

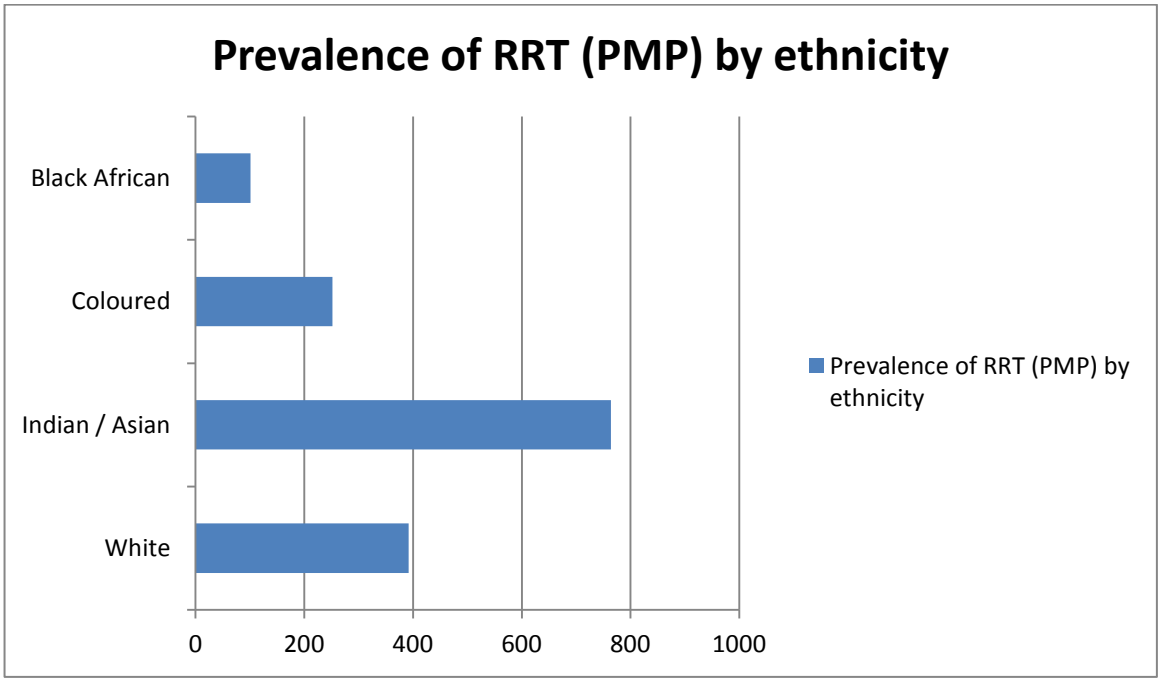
This table demonstrates the extent to which access to RRT has increased in the state and the private sector during the first eighteen years of democracy. Note that RRT has increased by 3160% in the private sector, and only by 7.7% in the state sector. When one considers that the state sector serves the majority of the population, it becomes clear that the vast increase in RRT facilities in the private sector is iniquitous.

	1994	2012	% increase
State sector	26	28	7.7
Private sector	5	163	3160
Total	31	191	516

[10] Terminology taken from the reference itself.

Figure F2.4: Prevalence of RRT (per million population) by ethnicity (Davids, Marais & Jacobs, 2012, p. 16)

The figure below illustrates the number of individuals per million population who are currently accessing RRT in South Africa. The figure shows that the Black African population – who form the majority of the country – are the least able to access these services. This is ironic because the burden of chronic renal disease in this population is worryingly high.



2.5.4. Organ allocation in Gauteng

Gauteng transplant is dominated by the private sector and inequalities are evident. Of the eight provincial transplant centres, three are state-based and the other five are private. It is not possible to obtain a heart or lungs through a state-based programme as they specialise in kidney transplantation only. It is sometimes possible for a state patient to obtain a liver in the private sector through public-private partnerships (ODF, 2013a).

As organ transplant is regulated on an *ad-hoc* basis, allocation policies vary provincially. The allocation of organs to specific potential recipients is ideally based on criteria of fairness, with priority given to recipients who require a transplant urgently (Fourie, 2011). In Gauteng, these factors are considered, as well as the organ size, immune compatibility and the proximal location of the donor relative to the recipient (Muller, 2013).

Kidneys are generally allocated in turn between the private sector and the state sector Britz & Crymble, 2011). Muller (2013) notes that the allocation of donor kidneys in South Africa runs according to a points system, and this process is relatively straightforward. However, as the waiting lists for other organs are much shorter than the kidney list, these are allocated by physicians according to various criteria. Livers are allocated on the basis of the location of the donor. There are also aspects of sharing to take into account, as a liver can be divided into two. As there are no state liver transplant programmes in Gauteng, liver lobes are only available to state patients if they are listed and if they have negotiated surgical services in the private sector. State patients are not generally listed for heart and lung transplants as these are not available in the state sector in Gauteng. Hence, hearts and lungs are allocated to listed individuals in the private sector, irrespective of whether the donor organs originate from a state or private hospital.

2.6. SOUTH AFRICAN TRANSPLANT RESEARCH AND THE TRANSPLANT CONTEXT

A small number of studies have been undertaken in South Africa which explore attitudes towards organ donation. They consider aspects like religious beliefs, social structures, donation awareness and cultural practices, all of which are also considerations in international settings, as Section 2.3 has shown. The results of these studies may go some way towards accounting for the low transplant rate in this country. The studies have been summarised in Table T2.5.

2.6.1. Willingness to donate organs

The findings of studies, detailed in Table T2.5, suggest there is a willingness amongst the samples to consider organ donation. This was particularly evident in quantitative investigations. However, this finding must be considered in light of a limitation of the quantitative research presented: very few participants had personal experience of organ donation or transplant, so their views may be hypothetical and could be a source of bias. It is possible that preferences will change when individuals are involved in an actual situation.

Table T2.5: South African studies on attitudes and knowledge about organ donation

#	Study Authors	Methods	Willingness to donate	Influence of religion	Knowledge about transplant	Limitations
1	Pike, Odell and Kahn (1993): *Public attitudes to organ donation in South Africa*	- Quantitative - 2,125 urban participants - 625 rural participants - Interviewer-administered questionnaire	- 82% willing to donate own organs - 78% willing to donate organs of a relative	- Christian teachings may have influenced attitudes of rural respondents	- Misconceptions and lack of knowledge in study population	- Long time frame - Not representative
2	Bhengu and Uys (2004): *Organ donation and transplantation within the Zulu culture*	- Qualitative study - Traditional healer - Transplant coordinator - Urban and rural lay-people	- Preference for donating to relatives over non-relatives or strangers - Needed to know donor preference for fear of displeased ancestral spirit - More willing to receive transplant than donate organs		- Misconceptions - Lacking knowledge - Education better provided by respected elders than the media (which was considered 'remote')	- Some sections of study population poorly represented
3	Van den Berg (2005): *Organ and Tissue Donation and Transplantation: A perspective of South African Baptists from the Baptist Northern Association and its implications for preaching*	- Quantitative study - 67 participants - Baptist study population - Self-administered questionnaire.	- 69% in favour of organ donation - 76% willing to donate organs of a relative - 23% unwilling to donate because of Netcare St. Augustine's Trafficking Scandal (Section 2.6.3.1)	- Were aware that Baptist scripture condones organ donation		- Single religion sample possible source of bias
4	Buthelezi and Ross (2011): *Gift of life or cultural taboo: Effects of an educational pamphlet on*	- Qualitative - 18 university students - Open-ended study instrument	- More willing to consider cadaver donation than living donation - More willing to donate to	- Christianity favours donation	- Entire sample aware of donation	- Entire sample aware of donation, could be source of bias

	young adults' knowledge and attitudes regarding organ donation	- Interventional study design	strangers than known individuals.			
5	Etheredge, Turner and Kahn (2013): *Public attitudes to organ donation among a sample of urban-dwelling South African adults: a 2012 study*	- Based on 1993 study (#1 above) - Qualitative - 1,048 participants - Representative of 5 major metropolitan (urban) areas of South Africa - Interviewer-administered questionnaire	- 77% would accept transplant - 70% would donate own organs - 67% would donate organs of relative	- Islamic participants slightly less willing to donate	- Majority had heard of donation - Television, word of mouth and magazines main sources	- Unsure if participants understood questions - Unable to probe contradictory responses - No rural participants
6	Etheredge, Turner and Kahn (2014): *Attitudes to organ donation among some urban South African populations remain unchanged: A cross-sectional study (1993 - 2013)*	- Statistical analysis - 2 data sets (1993 and 2013 – #1 and #5 above) - Considered changes in attitudes	- Less willing to donate organs of loved one without knowledge about preferences in the 2013 study than in the 1993 study. - Black African study population more willing to donate kidneys, less willing to donate heart, lungs and cornea in the 2013 study than the 1993 study. - More willing to receive transplant than donate organs			- Different sample sizes across studies - Different sampling strategy across studies - Different participants across studies

This variation in preferences is perhaps explained by the economic theory of dynamic inconsistency (Crain, 2004). The theory notes that the preferences of individuals change according to circumstances and depending on the context.

This observation is interesting when compared to the Spanish transplant experience, where the population seemed willing to donate, but this willingness did not translate into actual referrals and donation. It may be possible that this is happening in South Africa, and hence an exploration of transplant practices at the coal face – like the research reported in my thesis – is warranted and necessary.

2.6.2. Knowledge about organ donation

The results of studies in Table T2.5 suggest that knowledge about organ donation varied across study populations. In South Africa there are a small number of institutions and motivated individuals whose aim is to promote awareness of organ donation. The most prominent of these are the Organ Donor Foundation and the National Kidney Foundation. However, many transplant teams and centres also endeavour to educate the public. A number of channels are utilised with varying degrees of success. These include print media, social media, television, awareness days, seminars for healthcare professionals and community interventions (ODF, 2013b).

Literature suggests that promoting awareness about organ donation through the media and other educational means is important (Blok, 2006; Etheredge et al., 2013; Muller, 2013; Buthelezi & Ross, 2011). However, the efficacy of media channels in promoting organ donation is in dispute, and many question whether this is the most suitable way to increase awareness of it (Callender & Miles, 2010; Davis & Randhawa, 2004; Etheredge et al., 2013). In spite of these concerns, effective media campaigns appear to have been essential in increasing organ donation rates in both Singapore and Spain.

2.6.3. The effects of organ donation scandals

Van den Berg (2005) reported that a percentage of the study population were unwilling to consider organ donation due to the Netcare St Augustine's Hospital Kidney Trafficking Case (Netcare Case). This is an interesting finding, because it is

the only published South African research study where participants have reported that the case affected their attitudes to organ donation. At this point, it is prudent to consider the effects which such scandals have on transplant. Like Great Britain and Germany, South Africa has been involved in transplant scandals. Two high profile cases appear to have impacted upon organ transplant in South Africa. These are the Netcare Case and the Manto Tshabalala-Msimang liver transplant scandal. These cases are relevant to my research and the purported facts of each will be detailed in turn.

2.6.3.1. The Netcare St Augustine's Hospital Kidney Trafficking Case

In 2003 it was reported that 109 illegal kidney transplants had taken place at St. Augustine's Hospital in KwaZulu-Natal ("SA hospital pleads guilty", 2010). The recipients of these kidneys were wealthy Israelis who paid approximately US$ 120 000 (ZAR 1,08 million) to a transplant brokerage company (Hassan & Sole, 2011). The initial 'donors' of these organs were Israeli citizens who were paid approximately US$ 20 000 (ZAR 180 000) each. Subsequently, cheaper 'donors' were sourced from Brazil and Romania, and were paid on average US$ 6 000 (ZAR 54,000). Five of the 'donors' were children ("SA hospital pleads guilty", 2010). 'Donors' were flown to South Africa and underwent brief pre-transplant work-up followed by the surgical procedure. Post-transplant, 'donors' were immediately transported back to their country of origin with little or no postoperative care. They were unaware that many years of donor follow-up were required (Veriava, personal communication, 2010).

Following a lengthy investigation, Netcare South Africa and five South African doctors were charged with performing illegal kidney transplants. Netcare pleaded 'not guilty' to the charges ("Five doctors have been charged", 2010). However, when the case went to trial in 2010 the company entered a guilty plea, paid a ZAR 4-million admission of guilt fine and agreed to a ZAR 3.8-million confiscation order. Netcare has consistently maintained this was a technical plea and is not an acknowledgement of wrongdoing (Hassan & Sole, 2011). Based on the grounds of insufficient evidence, the four accused doctors were not prosecuted ("Kidney docs want justice", 2012).

2.6.3.2. The Manto Tshabalala-Msimang liver transplant case

On March 14, 2007, South African Minister of Health, Manto Tshabalala-Msimang[11] received a liver transplant in Johannesburg, Gauteng. Tshabalala-Msimang lived with her transplanted liver until December 16, 2009, when she died from graft-related complications.

The Sunday Times first broke the news about Tshabalala-Msimang's liver transplant, with a headline reading: "Manto's hospital booze binge" (August 12th 2007). The article presented the results of an investigation which began when Tshabalala-Msimang was hospitalised for shoulder surgery in Cape Town in 2005. The report suggested that Tshabalala-Msimang was not only a demanding patient who wielded her political power over hospital staff, but also that she consumed a large amount of alcohol whilst hospitalised. Furthermore, the report suggested that Tshabalala-Msimang was not eligible to receive a liver transplant in 2007, because she was suffering from alcohol-induced liver cirrhosis rather than auto-immune hepatitis (stated as the indication for transplant on her medical records). Tshabalala-Msimang was 66 years old at the time, and whilst age is not an absolute contraindication for liver transplantation, the Sunday Times argued that this, combined with her drinking habits, rendered Tshabalala-Msimang an unsuitable candidate for organ transplantation. The donor for Tshabalala-Msimang's 2007 liver was said to be a teenager who had committed suicide (Maker & Power, 2007).

2.6.4. Socio-cultural aspects of organ donation in South Africa – comparing international and local research findings

A large number of international studies have been undertaken which explore the socio-cultural aspects of organ donation. These often conclude that cultural (Danielson, 1998) or religious (Sharif et al., 2011) factors influence attitudes towards donation, as was the case in South Korea. However Morgan, Hooper,

[11] During her time as Minister of Health (1999 – 2008), Tshabalala-Msimang proved to be a controversial figure. Along with then-President Thabo Mbeki, Tshabalala-Msimang questioned the link between the HIV virus and AIDS, prompting an era of AIDS-denialism, which is thought to have affected the rollout of Highly Active Antiretroviral Therapy (HAART) for HIV infected South Africans. Tshabalala-Msimang refused to endorse the use of nivirapene prophylaxis for HIV-infected pregnant women and also blocked US funding for the rollout of HAART in Kwa-Zulu Natal (Beresford, 2010).

Mayblin & Jones (2006) argued that unwillingness to consider organ donation cannot be attributed to religious or cultural orientations and were shaped by more complex perceptions of life and death. Furthermore, Goolam (2001) suggests that issues at the beginning and the end of life are linked with the complex worldview of a group or groups of people. He argues that organ donation, being inextricably linked with both the end of one life and the prolonging of another, ought to be subjected to rigorous multicultural analysis.

Hence, international transplant literature suggests that whilst certain traits of different groups may influence willingness to donate, these are never absolute and other factors also need to be considered. However in spite of this a substantial amount of South African transplant research focuses on aspects like religion, culture and race and sometimes seems to overlook the more complex nuances of transplant, which my study proposes to address by considering transplant practice at the coal-face.

2.6.4.1. Organ donation and ancestral relationships

Bhengu and Uys (2004) note the importance of ancestors in the context of death and dying. Many Black African cultures, it is argued, are opposed to organ donation because there is a mandate that the deceased will join his or her ancestors in the life hereafter. It is important that the body of the deceased is whole for this transition. There is concern that if a family gives their consent to donate the organs of a deceased loved one, his or her ancestral spirit will be displeased and will be unable to rest. Thus, the spirit may return and haunt those still living in retribution for the removal of the organs. Other South African research which explores such attitudes and beliefs will be considered in Chapter 4.

2.6.4.2. Organ donation and religion

Gillman (1999) notes that most major religions endorse organ donation to some extent, and none absolutely condemn it. In South Africa it appears that Christian individuals may be willing to donate (Buthelezi & Ross, 2011; Pike et al., 1993; Van den Berg, 2005) and Islamic individuals slightly less so (Etheredge et al., 2013). However, the example of South Korea illustrates how important it is not to

generalise these findings across a population. Whilst the majority of South Koreans follow Confucianism, a religion that is thought to be anti-organ donation, the country still has a remarkably high transplant rate in comparison to South Africa. This comparison suggests that even in countries which one would expect to have preclusions to organ donation based on religious and cultural grounds, these can be overcome. For instance, South Korea's attempts to utilise the Spanish system of intensive communication and vigilant donor identification, whilst imperfect, may have had a positive influence on transplant numbers in that country. The experience of these two widely differing countries suggests that some accepted preclusions can be overcome by considering micro factors which influence organ transplant. My thesis proposes to explore some of those factors.

2.6.4.3. Family structure and organ donation in South Africa

A large amount of literature, some of which will be considered in more detail in a subsequent chapter, outlines the perceived patriarchal structure of Black African families, typically with an elder male as the principal decision-maker (Bell, 2002; Green, 2000; Kometsi & Louw, 1999; Reyneke, 2014). Bhengu and Uys (2004) found that the isiZulu speaking people of South Africa consider female relations as subordinate within the community. Whilst participants felt it was preferable that the extended family was involved in making a donation decision, male family members took a more prominent role in this process. In terms of willingness to donate there is some contradiction between Bhengu and Uys's (2004) study which found that related donation would be preferable and Buthelezi and Ross's study (2011) which found that donation to a stranger would be preferable. Donation literature suggests that findings from Buthelezi and Ross's (2011) study in this regard are implausible, as living people rarely donate organs to strangers (Truog, 2005).

The influence of family structure on organ donation has been explored in both America and Brazil. In their American study, Terrell, Moseley, Terrell and Nickerson (2004) found that African-American women were less willing to consider donating the organs of a relative. They speculated that this may be due to the traditional role of women in the family. As men were perceived as the decision-makers,

female family members did not feel empowered to make decisions about organ donation. In a Brazilian study which was discussed previously, Csillag (1998) noted that decision-making legislation for organ donation deferred to the eldest male family member, and thereafter to other family members. However, when the transplant rates of Brazil and the USA are compared it does not appear that family structure is a significant barrier to organ donation, and that it can be managed through thoughtful policy.

2.7. SUMMARY AND CONCLUSION

This chapter has aimed to explore organ donation from an international perspective, considering some of the fundamental tenets which underlie transplant policies. It has explored the efficacy of policies adopted by different countries and it has shown that South Africa lags behind its international counterparts in terms of the number of cadaver organ transplants performed per year.

Through a comparison of international and South African research it has become clear that whilst factors like transplant scandals, family structure, religious and cultural practices and knowledge about organ donation are common international barriers to transplant, these have been overcome to an extent in countries similar to South Africa. This is borne out in the transplant per million population number detailed in Table T2.1. Although social, religious and cultural factors cannot be ignored, it is surprising that South African transplant numbers are so low. This suggests that in order to account for the current state of transplant, one must look elsewhere for explanations and answers. My research project proposed to do this by considering communication and transplant from the perspective of those most immediately affected by it, those at the coal-face, as it were: the donors, recipients and transplant professionals. In order to fully understand Gauteng transplant at a grassroots level, it is essential that the structure of healthcare institutions within, and across which, transplant takes place is discussed. This will be the focus of the next chapter.

Chapter 3: Healthcare institutions – structure and interprofessional relationships

3.1. INTRODUCTION

The introduction of this thesis, along with Chapter 2, explored the South African healthcare system. The healthcare system was shown to be permeated by inequalities in terms of access to services and the quality of services provided. Because transplant takes place within institutions positioned in this system, it is now important to consider the structures of these institutions and how these structures manifest themselves in healthcare. This chapter will also consider some international research detailing the impact institutional structure may have on transplant.

This chapter begins by considering the healthcare hierarchy at an institutional level. The healthcare hierarchy is vital, because this thesis will show that it affects interprofessional transplant communication across both state and private health sectors in a number of ways. Secondly, this chapter will explore the concept of moral distress in the healthcare setting. In this thesis I will argue that moral distress in Gauteng transplant is a function of the healthcare hierarchy as it manifests itself within an unequal health system, and one where challenges to care provision are overwhelming. Finally, this chapter will discuss some important studies which illustrate the interplay of the health hierarchy and moral distress in the South African healthcare setting.

3.2. THE HEALTHCARE HIERARCHY

Much has been written about the concept of hierarchy in healthcare. Medical professionals are often perceived, or perceive themselves, as being superior to allied professionals, based on factors like the length of studies towards their degree, the advanced skill sets required and the complexity of their professional role (Galandiuk, 2013; Lupton, 2003; Porto & Lauve, 2006). Allied professionals are

often perceived, and perceive themselves, as 'lesser' than medical professionals (Lupton, 2003). This sentiment seems related to feelings of inadequacy, observations of a less complex role and situational power, authority and gender imbalances (Felblinger, 2008). According to the political economy perspective (Lupton, 2003), medical professionals take positions of power in both healthcare organisations and in society. Given the nature of their training and qualifications, medical professionals are assumed to be intelligent and wealthy.

This hierarchy is then entrenched through modes of social constructionism. Social constructionism is a popular sociological theory which questions the value of paradigms which society appears to take for granted. Social constructionism would argue that medical professionals are only seen as superior to allied professionals because society is organised in such a manner as to bestow power on some roles and not on others (Lupton, 2003). Because our society is organised to value wealth, productivity and justice, masculine values dominate. Because, traditionally it is men who become doctors, dominant male values are associated with being a doctor. Thus, male doctors, who are considered to be dominant in society, also take a position of relative prominence within their institution and profession (Lupton, 2003).

Allied professionals may assume a more submissive role, which both acknowledges their feelings of inferiority and entrenches the conventional hierarchy (Lupton, 2003). Similarly, medical professionals may view allied professionals as lesser than themselves. Because this hierarchy is accepted, it further ingrains power differentials. In short, and as my thesis will show, power asymmetries are accepted as the *status quo* in healthcare practice, and the attitudes and interactions of individuals in recognising and relating to conventional hierarchies serve to maintain the imbalance.

Lupton (2003) locates the essence of the healthcare hierarchy as a convergence of asymmetries in status, gender and the types of tasks performed. She argues that whilst more females are entering the medical profession, the majority of medical specialists are still male. The majority of nurses are female, with very few men entering the profession of nursing. Thus, nurses are linked to 'feminine' values

such as caring and giving; and some of their daily tasks can be considered menial and unpleasant.

In practice, academic literature suggests that the healthcare hierarchy may result in aggressive and disrespectful interchanges between medical and allied professionals, and between medical professionals themselves (Katz, 2006). A study on bullying behaviours in the workplace found that nurses who were on the receiving end of bullying behaviour did little to mitigate the situation (Felblinger, 2008). Rather, they would often choose to accept it within the framework of shame. This feeling of being shamed resulted in attitudes of "self-blame" and "avoidance" which were seen as psychologically damaging (Felblinger, 2008, p. 238). Furthermore, in Paris et al.'s 1995 study, allied healthcare professionals were found more willing to compromise and act diplomatically than were medical professionals. In a nursing article, May (1992, p.475) argues that nurses categorise medical professionals as either "good" or "bad" based on the manner in which they exercise power in the clinical encounter. Doctors were seen as having an ability to either facilitate or hinder the professional practice of nurses. In the case where this was hindered, it was argued that nurses felt unable to exercise professional autonomy.

The above consideration of the healthcare hierarchy portrays an environment that is ripe for conflict, where medical professionals may act in an unprofessional manner towards allied professionals, and this will be largely accepted. This is vital for my research, the results of which were permeated by considerations and acknowledgements of hierarchy. Furthermore, my thesis will show that the healthcare hierarchy in Gauteng transplant is a contributor to moral distress.

3.3. MORAL DISTRESS

The healthcare hierarchy has strong links to, and influences on, moral distress which is a pivotal ethical theory in my thesis and crucial to understanding the significance of my research findings.

Moral distress was first defined by Jameton (1984, p.6) who noted that: "Moral distress arises when one knows the right thing to do, but institutional constraints

make it nearly impossible to pursue the right course of action". This definition was refined by Nathaniel (2002[12], cited in Austin, Lemermeyer, Goldberg, Bergum, & Johnson, 2005, p.34): "Moral distress is the pain or anguish affecting the mind, body or relationships in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility and makes a moral judgement about the correct action; yet, as a result of real or perceived constraints, participates in perceived moral wrongdoing". Austin (2012) notes that moral distress describes the sensation of frustration and failure when health professionals feel unable to fulfil their fiduciary duty to their patients.

Academic literature on moral distress appears primarily located in the field of nursing (Burston & Tuckett, 2013; De Veer, Francke, Struijs & Willems, 2013; Range & Rotherham, 2010). Austin et al. (2005) argue that this orientation towards nursing is based on the caring role which nurses take on. This argument relates to the healthcare hierarchy, particularly the perception of nurses (female) as carers and the apparent powerlessness of allied healthcare professionals. However Austin et al. (2005) argue that moral distress is not unique to nursing, and that it has been identified as a factor in other aspects of medical practice. Førde and Aasland (2013) reported that medical professionals who worked in less specialised hospital positions experienced moral distress. Similarly, St Ledger et al. (2013) and Hamric and Blackhall (2007) found moral distress amongst doctors.

Austin et al. (2005) present an overview of moral distress for nurses based on a synthesis of literature and research. They argue that though obvious ethical dilemmas such as withdrawing life-sustaining treatment or assisting in late-term abortion arise regularly in practice, there is a more subtle type of moral decision-making which nurses undertake on a daily basis. This decision-making involves continuous demands for judgement and the need to balance obligations in order to satisfy various parties who have a claim on their work. These ethical challenges are embedded in context and time, they are framed by relationships with patients and medical professionals and take place within an institutional structure. Austin (2012) argues that these ethical challenges are becoming more complex as medical

[12] I have been unable to locate the original article.

technology advances. Within these frameworks and contexts, nurses may experience moral distress as they are unable to fulfil the mandate of caring due to internal and external constraints (Austin et al., 2005).

Internal constraints on acting in the manner one deems ethically appropriate are related to fear, self-doubt and a lack of courage to stand up for oneself, which is a function of the hierarchy. This suggests implications for professional autonomy (May, 1992) and may be related to nurse socialisation and the mandate of following orders, which is embedded in an institutional hierarchy where nurses are often subordinate to medical colleagues. External constraints include resource and staff shortages as well as hospital policies. Interestingly, these are often directed by the socio-economic policies of the country in which one practices, thus the larger socio-political context cannot be ignored in moral distress discussions (Austin et al., 2005; Varcoe, Pauly, Webster & Storch, 2012). For instance, a lack of resources has been identified as a cause of moral distress in both Malawi (Maluwa, Andre, Ndebele & Chilemba, 2012) and Uganda (Harrowing & Mill, 2010). South Africa has a unique socio-political context and this has its effects on transplant practice. My thesis will show how the South African context can heighten moral distress for transplant professionals.

Austin (2012) argues that an acknowledgement of hierarchy is vital to understanding moral distress. It appears that the power healthcare practitioners hold is bestowed upon them by the systems within which they function. This may explain why nurses and doctors experience moral distress differently. Whilst nurses may be functioning at a subordinate level and dealing with conflicting obligations to the institution, patients and medical professionals, doctors at the top of the hierarchy felt moral distress when society perceived that they were not performing their role adequately. Lutzen and Kvist (2012) and Varcoe et al. (2012) argue that moral distress must account for the relational circumstances and context in which interactions and decision-making take place. It is likely that the healthcare hierarchy, with its attendant tensions, contributes to this context.

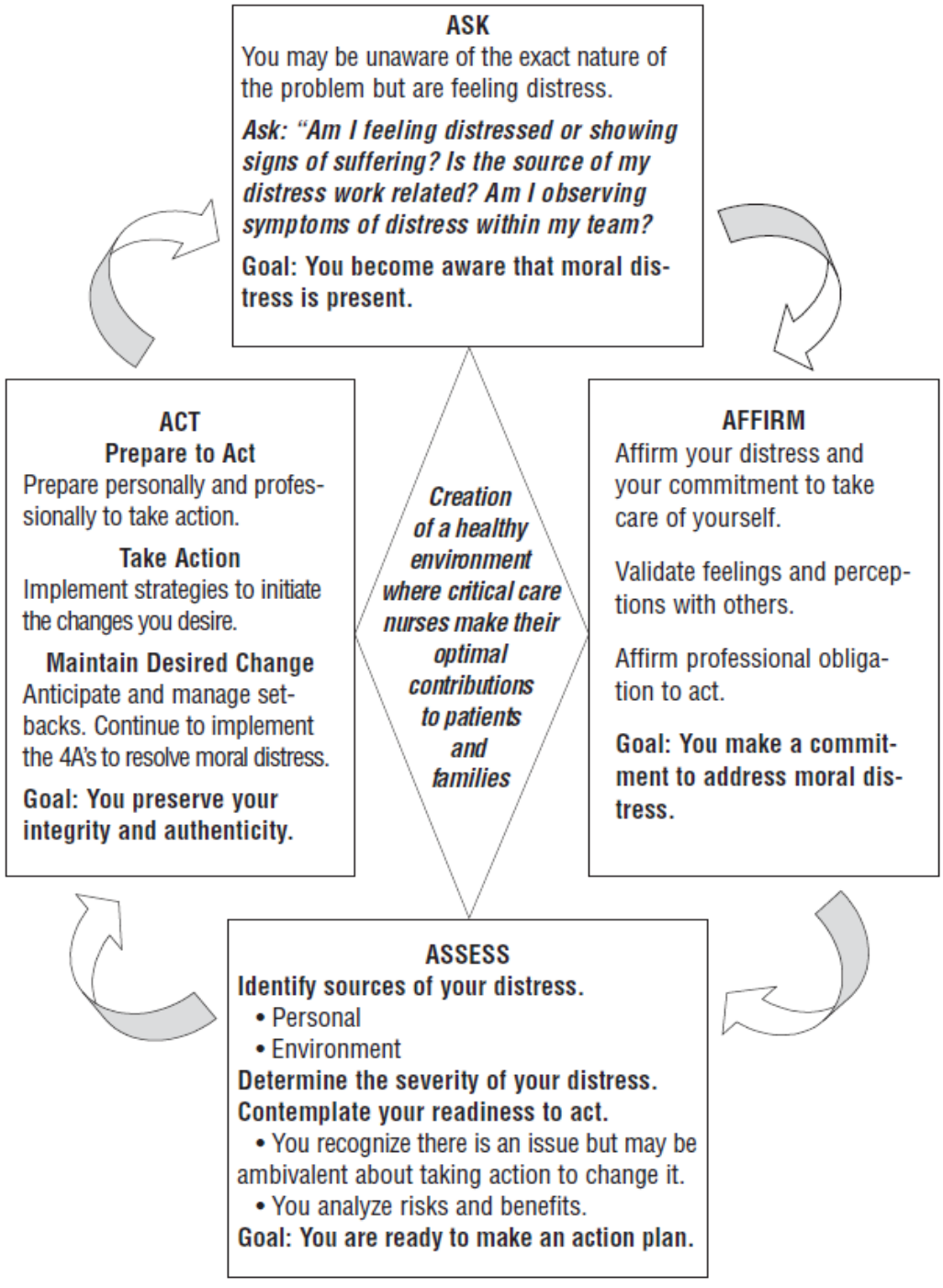
3.3.1. Moral distress in transplant

The concept of moral distress in an intensive care or critical care setting has been examined extensively (Gutierrez, 2005; Rushton, 2006; Schluter, Winch, Holzhauser & Henderson, 2008). As transplant takes place in these critical care environments much of this literature may be highly relevant to transplant practices. End-of-life decision-making that accompanies transplant is often seen as a source of moral distress, as are the extreme mechanical measures sometimes required to maintain life (Corley, 1995). In many studies, transplant is mentioned in passing, though little discussion or critical appraisal is forthcoming (Beca & Astete, 2011; Ersoy & Akpinar, 2005). Nierste (2013) notes that nurses may experience moral distress throughout the process of caring for transplant patients and their families. However, Nierste (2013) writes from a Christian perspective and there may be an element of religious bias in the work.

In a policy recommendation article, Roels, Spaight, Smith and Cohen (2010) argue strongly that moral distress is highly relevant in transplant and has significant implications which extend beyond job satisfaction and staff retention into the realm of personal beliefs and transplant context. To this end, a small number of studies have considered moral distress and transplant in a more critical fashion.

Milliken and Wall (2014) present a case study where a patient is approaching brain death and a nursing sister requests the attending doctor to call a transplant coordinator. The attending doctor is unwilling to comply with the nurse's request because he or she wishes to have an end-of-life conversation with the family. In this case, the nursing sister experiences moral distress because she is unable to initiate a course of action which she believes is ethically correct – giving the family an opportunity to make a decision about organ donation (Milliken & Wall, 2014). In commentary on the case, Milliken and Wall (2014) advise that health professionals in these situations should consider recommendations from the American Association of Critical Care Nurses (AACN, 2004, p.2) who advise four A's for coping with moral distress – ask, affirm, assess and act. The four A's are depicted in Figure F3.1.

Figure F3.1 – The four A's of moral distress (AACN, 2004, p.2)



Milliken and Wall (2014) conclude that the nursing sister is justified in any remedial action she feels necessary as she is vulnerable in this scenario, because of the health hierarchy.

Mandell et al. (2006) conducted focus groups with a large number of medical and allied transplant professionals. Moral distress was identified as a significant theme at the time when referral for donation and maintenance of the donor needed to take place. Moral distress appeared to be based on a lack of guidelines and protocols which caused confusion for participants. As the previous chapter showed, transplant in South Africa is poorly regulated, and such guidelines and protocols are also lacking in the Gauteng context. Wiegand and Funk (2012) show that nurses experienced moral distress when considering healthcare for *future patients* (potential transplant recipients). One nurse who participated in the study was hesitant about organ donation because of a concern that the potential donor was HIV positive. Pearson, Robertson-Malt, Walsh and Fitzgerald (2001) identified elements of moral distress amongst intensive care nurses managing brain-dead donors, though these are not explicitly acknowledged as such. They note that nurses felt uncomfortable maintaining brain-dead donors because there was an acknowledgement that the patient was dead but there was an obligation to treat that patient as though still alive.

3.3.1.1. Moral distress in tissue transplant patients

Begley and Piggott (2013) consider moral distress and how it may influence siblings in making decisions of whether or not to donate stem cells to another sibling – the pre-transplant process. Stem cells constitute human tissue, and tissue donation is less risky than organ donation because tissues regenerate. Begley and Piggott (2013) argue that an individual may feel moral distress if he or she is unable to fulfil the mandate of donating stem cells to a sibling. This mandate will either be unfulfilled because the individual is not a good match, or because of another contraindication to donation. Begley and Piggott (2013) emphasise that moral distress can only be experienced in an agent who is constrained from acting in a way which he deems morally correct. Thus, a transplant coordinator in this type of

situation may experience *moral stress* in trying to facilitate dialogue and balance opinion between siblings who can and cannot donate stem cells. However, a coordinator does not experience moral distress because although the behaviour of the other siblings prevents facilitation of a transplant for the potential recipient, this is not a moral choice made by the coordinator, it is simply the result of situational circumstances (Begley & Piggott, 2013).

3.3.1.2. Gaps in organ donation and moral distress literature

As this section has clearly highlighted, moral distress is well recognised in the pre-transplant process (which will be discussed in more detail later in the literature review, Section 3.3) when referral of donors, brain-death and donor maintenance are considered. However, there appears to be very little literature considering moral distress at other points of the transplant process, such as when caring for potential recipients pre-transplant and in the surgical phase.

3.4. THE HEALTHCARE HIERARCHY AND MORAL DISTRESS IN SOUTH AFRICA

This chapter aimed to describe two key concepts of my research, namely the healthcare hierarchy and moral distress. In each case literature has been cited, however this is seldom from South Africa, and so it does not account for context. Whilst the interplay of these two concepts in the South African transplant context has not previously been explored, a number of studies which identify moral distress have been undertaken (Jewkes, Abrahams & Mvo, 1998; Langley, Schmollgruber, Fulbrook, Albarran & Latour, 2013; Runkel, 2013; Van Waltsleven, 2014). A broader discussion of some of these studies is warranted here because they demonstrate the interaction between moral distress and the health hierarchy in a South African context.

3.4.1. Moral distress and the health hierarchy in relations with patients

A study by Jewkes et al. (1998), set in the Western Cape province of South Africa, comprised an analysis of 103 semi-structured interviews and extensive

ethnographic observation, with nurses and patients across three obstetric clinics. The study findings are contextualised within South Africa's hierarchical Apartheid history, and the authors argue that this has significantly impacted the role and perceptions of nurses in the country today. A difference between the Western Cape Province where Jewkes et al. (1998) did their study, and my research setting, is that the Western Cape is known to have better-resourced health services, hence it is possible that results from similar work in a Gauteng setting could be even more marked.

A rigid healthcare hierarchy dominated research findings in Jewkes et al. (1998), with nurses at the top of the pinnacle and patients at the bottom. This is different to the hierarchy which will be elucidated in this thesis; however, the previous section has demonstrated that the formative trends of this hierarchy (power relations in society, education levels) are similar. Interestingly, nurse participants felt the hierarchy permeated beyond the clinic setting, and that they were generally belittled by the community. The authors did not acknowledge that this finding may have implications for a social constructionist view of the hierarchy where societal perceptions and values transpose into institutional rank and file.

Jewkes et al. (1998) found that nurses frequently abused patients. The actual abuse which patients suffered may be indicative of moral distress experienced by nurses in their working environment. The study reported that nurses felt unsupported and that they were blamed for problems at the clinic. This resulted in a sense that poor outcomes were inevitable and served to damage morale. This finding seemed linked to resources, where a better-resourced study site in the sample reported less abuse of patients, possibly suggestive of a less morally distressing environment. Austin (2012) found that doctors felt moral distress based on societal perceptions of professional failure. This may be the case for nurses here, especially because, at one of the study sites, there was a community perception that nurses were abusive and untrustworthy.

Through considering Jewkes et al. (1998) it is clear that the healthcare setting in South Africa is influenced by the societal hierarchies which permeate it. These societal hierarchies, combined with a lack of resources and support, then produced

feelings of moral distress which manifested themselves in low nurse morale and patient abuse. My thesis will similarly show that the healthcare hierarchy in transplant can lead to moral distress and aggressive behaviour which can be traced along hierarchical levels.

3.4.2. Moral distress and healthcare hierarchy in interprofessional relations

Research on moral distress, or which identifies moral distress amongst nurses in South Africa, appears to be increasing, with a number of recent studies which explore it in depth (Langley et al., 2013; Runkel, 2013; Van Waltsleven, 2014).

Runkel's (2013) study took place in a private hospital in the Gauteng province, and hence the study context is likely to be very similar to mine. Utilising six semi-structured interviews and three naïve sketches, Runkel (2013) aimed to explore the experiences of critical care nurses after involvement in a sentinel event. A sentinel event was defined as an adverse event that occurs in a health setting as the result of a mistake or a deliberate nursing error, which causes serious harm to the patient and is unrelated to the patient's disease progression. Given similarities between study settings, it is noteworthy that Runkel (2013) found one of the consequences of a sentinel event was moral distress amongst nursing staff who had been involved. However the results of Runkel's (2013) study are not strongly linked into a moral distress paradigm. Features of the health hierarchy and its role in creating moral distress are evident in the findings. Nurses who participated recounted being blamed by medical professionals for the sentinel event, and stated that medical professionals sometimes considered nurses to be: "… incompetent or dumb…" after their involvement in a sentinel event (Runkel, 2013, p.44). Such situations where nurses felt they were being blamed then led to negative feelings such as prolonged guilt and anxiety.

Van Waltsleven (2014) conducted a study with nine professional nurse participants from the Northwest Province in order to develop and validate an instrument with which moral distress in nursing can be measured. The study made use of qualitative methods, semi-structured research interviews and focus groups. The

study population was drawn from the North West Province of South Africa. Like Jewkes et al. (1998) and Runkel (2013), Van Waltsleven (2014) identified factors which suggested that a hierarchy in the South African health setting can cause moral distress. The results of this moral distress were identified as high staff turnover, decisions to leave the nursing profession and overall job dissatisfaction. To this end, a number of questions in Van Waltsleven's (2013) study validated a moral distress instrument to address the notion of hierarchy. For instance, whether nurses feel doctors value their opinions about patient care, whether nurses feel they can advocate on behalf of their patients and whether nurses feel that their skills are valued (Van Waltsleven, 2014, p.42). All of these aspects related back to the healthcare hierarchy, and my research will show that during the transplant process similar themes of moral distress develop. The opinions of allied professionals are not readily solicited by medical professionals and allied professionals perceive patients as having little faith and trust in their medical skills.

It is interesting to note the differences in manifestations of the health hierarchy across contexts. In a 2012 Danish study, Rabøl, McPhail, Østergaard, Andersen and Mogensen explored hospital team communication utilising four focus groups with medical and nursing staff. In the Danish setting, a "flat hierarchy" was found (Rabøl et al., 2012, p.133). The authors noted that nursing staff felt they were able to easily communicate with medical staff, and that medical staff were comfortable communicating with nurses. One factor which may account for this difference is the setting. In South Africa, the hierarchy appears deeply ingrained, whereas in Denmark there may be greater equality between health practitioners.

3.5. SUMMARY AND CONCLUSION

This chapter aimed to demonstrate some relevant structures of the South African healthcare setting and it utilised a number of research studies (Jewkes et al., 1998; Runkel, 2013; Van Waltsleven, 2014) to show how the healthcare hierarchy and moral distress relate in a uniquely South African context. It considered international studies which have explored moral distress in transplant and which concluded it is a significant factor.

In Jewkes et al., (1998) one can identify the impact of those same factors which I will argue influence transplant, such as socio-economic inequalities. More narrowly, the studies discussed in this chapter show that aspects of a hierarchy-like role and status, mutual respect and the position of patients and professionals in the healthcare system - can lead to moral distress. Primarily, this was because the hierarchy shaped the manner in which professionals and patients communicate.

None of the South African studies above considered moral distress in organ transplant. When it comes to health professionals, transplant involves a much larger number of individuals and teams than any other surgical or ICU intervention. This thesis will argue that the health hierarchy in transplant is more complex and that moral distress occurs at a number of different levels within this hierarchy.

In terms of patients, transplant patients may be more empowered than their counterparts in Jewkes et al. (1998). This thesis will show that such empowerment is a function of socio-economic status, with transplant mainly accessible to the wealthy who may be better educated and hence more vocal. However, it will also show that the empowered patient can cause moral distress and upset in the health professional–patient relationship with similar implications for health staff. Jewkes et al. (1998) also reported that nurses felt patients were uncooperative and did not follow instructions. My research will show that transplant recipients are perhaps more cooperative, and that this may be linked to the desperate need for an organ, coupled with the empowerment mentioned above.

Organ transplant takes place within the hierarchical, morally distressing healthcare system. Bounded by this system, transplant is a complex process which spans a period of time and involves a number of distinctive stages. The following chapter will consider the transplant process.

CHAPTER 4

Literature Review- The transplant process

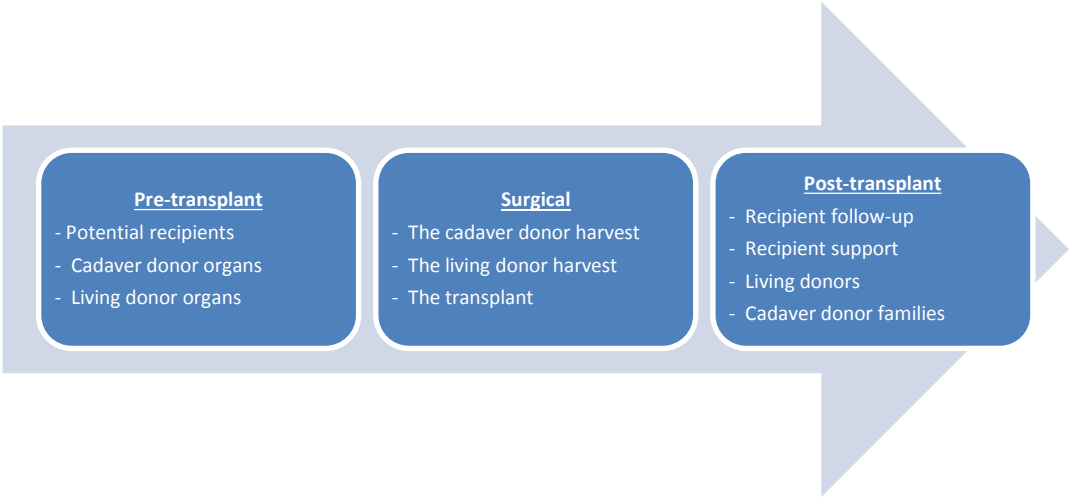
4.1. INTRODUCTION

In order to explore organ transplant at a grassroots level, as Chapter 2 argued was necessary, it is vital to understand that transplant is a process which takes place across and within hierarchical health institutions, the subject of the previous chapter. Without a notion of the scope of this process, subsequent literature on health communication and its implications for my research cannot be fully appreciated. As a rule, the transplant process comprises three distinct phases, each of which encompasses a variety of transplant-related tasks (Figure F4.1). Worldwide, transplant follows these patterns, with slight variations depending on local and hospital policy.

This chapter will consider the South African transplant process. As a process, organ transplant stretches over a period of time. The chapter will begin by describing the transplant process and identifying some aspects of time which influence it. International studies relevant to the transplant process will be discussed throughout. Important South African studies will be explored in detail and gaps in the South African literature will be identified.

Figure F4.1 – The transplant process

This diagram summarises the course of the transplant process, and indicates aspects integral to each phase of the process, which will be noted in the discussion to follow.



4.2. PRE-TRANSPLANT PROCESS

4.2.1. Listing of potential recipients for cadaver donor organs

An individual with any specific condition for which transplant is indicated may be worked-up as a potential transplant recipient. For each organ, there are differing clinical indications for transplant listing, however, these are highly scientific and hence not relevant to my thesis (Hammond, 2011; Muller, 2013; Smith, 2011; Sussman, 2011; Wadee, 2011). In addition to clinical indications, the individual should be mentally and physically healthy enough to withstand a transplant, and should have an established support system (Sideris & Fabian, 2014). This is determined during an extensive period of testing and work-up before transplant listing. The final decision as to whether an individual will be listed for a transplant takes place at a multidisciplinary listing meeting. Patients are then notified as to their listing status by either the recipient coordinator or their referring doctor.

4.2.2. Waiting for an organ

Patients who have been successfully listed for a transplant must wait for an organ to become available. Several studies have explored the feelings of potential transplant recipients whilst waiting for an organ. The waiting period is often characterised as very lengthy and emotionally complex (Brown, Sorrell, McClaren & Creswell, 2006; Jonsén, Athlin & Suhr, 2000; Macdonald, 2006). Although there is substantial research into the emotional challenges whilst waiting for a transplant, little has been published addressing the behaviour of potential recipients towards healthcare staff during this time and my research considers this factor. One renal study notes that dialysis patients can often be difficult and disruptive (Hashmi & Moss, 2008) and another, that alcoholic patients become disruptive when informed of the requirement for sobriety in order to receive a liver transplant (Fitz-Gerald, 2010).

4.2.3. Listing of potential recipients for living donor organs

As discussed previously, kidneys and liver lobes may be donated by living individuals to either genetically related family members or to non-related individuals.[13] The potential recipient of a living donor organ is required to undergo the same testing and evaluation as a cadaver recipient, and a decision about transplant will ultimately be taken at the listing meeting. MAC approval is required for non-related donors.

4.2.4. Procurement of cadaver donor organs

Unless organs are legitimately obtained from a living donor, the *dead donor rule* applies: "… patients must be declared dead before the removal of any vital organs for transplantation" (Truog & Miller, 2008, p.674).

Brain death is a widely accepted criterion for organ donation. Formally defined by the *Ad Hoc* Committee of Harvard Medical School to Examine the Definition of Brain Death in 1968, the 'Harvard Criterion' for brain death is now accepted

[13] The following relationships are considered within the ambit of living related donation: "Natural parents and children, brothers and sisters of whole/half blood, brothers and sisters of whole/half blood of natural parents, children of brothers/sisters whole/half blood, natural children of brother/sister of whole/half blood of natural parent" (Veriava & Swanepoel, 2011, slide 5).

worldwide (*Ad Hoc* Committee of the Harvard Medical School to Examine the Definition of Brain Death, 2006). In South Africa, issues like the moment of death and the definition of death are legislated in the National Health Act No. 61 of 2003. Here, legislation takes the view that a person is legally dead when they are diagnosed as brain-dead (Carstens & Pearmain, 2007).

4.2.5. Referral of cadaver donors

Cadaver donors are usually identified in the hospital environment, most frequently in Neurosurgical ICUs, General ICUs and trauma wards (Muller, 2013). When a healthcare professional believes that a patient is brain-dead or approaching brain death, he or she may opt to refer the individual as a potential cadaveric organ donor. Whether an individual health professional takes this action unilaterally, or as part of a team, depends on the setting in question.

Several factors influence whether or not a potential donor is referred. The personal attitudes of healthcare professionals towards transplant are considered significant. Staff members with a positive attitude were found more willing to consider referring potential donors than those who expressed negative sentiments (Gross, Marguccio & Martinoli, 2000; Naude, Nel & Uys, 2002; Weiland, Marck, Jelinek, Neate & Hickey, 2013).

A substantial body of literature explores the way healthcare professionals communicate with families about organ donation. This communication is often seen to be one of the most significant barriers to referral for a number of reasons which will now be discussed (Ozdag & Bal, 2001; Prottas & Batten, 1988). A study in the USA, which explored the interaction between healthcare professionals and families in the donation context, found that staff often avoided situations which would require communication (Paris et al., 1995). Another study reports that staff in referring units felt that they were adding to the family's distress by broaching the topic of organ donation (Wakeford & Stepney, 1989). Compounding this situation, in her 1999 article, Ballieu argues that families are not always given the choice to donate, because having a donation conversation makes staff feel uncomfortable. It is not surprising that healthcare professionals find these

conversations difficult because having end-of-life discussions, even where there is not an option of organ donation, is already problematic. In a 2013 Israeli study Granek, Krzyzanowska, Tozer and Mazzotta found that some of the main barriers towards discussing end-of-life issues were a lack of hospital protocol to direct these discussions, discomfort with the notions of death and dying and reluctance to accept responsibility for death.

According to protocol in Gauteng, potential donors should be referred to the cadaver donor coordinator at one of the regional transplant centres. This referral is generally made telephonically. The coordinator will travel to the referring unit and take over the management of the patient in conjunction with the current managing team because a large amount of information sharing is required. Upon receiving a referral, the coordinator initiates a communication process, alerting relevant parties that a potential donor has been identified and that there is the possibility of a transplant in the near future.

4.2.6. Obtaining consent for organ donation

Before a potential donor can be assessed from a medical perspective, the donor coordinator needs to obtain informed consent from the individual's next-of-kin. The main legislation regulating organ donation is found in chapter 8 of the National Health Act No. 61 of 2003, and the regulations pursuant thereto. Next-of-kin are considered: "a spouse or partner, or parent, grandparent, adult child, or brother or sister in the order listed" (McQuoid-Mason & Dada, 2011, p.97).

Asking consent is a sensitive process which requires tact, counselling skills, listening skills and an awareness of all aspects of the situation. Whether the next-of-kin is aware of the referral for organ donation depends on the managing team. If the managing team feels comfortable discussing end-of-life decisions, then relatives may have been told that a transplant coordinator has been called. If a managing team does not feel comfortable discussing death, the next-of-kin will hear for the first time about the option of organ donation when the transplant coordinator arrives (K. Crymble, personal communication, 10 May 2014).

Consent to cadaveric organ donation happens during a period of grief, where there is loss of a loved one. Transplant literature is inconclusive about the role which donating organs can have on the grieving process. Some studies found that donation is helpful for the family to make some sort of meaning out of the death (Bellali & Papadatou, 2006; Merchant et al., 2008; Pearson, Bazeley, Spencer-Plane, Chapman & Robertson, 1995). Others found that donation did not impact on the grieving process in any substantive manner (Cleiren & Zoelen, 2002).

Whether or not consent to donate an organ/organs is forthcoming is sometimes thought to depend on the attitudes of the healthcare teams involved, and their behaviour during the grieving process. For instance, Moritsugu (1999) describes the attitudes of healthcare staff and his personal experience of two organ donation situations. The first was when he donated the organs of his wife, the second when he donated the organs of his daughter. In the case of his wife, Moritsugu (1999) found staff to be informative, helpful and empathetic. In the case of his daughter, staff were disinterested, resistant and uncooperative. Moritsugu (1999) stated that had he not been predisposed to organ donation, he would have refused in this second instance, because the attitude of the staff was discouraging.

Should consent be forthcoming, the next-of-kin will authorise donation in writing. They may approve the donation of certain organs but not others, as well as the donation of tissue, bone and corneas.

4.2.7. Post-consent

Subsequent to obtaining consent, a battery of tests is carried out to determine whether the individual is medically eligible to donate, and if so which organs (and tissue) may be utilised. These tests are managed by the transplant coordinator. If the individual is eligible to donate, organs are offered to managing teams at relevant transplant centres. These teams decide whether they have a potential listed recipient for the organ based on compatibility with the donor and resource availability, as described in Section 2.5.4 which considered allocation processes. Provided a suitable recipient has been identified, the transplant centre will then notify the donor coordinator that they are able to accept the organ on offer. If not,

donor organs will be offered to other transplant centres, firstly in the region, and then nationally (Fourie, 2011).

Whilst a transplant is being organised staff at the referring hospital are responsible for maintaining the donor. In a 2001 study amongst critical care nurses in the USA, Day reported that a shift in mindset occurs once an individual has been declared brain-dead. Prior to brain death, the individual was a living being with a subjective reality. However, it was felt that after death the individual became an object, a source of organs. Although the critical care nurses in Day's (2001) study stressed that a brain-dead patient must still be treated with dignity, participants noted that they found it easier to care for a brain-dead organ donor as the individual was now considered 'a body' and therefore less could go wrong (Day, 2001).

4.2.8. Calling a recipient to present for transplant

Once a transplant centre accepts a cadaver donor organ, the identified potential recipient will be called to present for transplant. Transplant literature suggests that this phone call is a seminal moment in the lives of potential recipients. Waiting for the phone call has been identified as a most upsetting time, a time of great anticipation and hope, but also of disappointment (Brown et al., 2006). In some cases, more than one potential recipient will be called. The call to present for transplant does not guarantee that the individual will receive an organ. Although medical tests may indicate that organs are viable and healthy, this can only be finally determined by the harvesting surgeon at the time of harvest - by which point potential recipients should have already arrived at the transplant centre. The possibility of a false call, where a recipient presents for a transplant which, for some reason does not go ahead, is one of the most upsetting and stressful aspects of the transplant waiting period (Macdonald, 2006). Upon receiving the call, a potential recipient will inform the transplant team what time he anticipates arriving at the transplant centre, taking into account the required travelling time, which may include a flight.

4.2.9. Mobilising transplant teams

Whilst waiting for the go-ahead from transplant centres the cadaver donor coordinator officially initiates the process that will result in transplant. This involves mobilising a large number of medical and surgical teams at different locations, and coordinating their interactions (Regulations regarding the general control of human bodies, tissue, blood, blood products and gametes, 2012). This task demands extensive communication as every individual in every team needs to receive specific information. The following teams need to be mobilised:

- ICU team at the harvesting hospital to manage the donor until the time of harvest.
- Theatre teams at the harvesting hospital to make a theatre available for harvest and to assist in the procedure.
- Harvesting teams from the relevant transplant centres (there may be several for one donor), who will travel to the harvesting hospital and perform the harvest (this may involve flights, which the coordinator will need to book).
- Surgical teams at the relevant transplant centres who will receive the organs and transplant them.
- Theatre complexes at the receiving transplant centre which will need to make theatres available for transplant (sometimes more than one).
- ICU at the receiving centre which will be required to make isolation wards available for the recipients (sometimes more than one).

4.2.10. Organs from living related or non-related donors

If a potential living donor has been identified, the potential recipient will notify the living donor coordinator at the transplant centre, who will initiate the donor work-up process. Given that the potential donor is a living individual, there is not as much urgency in the transplant process as there is for cadaver donors. Hence, informed consent for a potential living donor is a continuous negotiation throughout the work-up process. The individual must first consent to undergoing

donor work-up, including detailed medical and psychological evaluation. If a potential living donor is deemed suitable, he must ultimately consent to the surgical procedure and commit to subsequent donor follow-up.

When a person is accepted as a donor, and when he or she has provided written informed consent to donate an organ, the living donor transplant coordinator will notify the relevant surgical and ICU teams of a transplant which will take place at a pre-specified date and time. This is scheduled according to theatre availability and the general surgery waiting list at the transplant centre. The procedure is not generally considered to be urgent, and there is more leeway for accommodating individual schedules. The living donor coordinator will also notify the donor and the recipient about the details of the procedure, and when they must present for final testing and surgery.

4.3. THE SURGICAL PROCESS

4.3.1. The cadaver donor harvest

Because a cadaver donor is a source of multiple organs which will be transplanted into multiple recipients, coordination of the harvesting teams is crucial. The harvesting process leaves certain organs without oxygen and blood supply (ischaemic) for varying lengths of time. Hence, the procedure is carefully planned, and precise timings for harvest are essential in order to minimise prolonged ischaemic times which could lead to organ degeneration.

Theoretically, Gauteng makes use of a procurement and harvesting protocol which specifies the surgical process for a cadaver donor harvest (Appendix 2). However, in reality it is very seldom that a harvest will correspond with these timings, as there are several factors which need to be considered. For instance, it is possible that a donor is medically unstable, which may necessitate expediting the procedure. Or there may be a delay at some point in the process which means that organs cannot be retrieved at specific times and that the harvest will need to be postponed (Kahn, Personal communication, 29 May 2014). When the first incision is made during a donor harvest, the donor should be anaesthetised, harvesting

teams should be on site and potential recipients should be *en route* to transplant centres.

The abdominal team will begin the surgical process of locating - and preparing to remove - abdominal organs from the donor. If there is to be a lung harvest, the lung team is required to initiate a similar process. At this point, the two teams will be working on the donor together. Soon afterwards, the cardiac team is expected to arrive in theatre and prepare for harvest of heart and lungs (if they are being used). At this point, up to three harvesting teams may be working on the same donor at the same time. When all is in place, the aorta is cross-clamped rendering the organs ischaemic. At this stage the organs are perfused *in situ* with ice-cold preservation solution to minimize further ischaemic damage. The cardiac team then have twenty minutes to remove the heart. After twenty minutes, the abdominal team will return to the table and remove the abdominal organs, even if the cardiac team has not completed their procedures. The organs are then placed in plastic bags containing ice-cold preservation solution, and stored in a cooler box under ice (Kahn, personal communication, 29 May 2014). Throughout the harvest an anaesthesia team will also be present in theatre to monitor donor status.

Organ harvesting may be a cause of discomfort for healthcare professionals. A 2009 Taiwanese study reported that theatre nurses involved in procurement felt they were slaughtering donors by retrieving organs. Concerns about the large amount of flesh removed during the harvesting process were also reported (Wang & Lin, 2009). The stress of travelling to unfamiliar locations was documented in Lloyd-Jones's 1996 study where medical professionals were advised to be aware of the impact their presence may have on other healthcare staff, and to practice sensitivity in these situations. A Canadian qualitative study of fourteen theatre nurses reported that harvesting is considered highly stressful. The primary factors contributing to participants' feelings of distress were strained relationships with surgical staff, concerns about the dignity of the donor and the wellbeing of the donor family (Regehr, Kjerulf, Popova & Baker, 2004).

A 2000 Swiss study examined the attitudes of healthcare professionals towards organ donation. The study made use of a lengthy questionnaire which was

originally distributed to 199 transplant professionals; a sample of only 74 participants was achieved. The authors argue that the small sample size is not a source of bias. Of the participants, nine were operating theatre staff. Amongst other factors, these participants were asked if they felt experience of an organ extraction would change their views on the procedure. 67% of operating theatre staff stated that it would not influence their beliefs or feelings, significantly more than any other healthcare professional group that was represented (Gross et al., 2000).

4.3.2. The living donor harvest

A living donor is unlikely to be giving more than one organ, so fewer healthcare teams and theatre staff are required for the harvest. As the living donor and the recipient generally undergo their surgical procedures at the same hospital, organ transportation is unnecessary, hence ischaemic times are significantly shorter. The harvesting and theatre teams will prepare the theatre for a pre-arranged cutting time, and prepare the donor. This will include anaesthesia and medication. The donor organ will be located, cross-clamped and removed. It will then be placed on ice and taken to a neighbouring theatre where the recipient is anaesthetised and ready for the transplant. Lesions created during the procedure will then be closed, followed by the lightening of anaesthesia and a period in recovery, prior to transfer to the surgical ICU.

4.3.3. The transplant

Whether organs are from a cadaveric or living donor, the transplant team receiving them must be prepared to commence implantation processes as soon as the organ arrives in theatre. Several teams are involved in preparing the recipient for implantation, including the surgical team, anaesthesia team and the ICU team. They will insert drips, catheters and attach monitors as well as pre-medicate the recipient.

Before a donor organ may be implanted it is necessary to remove the defective organ from the recipient (except in the case of kidney transplant where the new kidney is implanted into the iliac fossa and the patient ends up with three kidneys).

The time constraints which this poses must also be factored into the determination of cutting time for the recipient. This procedure varies in complexity depending on the organs in question and the nature of the organ damage.

When the donor organ is received the harvesting surgeon is required to communicate certain details to the transplant team, who will prepare the organ in a procedure known as 'back table'.[14] Once the back table is complete, the organ will be inserted into the recipient and stitched into place. Blood flow to the organ will then be initiated by removing the clamps, with perfusion of the organ (blood flowing through it and turning it pink) the first indicator that the surgery has been a success. Throughout this process, theatre teams communicate with each other regarding the status of the recipient and the progress of the procedure.

4.4. THE POST-TRANSPLANT PROCESS

Following a successful organ harvest and transplant, the recovery period for recipients and living donors begins. For a cadaver donor family, a period of mourning and grief ensues after organ donation and the death of a loved one. Post-transplant follow-up for each of these groups will be detailed in turn.

4.4.1. Recipient follow-up and adherence

During the period immediately post-transplant, recipients are highly susceptible to infection. They are kept in ICU isolation wards for a number of days in order to control this risk. Recipients are not generally allowed physical contact with visitors during this vulnerable time, and anyone entering the isolation cubicle is required to take extensive infection control measures. When the immune system of the recipient has stabilised and the organ function appears satisfactory, he or she is moved out of isolation, and may either spend a few more days in ICU or be transferred directly to a general ward. The surgical and medical team who performed the transplant monitor the patient during daily ward rounds, and the patient also receives counselling, dietary advice, physiotherapy, occupational therapy and education on medication and other aspects concerning recovery. The

[14] Here, the organ is still on ice, and the implanting team work to remove any excess fat or tissue, as well as ensuring that veins and arteries are exposed and prepared for surgical attachment.

aim of such management is to familiarise a recipient with his or her new way of life and provide support for his or her reintegration as a productive member of society (Holzner et al., 2001).

Post-transplant, a recipient is required to adhere to a lifelong management programme in order to maintain the donor organ. This involves regular follow-up and this process has been substantially documented (Cohen & Galbraith, 2001; Mize & Cupples, 2004). Through this follow-up, relationships develop between the recipient and the management team and these are seen to influence long-term adherence. Gremigni et al. (2007) and Lurie et al. (2000) note some associations. In Gremigni et al.'s (2007) study, participants cited a trusting relationship with their management team as a facilitator of adherence. Lurie et al. (2000) reported that when this relationship failed to develop, incidence of non-adherence was higher. Furthermore, frank and familiar long-term contact between the management team and the recipient has been found to affect the recipient outcome and apparently also the morale of healthcare professionals (Johnson et al., 1999*;* Raiz, Kilty, Henry & Ferguson, 1999).

However, the long term follow-up of transplant patients is complicated and the establishment of a trusting relationship is not the only factor which might influence recipient outcomes. As Raiz et al. (1999) note, recipient outcomes are often subjective and depend on perceptions of life post-transplant, with individuals who were older, satisfied with their level of social functioning and who found security in their condition being controlled by a powerful medical management force, reporting more favourable outcomes than those who were uncertain about their prognosis. Perceptions of negative aspects in transplant, like episodes of disease or perceived poor outcomes, were found to lead to increased morbidity and mortality in recipients and also to be associated with certain psychological factors (Dew et al., 2005; Olbrisch, Benedict, Ashe & Levenson, 2002).

In a South African study of health outcomes amongst 23 kidney transplant recipients, Burke (2006) made use of several validated measures, and reported that those who experienced graft rejection exhibited high levels of anxiety and did not feel in control of their health management, attributing the rejection to external

sources such as luck or fate. Furthermore, feelings of guilt could cause psychological distress in transplant recipients (Muehrer & Becker, 2005) and the influence of personal romantic relationships was also considered a significant factor in recipient wellbeing (Gee, Howe & Kimmel, 2005).

4.4.2. Caring for the carers – supporting the families of transplant recipients

Another factor which is thought to influence recipient outcomes is the nature of their support system post-transplant, a period when recipients require dedicated care. Often, a potential recipient will need to prove that there is a support system in place in order to be listed. Post-transplant, a recipient assumes a duty to maintain the donor organ, and in order to facilitate this management, family members are involved. A number of studies have examined the importance of support for a transplant recipient's family (Bohachick, Taylor, Sereika, Reeder & Anton, 2002; Christensen, Raichle, Ehlers & Bertolatus, 2002; Patel, Peterson & Kimmel, 2005). There appears to be a correlation between this support structure and a recipient's emotional wellbeing. Those recipients who perceived themselves as having a stronger support structure reported fewer emotional complications post-transplantation. Dew et al. (2005) found that heart transplant recipients who displayed signs of psychological disturbance post-transplant were found to have weaker family support systems.

4.4.3. Living donors post-transplant

Living donors are monitored post-transplant in surgical ICU, transferred to a general ward and typically discharged within a few days, provided there aren't any surgical complications. Living donors are required to present for a check-up regularly post-donation. They are also provided with physiotherapy, occupational therapy and counselling on health and nutrition.

4.4.4. Cadaver donor families post-transplant

Cadaver donor families are not involved in the surgical aspect of the transplant process, and hence medical follow-up is not necessary. Cadaver donor families are

not routinely offered psychological follow-up, and the onus is on the donor family to initiate and arrange psychological support or counselling should they feel it necessary. Depending on the structure of the managing transplant unit, cadaver donor families may be sent a letter or gesture of thanks for their donation. This letter may detail the number of lives saved, and provide vague information about who received each organ. They are also invited to an annual Donor Day, where the name of their loved one is memorialised in a garden of remembrance in the year after the donation was made. The identities of recipients are not divulged to the cadaver donor family, or vice versa, as this may introduce a factor of coercion into the transplant process. However, some donor families will receive letters from the recipients through the coordinating transplant centre.

In a review of qualitative transplant studies, Ralph et al. (2014) examine factors which influence wellbeing and perceptions of donor families post-transplant. They have identified a number of trends which are relevant to my research. They found that needing closure post-transplant was important to donor families. A thank you letter from the transplant coordinator was valued by donor families, as was some information about the outcomes of those recipients who were given donor organs (Ralph et al., 2014). In an Australian study, Thomas, Milnes and Komesaroff (2009) found that donor families valued thank you letters received from anonymous recipients but that the families felt unable to reply to these letters. Sque and Payne (1996) found that donor families felt unsupported when they left the hospital after the organ harvest had taken place. It was noted that hospitals did not routinely provide any emotional support to donor families when they left the hospital and that little formal follow-up of the families was undertaken. Families noted a feeling that once the hospital had the organs, they were "left" (Sque & Payne, 1996, p.1365).

4.5. SOUTH AFRICAN TRANSPLANT RESEARCH

A small number of South African studies, which are pertinent at various stages of the transplant process, have been undertaken, and these will now be discussed. Studies have been included in this chapter because the techniques used in obtaining their samples were similar. They made use of populations which had

already had exposure to the transplant process (families and nurses). Thus, it is possible that these studies are more representative than those discussed in Chapter 2, which noted the hypothetical views of certain sample populations.

4.5.1. Studies which sampled family members and decision-makers in cadaver donation

Two studies which sampled families and decision-makers have taken place in South Africa. These will be substantively discussed in turn, and common results and implications for the research presented in this thesis will be considered at the end of the section.

4.5.1.1. Reyneke's study

In her completed 2014 MCur dissertation, Reyneke described research titled *Understanding decisional conflict amongst family members in organ donation in the Western Cape Province*. According to Reyneke (2014) decisional conflict takes place when an individual who may be in an emotional state cannot easily decide on a course of action and experiences difficulty in clearly elucidating the options before him or her and then deciding between them.

Reyneke (2014) grounded her study within O'Connor's (2006) Ottawa Decision Support Framework which incorporates the work of a number of authors and utilises three categories to evaluate decision-making, namely decisional needs, decisional support and decisional quality. Decisional needs dictate the type of support which should be provided, and this influences the overall quality of the decision which is made. The choice of theoretical framework is interesting because my research will show that transplant coordinators consider it vital that informed decisions are made by families (whether affirmative or negative) and the decisional quality is emphasised. Decisional quality is determined by considering whether a decision was informed, if it accounted for the decision-maker's value system and whether there was sufficient time to make the decision.

Through data analysis Reyneke (2014, pp.63 – 66) identified seven major themes which can lead to decisional conflict:

1. The shock of finding out about the death of a loved one can affect psychological state and decision-making capacity, however, in organ donation families are often required to make a speedy decision. Participants stated that they were aware of this requirement.
2. Difficulty in understanding brain-death posed a challenge for decision-making because the loved one appeared 'alive' – was warm and had a pulse.
3. Certain values or beliefs were considered in the decision-making process, and Reyneke (2014) seems to argue that these were used to buy time or because families were unable or unwilling to make a donation decision. Such considerations involved reflections of what the patient was like whilst alive and questioning whether the patient would have wished to be an organ donor. Sometimes, these considerations included a conviction on the part of family members that the brain-dead patient would recover. This phenomenon, which Reyneke (2014, p.64) has labelled "projection" was also found in families who made repeated attempts to contact a relative who could assist in the decision-making, thus stalling the moment when a decision actually had to be made.
4. Participants felt conflicted about the appropriate decision to make on behalf of their loved one. This conflict manifested itself in repeated changes of mind until a final decision was reached.
5. Reality struck the participants when they started to accept the fact that the loved one was deceased, and that there was no longer a prospect of life.
6. Each family was found to have key decision-makers. Interestingly, the key decision-maker in each family did not necessarily reflect the norms of family structure, for instance a patriarchy which was discussed in Section 2.6.4.3. The male was not always the key decision-maker and some females in Reyneke's (2014) study sample seemed to be empowered.
7. The cause of brain-death was important in decision-making because it shaped the context within which a family was deliberating. If death was

crime related it was possible that the family did not know all the details. If death was sudden, the family felt a sense of disbelief.

4.5.1.2. Kometsi and Louw's study

Kometsi and Louw's (1999) study, entitled *Deciding on cadaveric organ donation in Black African families* was conducted with families on the topic of cadaveric organ donation in South Africa. Participants in the study were ten Black African families from the Greater Cape Town area. These families had either agreed to donate the organs of a deceased loved one or had declined to do so (Kometsi & Louw, 1999). Using a semi-structured interview schedule, the study examined factors that affected this decision. The inclusion of multiple family members as participants emphasizes the importance of the family unit in decision-making. This particular methodological approach informed the donor family interview phase of my study.

The following were identified as important themes during analysis of the interview data (Kometsi & Louw, 1999, pp.474 – 476):

- Death and criminality – As a reaction to the criminal elements which exist in South African society, families whose loved ones had died through a criminal act, had often decided against donation. It appeared that families felt there was a direct link between organ donation and failures in the South African justice system, especially where perpetrators of the crimes against loved ones had not been apprehended. Thus, families felt that they had become no more than a source of organs, and that society deemed it unnecessary to pursue justice for the deceased loved one.
- Time needed for consultation – The majority of families expressed a wish to consult loved ones from distant areas before taking a donation decision. This was often not possible due to time constraints. Participants expressed discomfort with the speed at which a transplant coordinator would request an organ donation after brain-death was declared.
- Death and transition to ancestry – Participants noted that cultural practices sometimes dictated donation decisions, expressing concerns that the donor, missing certain organs, would haunt the decision-maker.

- Brain-death – None of the participants in the study understood the concept of brain-death.

4.5.1.3. Discussing Reyneke (2014) and Kometsi and Louw (1999)

A weakness of Kometsi and Louw (1999), which was substantially addressed in Reyneke (2014), is the importance of family structure as a characteristic of the study population. Whilst they suggest that decision-making is truly a joint effort (Kometsi & Louw, 1999), Reyneke's (2014) finding of the importance of a key decision-maker seems more plausible, especially when considered in light of other previous research discussed in Section 2.6. However, whilst previous research suggests that an older male is likely to be the key decision-maker (Section 2.6.4.3, Green, 2000) Reyneke's (2014) study suggests that this is not always the case. My research considers factors of family structure primarily from the standpoint of healthcare professionals, and I will argue that some healthcare professionals assume a patriarchal family structure informs transplant decision-making, and believe that women and younger family members are not empowered to make decisions of their own accord.

A limitation of both studies, which is addressed in my research, is that neither considers aspects of the post-transplant process for donor families, and neither addresses post-transplant follow-up of the donor family. Whilst Reyneke (2014) sensibly recommends that transplant coordinators and nurses who have contact with grieving families on a regular basis receive some type of debriefing, this is not recommended for the families themselves. My research has avoided this limitation by considering the transplant process as a whole, from pre-transplant through to post-transplant. By adopting this approach, my research has been able to show that the post decision-making process for donor families is an especially fragile time, where follow-up and communication can have long-lasting effects.

When it comes to the samples in Kometsi and Louw (1999) and Reyneke (2014) some very interesting characteristics emerge. Both studies were able to recruit substantially more donor families than I was able to (ten and eight respectively, compared to two in my study). Notably, both Kometsi and Louw (1999) and

Reyneke (2014) obtained their samples in the Western Cape Province, whilst I obtained a sample from Gauteng Province. It is possible that the Western Cape is more amenable to this type of research than Gauteng, evidenced by the difference in numbers. One reason for this may be because of the established history of transplant in the Western Cape. Another may be because I was an outsider and had yet to build up trust within the Gauteng transplant community, whereas Kometsi and Louw (1999) and Reyneke (2014) were already familiar to the gatekeepers in the Western Cape transplant system.

4.5.2. Studies which sampled family members in living donation

4.5.2.1. Mbeje's study

In a 2013 study entitled *Perceptions of the relatives of patients suffering from chronic renal failure regarding kidney donation* Mbeje explored the views of 25 relatives of listed potential kidney recipients towards living organ donation in a South African setting. Mbeje's (2013) study took place in the Kwa-Zulu Natal Province of South Africa. Participants were family members of dialysis patients in a hospital within that province. The study aimed to explore the attitudes of these family members towards living kidney donation, based on the premise that this is the only viable alternative to dialysis or cadaver transplant for patients with end-stage renal failure.

Findings fell under three principal headings:

1. All participants were aware of living organ donation. This was primarily through the media, education from their listed relative or education from the kidney team. It was found that though all participants were aware of living kidney donation, not all were in favour of it. Mbeje (2013) concluded that intensive educational interventions by renal teams and the government may be helpful in changing these attitudes.
2. Religious affiliation appeared highly significant, with the majority of participants citing religious practices as aspects which would influence a donation decision. However, very few participants subscribed to religions that were entirely opposed to donation.

3. Whilst many participants would consider donating an organ to a family member, there were often contraindications to donation. Participants appeared fearful of the surgical procedure and anxious about the implications which donating may have for their future lives.

Mbeje (2013) reports that the donor work-up process which was described in Section 4.2. was sometimes a source of anxiety. It was noted that the stress of finding a donor was exacerbated when family members were found ineligible to donate, however this finding is not explored in any substantive detail. Furthermore, Mbeje (2013) has not considered the financial costs associated with living kidney donation and its implications for access to transplant services (which, if sought in the private sector, must be paid for) apart from noting that renal transplant is considered more cost-effective than long-term dialysis. In conclusion, Mbeje (2013) recommended that future research, which considered the role of the transplant coordinator in dealing with long waiting lists, would be beneficial.

I undertook to further explore the experiences of living donation by conducting a focus group with living donors. As with the previous studies discussed here, a fundamental difference between Mbeje's (2013) study and my research is that I considered the transplant process as a whole. Thus, my research was able to elucidate living donor insights in the post-transplant phase as well as in the period before the transplant took place. My study furthers Mbeje's (2013) findings by considering the financial implications of living donation in more detail.

4.5.3. Studies which sampled health professionals

4.5.3.1. Naude, Nel and Uys's study

In a 2002 study entitled *Organ donation: Attitude and knowledge of nurses in South Africa*, Naude et al. explored the attitude and knowledge of transplant coordinators and intensive care nurses towards various aspects of organ transplantation. This study included health professionals and transplant coordinators, thus it contains the sample most similar to mine. Specific emphasis was placed on cooperation between coordinators and nurses when it came to identifying potential donors (Naude et al., 2002). Self-administered questionnaires were used. These are not

available in the publication, thus is it not clear whether open-ended or closed questions were asked. There were separate questionnaires for transplant coordinators and intensive care nurses (Naude et al., 2002). Unfortunately, the paper does not explain how the data was analysed.

Study findings show that all transplant coordinators expressed a positive attitude towards organ transplantation. 12.9% of nurses expressed a negative attitude, with 21.2% indifferent. Both groups mentioned that communicating with family members is emotionally stressful. The study also showed that a healthcare worker's attitude towards organ donation could influence their decision to refer potential donors. In terms of knowledge, insufficiencies were identified in the nurse population, with good knowledge found amongst the transplant coordinators (Naude et al., 2002).

Some interesting results were forthcoming in terms of cooperation and professional role. Both groups felt that nurses were responsible for the identification and referral of potential donors. Conflict was evident in perceptions of which group was responsible for the maintenance of the donor, which takes place after consent has been granted and before the surgical phase begins. Both groups felt that this responsibility fell to them. Furthermore, conflict resolution between the two groups was considered problematic. This primarily arose from the different end-points of the two professions (for cadaver procurement coordinators the death of the patient is the ultimate goal, whilst for nurses the goal is to sustain life). Few intricacies of communication were reported in the study, which examined a number of aspects of which communication was just a small section.

4.5.4. Gaps in the South African transplant literature

The review of relevant South African transplant research presented above identifies gaps in local transplant literature which my study aimed to address to some extent.

Firstly, the specific issue of interprofessional communication in the transplant setting has not been explored in any detail, and has never been researched utilising

qualitative methods. Important aspects of interprofessional communication and how this is affected by context and practice is lacking. I proposed to do this by focusing specifically on communication. Furthermore, transplant professional – patient/family communication in South Africa has not been considered from the transplant professional point of view. Such an exploration was warranted in the unique and complex Gauteng healthcare setting.

Secondly, it appears that no qualitative study which explores the views of the range of transplant professionals in South Africa has been undertaken. As the first such study, the present research may add substantially to qualitative health communication literature (which will be discussed in the following chapter), possibly setting new research trajectories related to research design and settings.

Finally, my research is the first in South Africa to consider transplant as a process. As such, I have aimed to address a gap in South African transplant literature by including an exploration of the follow-up of donor families post-transplant, and by considering the experiences of transplant professionals throughout the process.

4.6. SUMMARY AND CONCLUSION

In order to consider transplant practice as it takes place within and across health institutions, this chapter aimed to provide an overview of the transplant process and attempted to portray its scale, especially the large and diverse number of healthcare professionals and teams involved. The general role of each team in the transplant process, and the individuals within it, was described. The transplant coordinator was shown as the locus of responsibility in organising a transplant by communicating with other transplant professionals involved. Additionally, the chapter considered some of the roles and responsibilities of donor families, potential recipients and recipients in the transplant process. It detailed the requirements for transplant listing and post-transplant follow-up. A large amount of international literature pertaining to the transplant process was referenced, however there is a paucity of local information. This was specifically related to donor family follow-up, which did not appear to have been addressed in local literature at all.

It is clear from the South African transplant research reviewed in this chapter that communication amongst a variety of healthcare professionals and patients – as it takes place across the transplant process – has not been explored before in this country. Because this thesis considers communication between transplant professionals and patients in these settings, it is important to discuss health communication in South Africa. This will be done in the following chapter.

Chapter 5: Communication in healthcare and organ transplant

5.1. INTRODUCTION

I aimed to explore communication in organ transplant in Gauteng province. I considered both interprofessional communication and communication between professionals and their patients and families, both within the hierarchical healthcare system and also throughout the transplant process. Because communication is fundamental to my research, the aim of the current chapter is to consider health communication in South Africa in detail. The chapter will begin by describing fundamental aspects of health communication in South Africa. It will then consider South African health communication literature, first looking at professionals' communication with patients and then at interprofessional communication. Pertinent studies will be linked to ethics in healthcare, and I will argue that effective health communication is an essential element of ethical practice.

Longman (2013) argues that communication is vital in the health setting because it allows for the conveying of information, expressing of emotion and clarification of instruction which accompanies the healthcare process. At its most basic, healthcare involves a patient seeking medical expertise. The patient must be able to explain his or her ailment and the healthcare professional or team must be able to respond. Ideally, through two-way communication, the patient and the health provider negotiate acceptable health management. I argue that communication is an essential pillar of the South African healthcare system. Firstly South African legislation and practice guidelines mandate patient centred care (Health Professions Council of South Africa, 2008b) which involves the provision of health services which a patient deems to be in accordance with certain of his or her life priorities. Secondly, the South African Constitution explicitly requires informed consent for health treatment. One of the main foundations of informed consent is

providing the patient with the information necessary to make a management decision. This is achieved through communication.

As health interventions become more complex, health communication extends beyond the practitioner-patient relationship into the institutional realm. With the modern objective of multidisciplinary care which is epitomised in transplant, there is a need for health professionals to communicate with each other, especially in terms of sharing details of patient management. This sharing of patient information amongst a multidisciplinary group of health professionals is known as continuity of care (which will be discussed in Section 5.6) and it requires effective interprofessional communication.

5.2. HEALTH COMMUNICATION IN SOUTH AFRICA

Because of a number of systemic complexities, health communication in South Africa poses a substantial challenge. The Health Communication Research Unit, where I was based for this study, has undertaken significant work in order to explore these challenges and to suggest and implement recommendations. Penn and Watermeyer (2012b) argue that the healthcare sector can be seen as a microcosm of society, and that societal norms pervade the healthcare setting. Thus, challenges in health communication require an exploration of context which has a specific effect on the type and quality of interaction which takes place.

5.2.1. The role of language

As explained in Chapter 1, South Africa has eleven official languages, all of which are spoken to some extent. However, language mismatches between health professionals and patients are common. In many cases, health professionals, especially medical doctors, have been educated in English and are unable to speak any other language (Longman, 2013). This can complicate communication because the majority of the South African population does not have English as its home tongue. Everett, Odendaal and Steyn (2005) found that medical professionals were aware of some communication gaps, and were eager to engage in activities to improve their interactions with patients.

A number of studies have explored the use of interpreters to bridge language barriers between health professionals and patients. These studies hypothesise that by more closely matching the language in health interactions patients will be better informed about their condition and management plan. However, interpreters are not always effective, primarily because it is unclear if important information is accurately conveyed by the interpreter (Penn & Watermeyer, 2012a; Penn & Watermeyer, 2012b). In their 2012 papers, Penn and Watermeyer develop the role of the interpreter. Firstly the interpreter can establish rapport with both the patient and the health professional through asides which are not directly related to the health consultation (Penn & Watermeyer, 2012a). Secondly, the interpreter can act as a cultural broker, possessing knowledge of a patient's cultural practices, and can convey information in a culturally sensitive manner which the patient can understand (Penn & Watermeyer, 2012b).

Although my study explored communication, the issues of language and the use of an interpreter when communicating with patients was not one of the major themes that emerged. However, it appeared that transplant professionals who participated in my study preferred to communicate in English and felt comfortable doing so, provided patients had basic English language skills. My study has produced results which differ from those found in other investigations in some of the literature (Longman, 2013), and this may be because transplant is a tertiary intervention which is only accessible to a few, many of whom are relatively empowered, and therefore may have a better command of English than those study participants from rural areas, where primary care communication has been investigated.

5.3. HEALTH PROVIDER – PATIENT COMMUNICATION RESEARCH IN SOUTH AFRICA

In a study entitled *Affordability, availability and acceptability - barriers to health care for the chronically ill: longitudinal case studies from South Africa,* Goudge, Gilson, Russell, Gumede and Mills (2009) report on longitudinal research undertaken amongst thirty households affected by chronic illness in rural South

Africa. Whilst the objective of the study was to explore barriers to accessing chronic healthcare, a number of communication barriers were also identified (Goudge et al., 2009).

Patient-health provider interactions were a barrier to accessing healthcare (Goudge et al., 2009). The study reports that inadequate communication left many patients unaware of the specifics of their chronic condition, which resulted in inappropriate management (Goudge et al., 2009). However, the study also reported that when patients and healthcare providers communicated well, patients were better able to understand their diagnosis and management (Goudge et al., 2009). It is interesting to see how good communication facilitates both the adherence to and the provision of care, which are required to control a chronic disease. This is an example of how communication, in this case by providing adequate information, can facilitate autonomy which is a vital aspect of ethical practice. My thesis will extend this argument, further showing how communication is vital to ethical transplant practice.

5.3.1. Health professional – patient communication in transplant – the role of uncertainty

The results of my research will show that throughout the transplant process, various points of uncertainty exist. This begins with the potential recipient who is uncertain whether he or she will receive an organ. It continues into interaction with the potential donor family who may be uncertain about making a donation decision. Post-transplant recipients face uncertainty in terms of their overall health and survival, living donors may feel uncertain about similar issues and donor families may feel uncertain about their decision. I will argue that communications in the transplant process need to take these uncertainties into account and manage them effectively in order to facilitate caring, ethical practice.

5.3.1.1. Uncertainty management theory (UMT)

According to Yoshitake (2002, pp.178-179) there are three essential elements of UMT.

1. Uncertainty - the cognitive condition of being unable to predict future happenings. In transplant perhaps this is most evident when waiting for an organ.
2. Anxiety - an emotional response to uncertainty, depending on the situation. In transplant, this is also evident in the emotions of potential recipients.
3. Mindfulness – a continual effort to reflect on and consider the information needs of the patient. Effective communication should be tailored to account for uncertainty and anxiety in one's communicative partners. In transplant this may be most evident when transplant coordinators seek family consent for cadaver organ donation and tailor communication to accommodate the family's grief.

I have chosen to use the term communicative partners above, rather than communicative object (which is commonly used in UMT literature) as this is more consistent with the notion of shared decision-making in the medical encounter, where a patient is considered an equal participant rather than the object of medical management.

5.3.1.2. Brashers' theory of uncertainty management

Brashers proposed a theory of uncertainty management largely based on Mishels theory of uncertainty in healthcare (1988). Mishel argued that uncertainty results when a predicted situation does not arise, for instance when a medical management plan does not produce the anticipated effect. It appears that uncertainties are further compounded by other aspects of health and illness (Mishel, 1988). Later, Mishel (1990) widened her theory to account for uncertainty in chronic illness, where she argued that it becomes an integral part of daily life. There are two notable differences between Brashers' theory and Mishel's work. Firstly, Brashers argues that uncertainty is not always a negative condition which

should be altered. Secondly, Brashers et al. (2003) propose three distinct categories of uncertainty in healthcare, which are discussed below.

Brashers' theory emerged primarily through studies of HIV-positive individuals (Brashers et al., 2000; Brashers, 2001 & Brashers, 2007). The main hypothesis of this theory is that individuals may consider uncertainty as either potentially harmful or potentially beneficial. The way in which an individual conceptualises uncertainty will dictate his or her actions in managing it. This will either entail gathering information to mitigate uncertainty or avoiding new information to maintain an uncertain state. An individual may wish to maintain uncertainty because of fears that new information could have negative psychological consequences. Communication is a source of such information and an individual will engage in it or avoid it, depending on his or her current attitude to uncertainty.

However, information seeking or avoidance does not always have the desired outcome. An individual may believe that an increase in information will produce a corresponding decrease in uncertainty because better information can assist in clarifying alternatives and their predictability. However, new information may inadvertently lead to increased uncertainty as a larger number of unpredictable situations and scenarios are identified. Furthermore, information seeking will not reduce uncertainty if the sought knowledge is unforthcoming or ambiguous. These confounding factors of information seeking and their ramifications for uncertainty may call for specific management. For instance, managing uncertainty may involve adjusting individual perceptions of the uncertainty itself.

5.3.1.3. Uncertainty management and patient communication

Three categories of uncertainty, specific to healthcare, are identified (Brashers et al., 2003, pp.502-514):

1. Medical uncertainty involves ambiguities in diagnosis, prognosis and management. These are often compounded when management is complex.
2. Personal uncertainty is related to self-image and individual synthesis of conflicting roles and expectations to act in a certain way (the 'sick role' verses the 'well role'. The 'care giver' verses the 'care receiver'). It involves

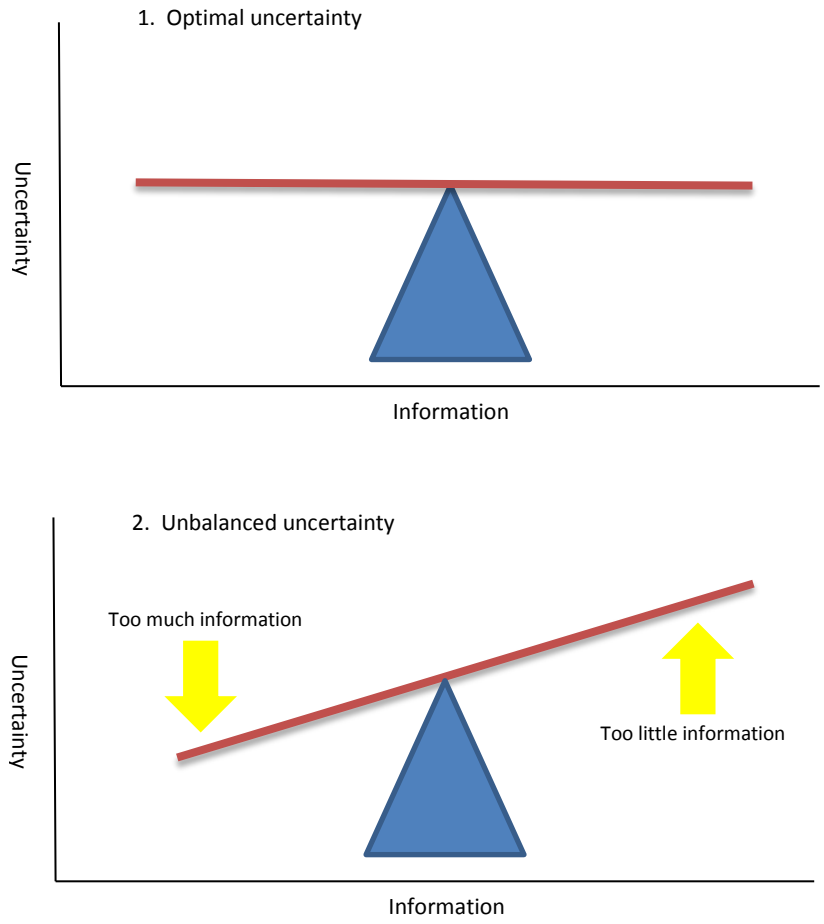
finding personal identity (or re-identifying oneself) in relation to a disease or condition. Financial consequences of illness also contribute to personal uncertainties.

3. Social uncertainty encompasses fluid relationships with acquaintances and society at large. It involves ambiguities about social acceptance and the longevity of future relationships in the context of illness, especially with those individuals who may be relied upon to provide support.

Within these factors of healthcare uncertainty, professionals are obliged to practice mindfulness in order to recognise and react to it. This may be achieved through providing information or by trying to change and influence patients' perceptions of the uncertainty itself. In summary, it would appear that substantial social skills and sensitivity to patients' emotions are required to manage uncertainty and to tailor communication accordingly. This includes acknowledgement of, and balancing of, temporal factors (the recipient's journey), insight into the patient's perceptions of hope and the corresponding need for information in order to achieve an uncertainty balance (i.e. a state of affairs where the amount of information is such that either more or less would increase uncertainty, Figure F5.1) (Brashers, 2011).

Figure F5.1 – Achieving an uncertainty balance in patient communication

This figure presents two depictions of uncertainty. The first is optimal uncertainty, where the requirement for information is balanced with the amount of information provided. The second demonstrates the imbalance that occurs with the provision of too much information or too little information. The figures are placed on generalised non-linear axes representing information and uncertainty. I have extrapolated this figure from Brashers (2011).



5.3.1.4. UMT and organ transplant literature

Although the transplant process appears imbued with uncertainty, few research studies have applied UMT to transplant. Three such studies, Martin, Stone, Scott and Brashers (2010), Scott, Martin, Stone and Brashers (2011) and Stone, Scott, Martin and Brashers (2013) have been identified. These three studies are based upon a data set which comprised a study population of thirty-eight transplant patients, eight of whom were in the pre-transplant phase and thirty of whom were post-transplant. The earliest study, which will be discussed in more detail below, is particularly relevant to my research. The latter two studies focus on transplant recipients and the ways in which they manage uncertainty.

Scott et al. (2011) focus on social uncertainty - a recipient managing uncertainty within his relational support system. The study found that recipient support structures were important for reinforcing security in personal relationships. However, the social support system also posed challenges for uncertainty management, and was prone to foster situations where an unwelcome increase in uncertainty occurred. Stone et al. (2013) examine the ways in which transplant recipients manage the sources of information around them in order to balance uncertainty. The study found that participants preferred to receive information from other people, rather than from the internet or print sources. It also found that transplant recipients do not appreciate stories of bad news, preferring to maintain some uncertainty about the potential negative consequences of transplant (Stone et al., 2013). These two studies are less relevant to my research as it did not explore recipient experiences.

<u>Martin et al.'s Study</u>

Martin et al.'s 2010 study entitled *Medical, Personal, and Social Forms of Uncertainty Across the Transplantation Trajectory* was unique in that it examined uncertainty management for transplant recipients throughout the transplant process, rather than at specific points. This is vital in terms of the temporal factors of uncertainty management mentioned above. Results of the study were presented in a framework from listing through to follow-up (Martin et al., 2010).

Three categories of uncertainty (Table T5.2) were identified, and they correspond with Brashers' categories:

Table T5.2: Three categories of uncertainty in the transplant process for transplant recipients (Martin et al., 2010)

	Pre-transplant	Post-transplant
Medical Uncertainties	- Experience of illness - Waiting for an organ	- Possibility of rejection - Possibility of requirement for another transplant if rejection occurs
Personal Uncertainties	- Being identified as "ill" - Financial uncertainties	- Living life with an organ from another person - Financial uncertainties
Social Uncertainties	- Questioning from others - Will transplant affect personal relationships?	- Pre-transplant uncertainties continued - Complex relations with donor family

The finding of social uncertainties in interactions with a cadaver donor family is particularly interesting, although it is not discussed in much detail in the paper. In terms of the experience and meaning of uncertainty, recipients felt unsure of whether, how or when to thank a donor family. One participant expressed a desire to do so, but struggles with the recovery experience made her feel more uncertain. The emotional responses to these uncertainties were a sense of guilt from an inability to express gratitude and fear about how the family would react to any gesture. The corresponding behavioural intervention is only noted in one case, where a recipient thanked the family and the situation of uncertainty was relieved.

Gaps in the UMT literature on transplantation

Martin et al. (2010), Scott et al. (2011) and Stone et al.'s (2013) studies have demonstrated substantial empirical applications of UMT in transplant recipients. However, it does not appear that UMT has been applied to other role-players in the

transplant process. My study responds to this gap in the literature by applying UMT to cadaver donor families and healthcare professionals. The application to donor families is particularly relevant in terms of the data that will be presented in Chapter 9 and given the general paucity of information regarding donor family follow-up in the South African transplant literature. This was discussed in Chapter 4 when reviewing South African studies.

5.3.2. The role of organisational routine

As Chapter 4 has shown, transplant requires a large number of healthcare professionals, patients and their family members to interact and communicate effectively within a clinical space. A number of studies have specifically examined organisational routines and their application and effectiveness in the clinical setting. Greenhalgh, Voisey and Robb (2007) describe organisational routines as frequently repeated actions in which a number of interdependent role-players cooperate within certain rules and boundaries to bring about a specific outcome. Becker (2004) notes that organisational routines can be advantageous because they promote a sense of stability and provide a framework of support for decision-makers. For instance, the presence of an organisational routine can reduce uncertainty regarding difficult choices about patient management. However, Greenhalgh et al. (2007) note that organisational routines require substantial buy-in if they are to be effective. In cases where role-players did not understand what was required of them, were opposed to the framework or substance of the routine, or in a situation where communication was poor, organisational routines were not always established.

However, in a 2012 South African study, Watermeyer found that caregivers of TB patients felt that healthcare provision was more effective when organisational routines were evident. Her study suggested that these routines made both healthcare providers and patients feel supported in their healthcare management. Another South African study examined organisational routines related to TB as 'rituals'. These rituals were DOTS (Directly Observed Treatment System) and morning prayers at the clinic. The study found that although patients seemed to consider the routines effective, they also served to entrench the healthcare

hierarchy and the notion of the patient as subordinate to the healthcare professional (Lewin & Green, 2009). The authors state that rather than an aid to collaboration, the organisational routine of DOTS is a means by which the patient may be controlled by the healthcare practitioner. Lewin and Green (2009) argue that rather than promoting cohesion between patients and healthcare professionals the position of power and authority that one has over the other during the physical enactment of the 'ritual' is further embedded.

When it comes to organisational routine, my research will show that this may be an effective way to manage uncertainty for recipient families at the time of transplant. The fact that organisational routine appeared helpful in the transplant setting may be due to the high levels of anxiety and fear which are experienced by a family as their loved one enters the surgical phase to receive a transplant. These feelings in a recipient family may be more acute than experiences lived by TB patients which represent a more chronic form of uncertainty (Mishel, 1990).

Whilst it will be argued that uncertainty management – perhaps facilitated through organisational routines - is pivotal to ethical transplant practice, issues such as language mismatches and the use of an interpreter in transplant professional–patient communication were not found to influence ethical transplant practice as much as interprofessional communication did. This is one of the major themes in my thesis. This finding may be due to the fact that my study is set in an urban area and that transplant is a tertiary intervention. I will argue that interprofessional communication is a significant barrier to transplant care and that it poses serious consequences for ethical practice. Hence, this chapter will now consider interprofessional communication in healthcare.

5.4. INTERPROFESSIONAL HEALTH COMMUNICATION

In order for transplant to take place, a large number of healthcare professionals are required to communicate with each other. Like patients, these professionals are a diverse, multi-cultural, multi-lingual group. Although health professionals have had the benefit of a tertiary education, and thus may have greater societal standing than patients, hierarchies within healthcare institutions, as discussed in Chapter 3,

seem to affect interprofessional interactions. A number of South African studies have explored interprofessional communication in the healthcare context.

Sekokotla, Steyn, Bradshaw and Mbananga (2003) undertook a large quantitative study which explored barriers and facilitators to providing hypertension care in the Limpopo Province of South Africa. Utilising questionnaires for both doctors and nurses across study sites, an interesting finding was that of the 519 healthcare facilities from which the sample was drawn, the concept of two-way communication between doctors and nurses was only acknowledged at two sites. The lack of top-down communication from doctors to nurses may relate to the healthcare hierarchy where nurses sit lower down and medical professionals may sometimes deem that they are not necessarily worthy of possessing all the relevant information. In terms of ethical patient management, the apparent silence between doctors and nurses found in Sekokotla et al. (2003) illustrates challenges in interprofessional communication and team cohesion.

Longman (2013) undertook a study entitled *Interprofessional communication in a rural hospital*. The study aimed to understand and describe the nature of interprofessional communication, making use of qualitative methods such as ethnography and in-depth interviews. The study demonstrated the power of qualitative research to explore a phenomenon like interprofessional communication in the South African context, and yielded useful, comprehensive data. Of all the South African studies reviewed in this thesis, Longman's is the most methodologically similar to mine and it will be critically analysed in detail.

One of the methodological strengths of Longman's (2013) research was the use of ethnography, which she was able to undertake effectively because the research took place in a single setting. My study did not use ethnographic methods for two reasons. Firstly, it took place across multiple settings and secondly, given the *ad hoc* and urgent nature of transplant, obtaining consent for observation of transplant interactions proved to be ethically difficult.

Longman (2013) had had previous involvement at her research site. The function of relationships in qualitative research is interesting and will be discussed in more detail in the methodology chapter; however it bears a mention here. There are

clear differences between Longman's (2013) orientation to her participants and my own orientation to participants in my research study. Qualitative research literature is polarised on whether it is beneficial for a researcher to have had previous experience of a study context. Some argue that this is helpful because it brings insight and trust. Others argue it is better to enter the study as an outsider because it prevents bias. Both appear to have their merits. Being familiar with the research site and some participants, Longman's study had more potential for bias than mine did. However research is never entirely without bias, which can be instilled purely through reading and literature reviewing. My research may have been less susceptible to bias because I had no prior relationship or experience in the transplant field.

Longman (2013) found differences in communication styles across areas of her research site. In the theatre complex doctors and nurses were found to socialise and engage in small talk more frequently than in the ward setting. Communication in the wards was typically formal, objective and to the point. Whilst my study confirms Longman's (2013) findings related to the ward setting, findings regarding communication in the theatre complex differ substantially. Indeed, my research will show that in the transplant process, the surgical phase is one of the most problematic for communication and one which has serious implications for ethical practice. The difference between these study findings may be related to the urgency of transplant surgery which is not a factor in Longman's (2013) setting.

The influence of the healthcare hierarchy on communication is apparent in Longman's (2013) study. Staff at the top of the hierarchy were uncommunicative with those lower down, and were also more likely to be involved in conflict with other healthcare professionals of similar rank and those perceived as lower down. This was because staff at the top of the hierarchy felt more comfortable expressing themselves and were better able to assert themselves in situations where there was disagreement or debate. Hierarchy also influenced the tone of interprofessional interactions. At the bottom of the hierarchy, allied staff experienced difficulty contacting doctors. Poorly defined professional roles were

also problematic. All of these findings are confirmed in my research, although they sometimes appear to be heightened in the transplant process.

Wagner, Bezuidenhout and Roos (2014) made use of a quantitative survey to assess the attitudes of nursing staff in relation to communication across three public hospitals in Johannesburg, Gauteng. The sample included 265 nursing staff, representing operational managers, nurse managers and professional nurses. The study found that in terms of organisational structure nurses in more junior positions felt that nursing management did not communicate adequately, and that information was not always disseminated through the hierarchical nursing structure (Wagner et al., 2014). The study also found that 33% of nurse participants did not feel motivated to achieve their goals within the hospital setting and that 36.2% of respondents seemed indifferent to whether nursing staff have good communication skills or not.

These results suggest that within the health hierarchy, smaller hierarchies exist and that this extends into nursing staff. The fact that participants seemed indifferent to communication skills is interesting. Other studies reviewed in this thesis (Longman, 2013; Runkel, 2013; Van Waltsleven, 2014) suggest that nursing staff are not always recipients of important information because of their position in the hierarchy. If, as Wagner et al., (2014) suggest, nursing staff are indifferent to communication this may be another factor explaining why nurses do not assert themselves in the health setting (Lupton, 2003).

The findings of this study are also thought-provoking in terms of moral distress. Other South African literature (Longman, 2013; Runkel, 2013; Van Waltsleven, 2014) suggests that nursing staff find miscommunication frustrating, so it is surprising that almost one third of participants were indifferent to nurses' communication skills. These differences may be explained by methodology choices. Whereas Longman (2013), Runkel (2013) and Van Waltsleven (2014) all used qualitative methods, Wagner et al. (2014) opted for a quantitative survey. This did not allow for the exploration of such an unexpected finding in much detail. It is possible that had Wagner et al. (2014) introduced a qualitative component the complexity of such findings could have been further investigated.

5.5. TEAMWORK AND TRANSPLANT

Chapter 4 showed that transplant is a truly multidisciplinary health intervention where teamwork is essential. Interprofessional communication is a vital facilitator of this teamwork, because transplant teams need to coordinate and communicate in order to carry out their tasks. I will argue that individual transplant teams function effectively and hence are able to practice ethically. However, I will also show that when these individual teams are required to interact with each other, teamwork is much less effective and ethical transplant practice is compromised.

Efficacy of individual teams is determined according to the following criteria (Kozlowski & Bell, 2001, pp.31-37):

a. Cohesion

Cohesion is a multi-dimensional aspect of a team. It arises from both task cohesion and interpersonal cohesion. Task cohesion involves collaboration and the effective attainment of objectives. Interpersonal cohesion considers individual relationships within the team and the extent to which individuals enjoy participation in the team.

b. Collective mood or group emotion

There are two paradigms for considering collective mood and group emotion and its influence on team effectiveness. Top-down approaches consider the team as a whole and examine how emotional responses arise out of group dynamics. Bottom-up approaches consider how emotional reactions of individuals combine at a group level and affect the team as a whole.

c. Collective efficacy

Collective efficacy is an assessment based on self-reflection of how effective individual members of the team perceive the team to be. This is often ascertained by appraising whether a team is able to carry out the tasks required of it.

d. Conflict and divisiveness

Conflict is a common characteristic of professional teams and its management in the professional environment is essential, as it has been shown to adversely affect team efficacy. Marks, Mathieu and Zaccaro (2001) delineate two types of conflict

management: pre-emptive and reactive. Pre-emptive conflict management involves attempting to avoid conflict by implementing measures that will stop it before it takes place. Reactive conflict management involves real-time negotiation in conflict situations.

Evaluating multi-team interactions is more complicated. Lichtenstein, Alexander, Mccarthy and Wells (2004) state that cross-functional teams (also known as multidisciplinary teams) are integral to modern healthcare systems. They account for the complexity of modern biomedicine by enabling a variety of experts to lend their skills to complicated healthcare interventions, such as transplant.

In a relevant South African multi-team research study medical student teams were asked to work with nursing teams on a complex simulation where a patient was unable to breathe and was bleeding from a laceration on his arm (Treadwell, Van Rooyen, Havenga & Theron, 2014). After the simulation, the impressions of medical students about teamwork and interaction were considered. Students noted that teamwork was essential and through the multi-team collaboration process, found they gained a better understanding and appreciation of the scope of nursing practice. Students expressed surprise that nurses were able to undertake more complex tasks than they had previously been given credit for. Students also felt that trust was vital to good multi-teamwork and that clear communication in these circumstances was essential. The overall efficacy of the teamwork which participants undertook was not evaluated. It can be seen from this study that good communication, trust and mutual respect are essential for multi-team interaction (Treadwell et al., 2014). My study will show how the establishment of clear communication and trust between teams pose particular challenges to transplant teamwork.

5.5.1. Studies on transplant teamwork

Two studies that have considered transplant teamwork are particularly pertinent to my research and these will now be discussed.

5.5.1.1. Lingard et al.'s Study

In their 2012 qualitative study entitled *Representing complexity well: A story about teamwork, with implications for how we teach*, Lingard et al. aimed to characterize the complexity of activities and interaction in a transplant team distributed across one healthcare institution in Canada. In total, thirty-nine individuals participated in the study. They included medical professionals, allied professionals and transplant coordinators. The methods employed in the study were multi-faceted and included many hours of observation and field interviews with participants, as well as a number of formal participant interviews. There was a specific focus on improvisation in the face of daily teamwork challenges, which may involve an element of reactive conflict management (Section 5.5.1.1).

Lingard et al. (2012, p.872) identified three challenges to teamwork in the transplant setting:

1. Core team challenges which involved interactions within the transplant team itself.
2. Interservice challenges which referred to the interaction between the core transplant team and all the other teams contributing to the transplant process.
3. Outside challenges which involved interactions with larger social forces, administration and the general public.

The 2012 study describes these challenges in significant detail, recounting the story of a patient who required a transplant and the conflicting opinions of various teams who would be involved in the procedure. Core team challenges were identified and involved the negotiation of roles in the transplant team. However, Lingard et al. (2012) argue that these challenges were not significant because the team shared a mandate of transplant care. Hence, the focus of the study was on interservice challenges in transplant, which were perceived as substantially more complex.

Two characteristics of interservice challenges were identified. The first was division of labour, where work schedules, physical proximity and timetables influenced multidisciplinary interactions. This situation was further complicated by the

differing opinions of key parties where none had absolute authority to make a decision. Thus, rapid troubleshooting and negotiating, labelled "knotworking" (Lingard et al., 2012, p.872) was required between teams to reach a consensus. The study focused on knotworking, noting that it is not an indicator of dysfunctional teams, but rather a means to deal with everyday challenges, which are nonetheless unpredictable.

The second characteristic of interservice challenges was that of multiple objectives, where teams were not necessarily working towards a common goal. For instance, the objective of an anaesthesia team is to ensure adequate sedation. This differs from the objective of the transplant team – which is to complete the transplant. However, this cannot be done without cooperation from the anaesthesia team. The objectives of both transplant and anaesthesia teams differ from those of the radiology or pathology teams, which are required to ensure the patient is physiologically fit for transplant. Once again, the transplant team cannot move forward with their objective of transplanting the potential recipient without cooperation from these teams (Lingard et al., 2012).

Though Lingard et al.'s (2012) study makes use of similar methodology to mine, the study took place across only one transplant hospital. This is possible in Canada as transplant is much better integrated than in South Africa. My study took place across several transplant settings in order to give an overview of the Gauteng transplant process. These multi-settings added to the complexity of interservice challenges in the Gauteng context, and so I was able to explore multi-team interactions in more depth than Lingard et al. (2012) have done.

5.5.1.2. Samela, Fennelly, Brosnan & Robinson's study

In a study entitled *Interdisciplinary approach to the management of intestinal transplant recipients: Evaluation, discharge, and lifetime management,* Samela et al. (2005) describe the role of allied transplant professionals in managing intestinal transplant patients, beginning at listing, through to lifetime follow-up. The study does not include an empirical arm - instead it is an account of personal experiences at the transplant centre. The role of each team member and their interactions with

other team members is detailed, and the objectives of each team are also emphasised.

Samela et al. (2005) argue that in light of differing objectives, the key to improving interdisciplinary, multi-team collaboration in recipient management is for each team to appreciate the scope and role of the others, and to share responsibilities for the patient. This is considered essential for facilitating an integrated approach to patient management. It is emphasised that this does not change once a patient is discharged, and must continue for the duration of the transplant recipient's life.

Samela et al.'s (2005) study is relevant to my research because it highlights the role which the scope of practice plays in the healthcare setting. I will argue that poorly defined scopes of practice in Gauteng transplant can lead to interprofessional conflict, and that in order to mitigate some of this conflict and promote ethical practice through cohesion and team effectiveness, scopes of practice in transplant need to be much better defined.

5.6. CONTINUITY OF CARE

Continuity of care is typically defined as a relational concept, which involves communication and the presence of health care providers – who are familiar with the case - throughout the patient journey (Tousignant et al., 2014). In spite of its importance in the healthcare process, the World Health Organisation Collaborating Centre for Patient Safety Solutions (WHOCPS) (2007) notes that miscommunication, especially at the time of patient handover, can have serious consequences for continuity of care. One of these consequences is that the provision of care may be delayed because the necessary information has not been communicated in a timely manner (WHOCPS, 2007).

Handover occurs at a number of stages during the patient journey through the health system (WHOCPS, 2007). An inpatient, for instance, may be cared for by a large number of people working shifts during a hospital stay. Furthermore, as multidisciplinary healthcare has burgeoned the patient may be required to visit a number of different health centres. At each stage, where the patient comes under the management of a different health professional, a handover is necessary. In this

handover the current managing health professional is required to pass essential management information onto the professional who is taking over (WHOCPS, 2007). Rabøl et al., (2012) explored hospital team communication and found it was particularly challenging at the time of handover. Barriers to effective communication in the handover process were the result of poorly defined professional roles, where individuals were not certain about the scope of their involvement in the handover process.

In South Africa, Goudge et al., 2009, found that continuity of care was lacking in the patient referral system, especially in referrals between primary clinics and hospitals. Goudge et al. (2009) provide a number of examples where communication between institutions and communication with patients was inadequate and resulted in a patient's inability to obtain care. Interestingly, the findings presented in Goudge et al. (2009) show that continuity of care is a problem systemic to the South African healthcare system and that it permeates all health settings, regardless of whether they are rural or urban. My study will demonstrate that continuity of care, an essential aspect in the care of transplant patients, is lacking in the Gauteng transplant system and that communication errors at handover can delay the transplant process.

5.7. COMMUNICATION AND ETHICAL PATIENT MANAGEMENT

From the exploration of health communication research in this chapter, a number of themes and characteristics have emerged. These include the health hierarchy, factors when using interpreters, the notion of continuity of care, aspects of teamwork and questions about managing uncertainty. I argue that all these aspects of communication can have implications for ethical patient management, primarily based on informed consent and the notion of patient centred care (Table T5.3).

According to the National Health Act No. 61 of 2003, (Chapter 2), a mentally competent patient has a right to be involved in any decision about his or her management and this can only be implemented with his or her informed consent.

Table T5.3: A summary of health communication and its influence on ethical health practice

Theme	Implication for communication	Implication for ethical practice
Healthcare hierarchy	Unavoidable, affects both professional-patient and interprofessional communication (Jewkes et al., 1998; Longman, 2013). Manifested in poor information dissemination from the top of the hierarchy and unwillingness amongst the top of the hierarchy to engage with those lower down (Van Waltsleven, 2013). Creates conflict (Runkel, 2013).	Potentially compromised patient management based on lack of necessary information being passed from health professionals at the top of the hierarchy to those lower down.
Interpreters	Double-edged sword. Can facilitate communication but health professionals were found to doubt the quality of information which was transferred (Penn & Watermeyer, 2012a; Penn & Watermeyer, 2012b).	Potential to transcend language and culture barriers and hence vital for informed consent which involves information dissemination in an appropriate language.
Continuity of care	An issue both across and within health institutions (Goudge et al.,2009; Lingard et al., 2012).	Negative consequences for patient care because healthcare professionals are not provided with necessary information; hence they cannot provide the care a patient needs.
Uncertainty	Significant in transplant and affects professional–patient communication and patient emotional wellbeing (Martin et al., 2010; Scott et al., 2011).	Needs to be managed sensitively in order to avoid unpleasant situations and interactions, to promote patient wellbeing and patient - centred care.
Poorly defined professional roles	Unclear who should be apprised of what information and doubts about the competencies and scope of other health professionals (Longman, 2013; Runkel, 2013).	Lack of professional respect which results in communication failures which have implications for patient care.

To this end, the National Health Act No. 61 of 2003, (Chapter 2) states that a patient must be made aware of his or her medical condition, the range of management options available and whether these have any potential risks as well as the anticipated costs of such management. This information must be presented to the patient in a language which he or she can understand. Here, the issue of interpreters becomes relevant, because an interpreter may be necessary to facilitate informed consent.

Because of the legal and ethical (HPCSA, 2008a) mandates for patient-centred care and informed consent, I argue that a patient should, technically, be involved – or at least informed – of any option regarding management, throughout the process of care. Hence, in cases where essential information has not been communicated interprofessionally (because of the effects of the hierarchy, implications of multi-team interaction and a lack of continuity of care) it may not be possible for some health professionals to manage a patient ethically. This is because these health professionals are unable to provide the patient with information due to the fact that this information has not been communicated between the health professionals themselves.

5.8. SUMMARY AND CONCLUSION

This chapter discussed health and transplant communication. It focussed on factors of language, uncertainty management, teamwork and continuity of care. In this chapter I argued that good communication is essential for ethical patient care, because communication provides the way for information to be conveyed. The South African literature reviewed in this chapter showed that qualitative explorations of communication phenomena yielded powerful results, however, it was shown that transplant had not previously been the subject of such inquiry in a South African setting. Teamwork was shown to be an important feature of transplant, but this too had not been previously considered.

Chapter 6: Principlism and the ethics of care as theoretical framework

6.1 INTRODUCTION

This thesis involves a number of ethical principles and frameworks, with the ethics of care as the main theoretical framework for the project. However, organ transplant is imbued with ethical issues (Cox, 2014; Shafran, Smith & Goldfarb, 2015; Van Dijk, Hilhorst & Rings, 2014) and this chapter will discuss a number of these, with the ethics of care receiving particular detail.

6.2. PRINCIPLISM

Bioethics started to gain prominence in medicine in the 1970's as it started to become clear that advances in medicine, the move towards patient-centered care and innovations in research and development presented a multiplicity of complex moral questions without straightforward answers. Over the past sixty years, theories of bioethics have been refined, with a number gaining particular prominence (Pellegrino, 2000). One such theory is that of principlism, the brainchild of Beauchamp and Childress, first published in 1979 and refined over the years (Rauprich & Vollmann, 2011). Essentially, principlism is a set of four normative moral considerations (autonomy, beneficence, non-maleficence and distributive justice) which are designed to guide medical decision-making. The principles are not mutually exclusive, and often need to be weighed against one-another (Rauprich & Vollmann, 2011). My thesis will show that in transplant these principles are particularly important and relevant, and can be applied and considered at different points of the transplant process. Although a number of other ethical theories may have been useful in explaining my findings, principlism is the most encompassing and frequently utilised one in clinical practice (Muirhead, 2011).

6.2.1. Autonomy

The principle of autonomy is related to self-determination, and advocates that individuals ought to make decisions which are consistent with the manner in which they have chosen to live their lives, for instance, considerations of religious practices or financial limitations may be of relevance (Beauchamp and Childress, 2001; Gillon, 2003). In the healthcare context, autonomy can be linked to informed consent (Veatch, 1987), where it is necessary that a patient is apprised of all relevant information regarding the management options available to enable him/her to decide which would be the most appropriate one. In terms of organ transplantation, an individual may feel that donating the organs of a loved one conflicts with their personal religious practices (Falahati, 2014) and, in exercising autonomy, may decide that organ donation would not be morally correct. The role of the health professional in this case is to respect and facilitate the decision of the autonomous agent – who, in the case of a cadaver donor, would be the donor family. In bioethics, decisional autonomy is closely linked with informed consent because both concepts stipulate that an agent must be provided with sufficient information to make a decision (Veatch, 1987). Thus, in South Africa, the legal requirement of informed consent could be seen as a practical extension of autonomy.

6.2.2. Beneficence

In bioethics, the concept of acting in the best interests of the patient is an important, though not overriding, ethical factor (Beauchamp & Childress, 2001). Historically, acting in the best interests of the patient was often linked to paternalism, and hence the notion has become somewhat tainted. Furthermore, with the current era of patient-centred care, autonomy and informed consent appear to be the primary *locus* of bioethical discourse (Gillon, 2003). However, healthcare interventions cannot take place without some consideration as to the best interests of the patient, and without keeping the patient in mind. In Gauteng transplant, my data suggests that the patient seems to be forgotten sometimes.

6.2.3. Non-maleficence

Non-maleficence means 'the doing of no harm' and the principle can be related back to the earliest version of the Hippocratic Oath (Berdine, 2015). Practically speaking, the non-maleficence principle must be weighed against the others (Beauchamp and Childress, 2001). Hence, for example, when considering non-maleficence, it may be less harmful for a devout Jehovah's Witness patient to accept the consequences (possibly including death) of refusing a blood transfusion – provided the decision was made autonomously – rather than causing the patient harm by forcing him or her to undergo the procedure.

6.2.4. Distributive justice

According to Beauchamp and Childress (2001) the principle of justice requires the fair distribution of medical risk and benefits, medical costs and resources. It advocates that like patients should be treated in a like manner (Beauchamp & Childress, 2001). In the South African context, when one consider the inequalities found both across society and within the healthcare system, as described in Chapter 1, it is clear that benefits and risks are not equally shared, and that individuals are not equally treated, as, for example, in the way members of a medical aid scheme get better access to resources. When it comes to transplant, it is not only medical resources which should be distributed in a just manner, but also the organs themselves.

6.3. THEORETICAL FRAMEWORK – THE ETHICS OF CARE

The concept of care permeates the health setting. It is for this reason that people talk about health*care* and health*care* professionals. Care is the provision of services necessary to promote health, welfare or a similar desirable state. It is also defined as a feeling of concern for, or an interest in, a person or object which necessitates looking after them/it. Care is a societal ideal, and patients in a health interaction expect to receive fair, equitable and just care. However this literature review has shown that the South African health system is characterised by hierarchies, inequalities and uncertainties which have led to challenges in access

to, and provision of, healthcare services. It could even be argued that the South African health system is not very caring.

This section on the ethics of care will show that good caring must be taken into account in interpersonal relationships and that it cannot be rules-based. As the previous chapter argued, communication provides the foundation of these relationships in healthcare. Through communication, healthcare provision and receipt is realised. It follows, then, that organ transplant, which involves significant communication across a myriad of interpersonal relationships, may be especially interesting from the point of view of ethics of care arguments.

This chapter will demonstrate that transplant makes demands of care at two levels. Firstly, organ transplant normatively requires a distributive justice which allows everyone fair and equal access to healthcare services. Secondly, organ transplant requires resources – organs themselves – which are obtained through an act of caring, often in the context of death and grief. My thesis will show that ethical care becomes problematic because expectations of care cannot be realised within an unequal transplant context and it will show that an institutional ethics of care has not fully developed in Gauteng transplant.

As the previous chapters of this thesis have shown, transplant involves a large number of people, and amongst them, a large network of interactions and relationships. These interactions and relationships play out in the Gauteng healthcare system, primarily across a number of hierarchical health institutions. These relationships contain within themselves different expectations and involve many different personalities. This section will demonstrate that as a situational moral theory, which considers individual relationships and their context in hierarchical institutions, the ethics of care can provide an insight into the implications of this research.

Over the last few decades the ethics of care has become a prominent moral theory, thought to offer a viable alternative to rule-based theories like deontology and

utilitarianism[15] (Held, 2006). Held (2006) and van Bogaert (2006) agree that the ethics of care is rooted in femininity, noting that kindness, empathy and caring for others suggest the importance of relationships and connections amongst people. The expression of these values is dictated by emotion and personal understanding, qualities commonly associated with women. Values such as autonomy, fairness and normative justice are considered to be more masculine ones. They focus on separation, and the application of rules-based reasoning on a universal scale (Van Bogaert, 2006).

I now go on to discuss the philosophical development of the ethics of care, emphasising the work of Joan Tronto, which is of particular relevance for my thesis. The ethics of care will then be integrated into the framework for the research argument.

6.3.1. Development of the ethics of care

The ethics of care was first conceptualised by Carol Gilligan in her landmark paper, *In a Different Voice* - a response to the work of several male psychologists, most notably Lawrence Kohlberg (Gilligan, 1977; Van Bogaert, 2006).

Kohlberg advanced a theory for Levels of Moral Development which is briefly depicted in Table T6.1. Gilligan notes that Kohlberg identified women as typically functioning at the third stage of moral development (Gilligan, 1977) and hence with a lesser capacity for morality than men, who functioned at the fifth or sixth stage. Gilligan challenged this, arguing that women are not less moral then men, but rather that women have a different type of morality (Van Bogaert, 2006). Gilligan went on to conduct substantive studies on the moral voices of women, and she concluded that women tend to view morality from an orientation of caring for others, and a responsibility towards others on a personal level (Gilligan, 1977).

[15] Deontology and utilitarianism are two rules-based ethical theories. Deontology is a normative theory which guides agents in choosing their actions. It is based on a set of moral rules for determining actions that are acceptable or unacceptable. It is a moral framework for determining what an agent ought to do (Stanford Encyclopaedia of Philosophy, 2012). Utilitarianism is a moral theory which guides agents in their actions by suggesting that the morally correct action is the one which produces the greatest amount of good (utility) for the largest number of people (Stanford Encyclopaedia of Philosophy, 2014).

Table T6.1: Kohlberg's levels of moral development (Kohlberg & Hersh, 1977, pp.54–55)

Level	Stages	Description	Orientation
Pre-Conventional Level	1. Punishment and obedience orientation	Represents basic moral development	Children
	2. Instrumental relativist orientation		
Conventional Level	3. Interpersonal concordance or "good boy-nice girl" orientation	Based on interpersonal relationships and the recognition of responsibility towards others, such as family and friends. It emphasises an agent's role and place in society. An agent developed to this stage of morality is aware of their obligations to society, which are dictated by their societal standing. Furthermore, an agent at this stage of moral development will act in such a way as to maintain and justify the social order which constrains his actions.	Women
	4. Law and order orientation		
Post-Conventional, Autonomous, or Principled Level	5. Social-contract legalistic orientation (generally with utilitarian overtones)	These levels represent the ultimate in moral development, where one's actions are directed by principles and maxims, and do not regard the self, or others, on any individualistic level. These maxims include justice and equality.	Men
	6. The universal ethical-principle orientation		

Many ethics of care theorists have since objected to some notions of Gilligan's work, and have concentrated on refining the ethics of care. In her 1987 article, *Beyond gender difference to a theory of care,* Joan Tronto expands on Gilligan's ethics of care argument. Tronto's main objection to Gilligan's work is that Gilligan locates the morality of women as a function of their gender, and thus serves to highlight the difference between men and women, rather than to morally empower women in any substantive sense (Tronto, 1987). I agree with Tronto here. Gilligan's contention that women's morality is based on caring and is different to men's morality entrenches the notion that women and men are morally different; and it could open the door to challenges between the sexes.

Tronto offers an altered interpretation of Gilligan's theory, arguing that the caring morality which Gilligan associated with women, is a function of their subordination in modern society rather than their essential femininity (Tronto, 1987).

Viewed in this way, the morality which Gilligan has attributed to women could be ascribed to most minority groups in society - many of whom are subordinate and assume the roles of caring (Tronto, 1987). This claim echoes some of Lupton's (2003) observations in relation to healthcare hierarchy, where nurses – who assume caring roles - were typically female and were seen as subordinate in the health context. Tronto cautions, however, that locating caring roles as a function of social order tacitly endorses Kohlberg's claim that women (and minority populations) fail to develop properly. These groups perceive themselves as subordinate and thus they cannot attain a higher level of morality within Kohlberg's framework (Tronto, 1987). Tronto suggests that we stop considering the ethics of care as a feminist theory and rather view it as a moral theory (Tronto, 1987).

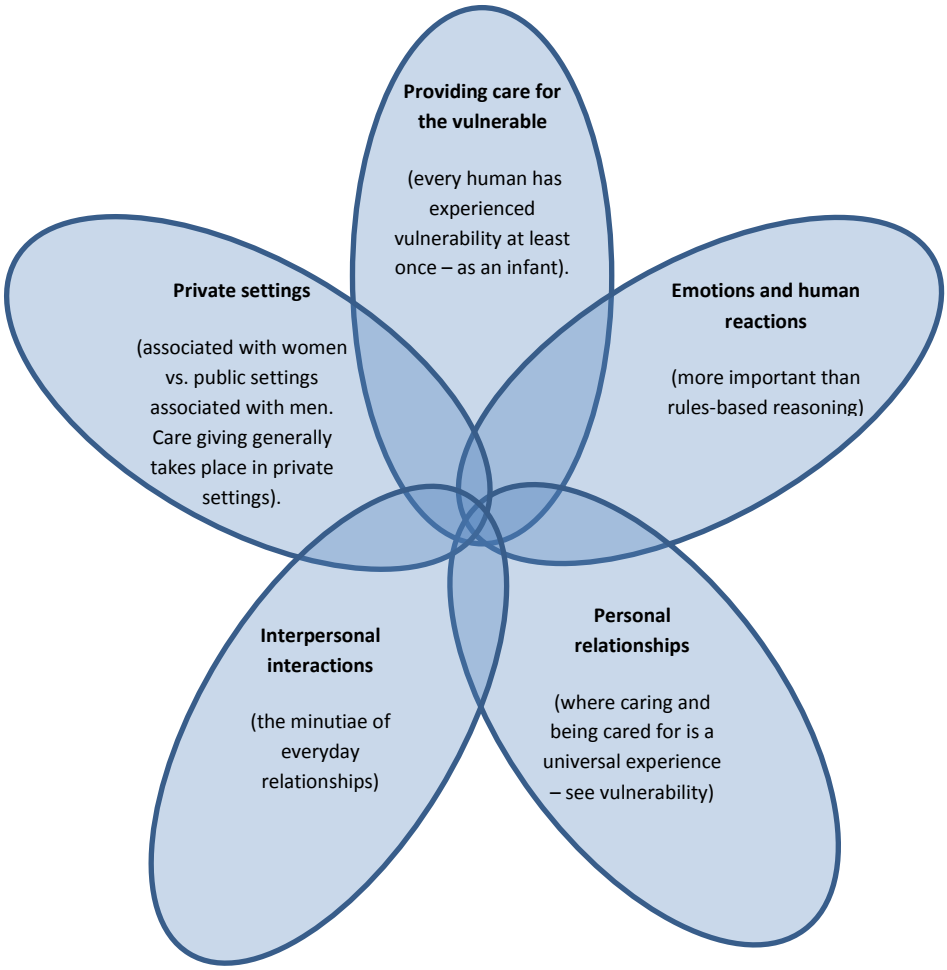
These notions have implications for the South African research context. Subordination in Tronto's (1987) ethics of care is relevant because this literature review has shown that both patients (Jewkes at al., 1998) and allied health professionals (Langley et al., 2013; Runkel, 2013; Van Waltsleven, 2014) can be subordinated in the health system. Thus, a consideration of subordinate relationships throughout my thesis is important.

6.3.2. An overview of the ethics of care as a moral theory

For Virginia Held, the ethics of care involves values enshrined in the processes of caring and being cared for (Ethics of Care, 2012). Having a caring disposition or a motivation to care is insufficient, there must be corresponding action (Held, 2006). As this literature review has shown, transplant is a process where care provision is required in different forms throughout. Hence, transplant appears to provide a platform which could lend itself to the application of the ethics of care. In a definitive book entitled *The ethics of care: personal political and global*, Held identified five major characteristics of the ethics of care as a moral theory (Held, 2006, p.10–13). These are illustrated in Figure F6.2.

Figure F6.2 – Five characteristics of the ethics of care (Held, 2006, p.10–13)

This figure shows the five characteristics of the ethics of care as a moral theory. All five characteristics converge, and this results in a morality which encompasses not only physical processes of care, but also reflexivity and universal experiences of care.



6.3.3. Joan Tronto's ethics of care

Whilst Held (2006) argues that, through the act of providing care, there emerges a space for reflection and moral action, Tronto takes the notion of caregiving further and suggests a mechanism by which care may be assimilated into everyday life. She acknowledges the importance of the five characteristics of the ethics of care, as shown in Figure F6.2 above, arguing that "power requires a moral base" (Tronto, 1993, p.93) and goes on to propose a framework of four levels of care which could constitute this moral base (Table T6.3).

This framework is set within the context of an essential question which ethics of care compels every individual in society (man, woman, rich, poor etc.) to ask: "How can I (we) best meet my (our) caring responsibilities?" (Tronto, 1993, p.137).

Table T6.3 – Tronto's four levels of care (Tronto, 1993, p.105-108)

Level 1	Caring about	An overt realisation or recognition that care is needed and that something must be done to meet this need.
Level 2	Taking care of	Assuming some responsibility for fulfilling the need for care identified at Level 1 and determining the appropriate response.
Level 3	Care giving	Taking direct action to meet the needs for care by combining caring about and taking care of (cannot involve giving money).
Level 4	Receiving care	Considering the way in which the object of the care responds to the care that is given. This helps to identify whether the original need, which was identified in Level 1, has been met.

Within Tronto's framework, responsibility and relationships are considered more important than rights and rules. Moral actions, which are expressed by the physical activity of caring, take place within a specific, relational context (Tronto, 1993). The notion of a relational context is relevant my research, given that much of this literature review has explored the South African context within which the transplant process takes place. Considering the implications of this context for the ethics of care may enhance my research results.

Tronto argues that in order to provide effective care, all of these levels need to be assimilated in a moral agent. Tronto further argues that it is imperative to provide good quality care. Her suggested standards for this care provision are given in Table T6.4.

Table T6.4: Tronto's five aspects of 'good' caring (Tronto, 1993, p. 108–110)

1	Practice	Good caring comes about through repeated decisive thought and action
2	Conflict resolution	The caring agent is required to negotiate the complex territory of what kind of care is acceptable, and to whom
3	Particular and universal aspects	Good care should acknowledge particular aspects such as individual needs, but also place these within a sensitive interpretation of universal constraints such as respecting an individual's culture
4	Resources	Good caring cannot take place without good resources
5	Care as a standard	A high standard of care can be used as a tool by which we may judge the appropriateness of actions and situations

Tronto's five aspects of good caring are interesting when viewed in the context of South Africa's healthcare system, which is permeated by inequalities, particularly in resource distribution. The fourth aspect of good caring – the requirement for resources - seems a challenge in the South African setting where resource distribution is a pressing issue. Interestingly, Tronto's premise that care is a function of resources may serve to explain some of the findings from the study by Dhai et al. (2011) that patients in the state sector – which experienced serious resource shortages in comparison to the private sector – felt they received sub-optimal care.

6.4. THE ETHICS OF CARE AND HEALTHCARE INSTITUTIONS

Health institutions are relational spaces where an expectation of care is traditionally enshrined. This can perhaps be traced back to the Hippocratic Oath, which acknowledged the inherent vulnerability in being a 'patient' and the power

in being a physician, and advised physicians against the misuse of this powerful position. As I have shown in Chapter 3, the notion of asymmetrical power relationships seems to pervade healthcare institutions today. This, though problematic for the provision of care, does mean that the healthcare environment is ripe for the application of the ethics of care, which acknowledges a hierarchy and the importance of relationships within it.

In a 2010 article entitled *Creating caring institutions: politics, plurality and purpose* Tronto argues for the extension of her ethics of care into the institutional setting, and explores what this would entail for institutional structure and governance. She proposes three facets which are necessary to create an institution where care is appropriate. These are an agreement on the purpose of the care provided, an acknowledgement of power relations within the institution and a commitment to tailor care to meet individual needs. These are framed in arguments related to power, purpose and particularity.

In terms of the purpose of care provided, Tronto (2010) notes that this requires a form of institutional objective which all role-players understand and upon which everyone agrees. The purpose and end-points of transplant have been considered in the transplant process; however in discussing teamwork, the study by Lingard et al. (2012) showed that the purpose of transplant may not always be the same for everyone involved. The study by Naude et al., (2002) showed that the purpose of transplant professionals may also differ, depending on perceptions of their individual role (as a nurse or a transplant coordinator) and their scope of practice.

Tronto (2010) argues that the notion of asymmetrical power relations within an institution must be brought to the foreground of debate, where it helps to broaden debate and helps to identify points where policies to keep power in check, must be introduced. Power relations in the health setting have been explored through the health hierarchy and in this literature review I have argued that the hierarchy is a prominent feature of the South African health context.

Particularity emphasizes the way in which caring activities are unique to those involved in them, and the way in which the needs for care change over time, depending on the requirements of the situation (Tronto, 2010). My research is well

positioned to ascertain needs for care in transplant by considering the transplant process in detail as it unfolds over time and discussing the care needs of role-players within it at different stages – for instance the differing needs of recipients pre- and post-transplant.

In her 2010 article Tronto also presents seven criteria by which we may evaluate institutions and the quality of care they provide (Table T6.5). In this case she flags trends which could indicate compromised care.

6.5. ETHICS OF CARE AND COMMUNICATION

As I have argued in Chapter 5 of this literature review, communication takes place between professionals and patients (Goudge et al., 2009; Penn & Watermeyer, 2012a; Penn & Watermeyer, 2012b), and interprofessionally over the course of a health interaction (Longman, 2013; Wagner et al., 2014). This communication may be particularly detailed, for instance during the handover process (WHOCPS, 2007), or it may conform to some general trends (which seem to be propagated by the health hierarchy) such as the findings that allied professionals feel that medical professionals do not always communicate information adequately (Runkel, 2013).

Both the ethics of care and communication seem to have implications for healthcare as a process. Providing good institutional care relies on the notion of caring as a process (Tronto, 2010). Because care requires good information dissemination as a patient moves through an institution (WHOCPS, 2007), communication is also a process.

I would argue that both the ethics of care and communication have personal relationships at their core. Both Held (2006) and Tronto (1993) emphasise the importance of examining and improving these relationships, especially through an acknowledgement of particularity (Tronto, 2010). Similarly, communication has been shown to help to establish personal relationships (Johnson et al., 1999; Raiz et al., 1999) which tended to lead to favourable patient outcomes and had positive effects on the morale of health professionals. Here again, the ethics of care and communication are complimentary, because both require attention to detail in appreciating and facilitating interpersonal relationships.

Table T6.5 – Care as a standard - seven signs that institutions are not caring well (based on Tronto, 2010, pp.163-166)

Those who require care are considered unfortunate	An interesting position based on the notion of the dominant, independent (male) who does not require care, the corollary of which is that those who require care are somehow unlucky or unfortunate because they have lost this trait of dominance. Tronto argues that we all need care at some point, and this should be recognised.
The needs of those who receive care are considered identical	An institution which presumes that the needs of all those who require care are the same is likely to fail in providing care, because care requires particularity – accounting for individual needs based on specific situations.
Care is considered a commodity	Care should be seen as a process; it is not something to be bought and sold. Considering care as an economic construct seems to invoke notions of scarcity, and care should not be scarce. Tronto finds this commodification of care objectionable because it implies that individuals are consumers and are hence limited in the extent to which they may choose how their care needs are fulfilled.
Care receivers are considered unable to make judgements about the care they need	The power format of institutions often results in independent powerful individuals issuing care instructions which are carried out by less powerful individuals. This 'care' is then extended to the person in need who may be seen as relatively powerless, unable to understand their condition and unable to make a decision about acceptable care.
Care is considered as 'care giving' rather than a process	Care 'attentives' and care responsibilities are important for providing good institutional care as they bestow the act of caring with institutional import. Where either of these is not given adequate prominence, the carers in an institution become marginalised and the process of care becomes mechanical.
Caregivers consider organisational requirements as hindering provision of care	The role of a manager in an organisation is often more powerful and better compensated than that of a caregiver. When caregivers start noting that institutional management has become a hindrance, the caring capacity of the institution is diminished. In these cases, institutional policy should be reconsidered in order to help caregivers with care provision. This may be a function of the healthcare hierarchy (Section 3.2) because it addresses the roles of different individuals.
Caregiving roles are considered to be the province of a certain class, caste, gender or race	In institutions where women, racial minorities or previously disadvantaged groups typically assume caring roles and men, perceived to be independent and powerful, take on the roles of leadership, caring can be compromised. This related to the healthcare hierarchy, which shows that healthcare institutions are typically characterised along these lines. This aspect comes back to the role of societal subordination, which is one of the founding principles of Tronto's ethics of care.

This literature review has shown that transplant itself encapsulates many of the same aspects which are vital to care and communication. Transplant is a process. At its core it involves a very large number of personal relationships. These relationships vary in nature and are shaped by emotion, desperation, frustration or anger, depending on who is interacting with whom at the time. I argue, then, that the ethics of care is a suitable theory with which to better understand and portray transplant communication, because of the key similarities between the main concepts.

6.6. ETHICS OF CARE AND TRANSPLANT RESEARCH

Very little research has been undertaken which considers the ethics of care and organ transplant in detail. McNeal (2012) recounts a complex transplant case and notes an ethics of care is needed, but never actually explains the need further. Similarly, Stabile (2011) and Tong, Bastron and Graber (2012) seem to imply a relationship between ethics of care and transplant but do not substantiate it.

Heinemann (2014) considered motivations for seeking transplant services and the implications these had for caring relationships between transplant recipients and their loved ones. Heinemann emphasises multi-directional care and the context of care, noting that one can be simultaneously care giver and care receiver, depending on context. She argues that transplant recipients enter the transplant process as individuals who are often relied upon to provide care for others, and that receiving a transplant was seen as a way to reassume this caring role which might have been lost. Interestingly, Heinemann argues that this need to reassume a caring role fuels desperation to receive a transplant, so transplant may be pursued primarily in order to sustain the role of caring.

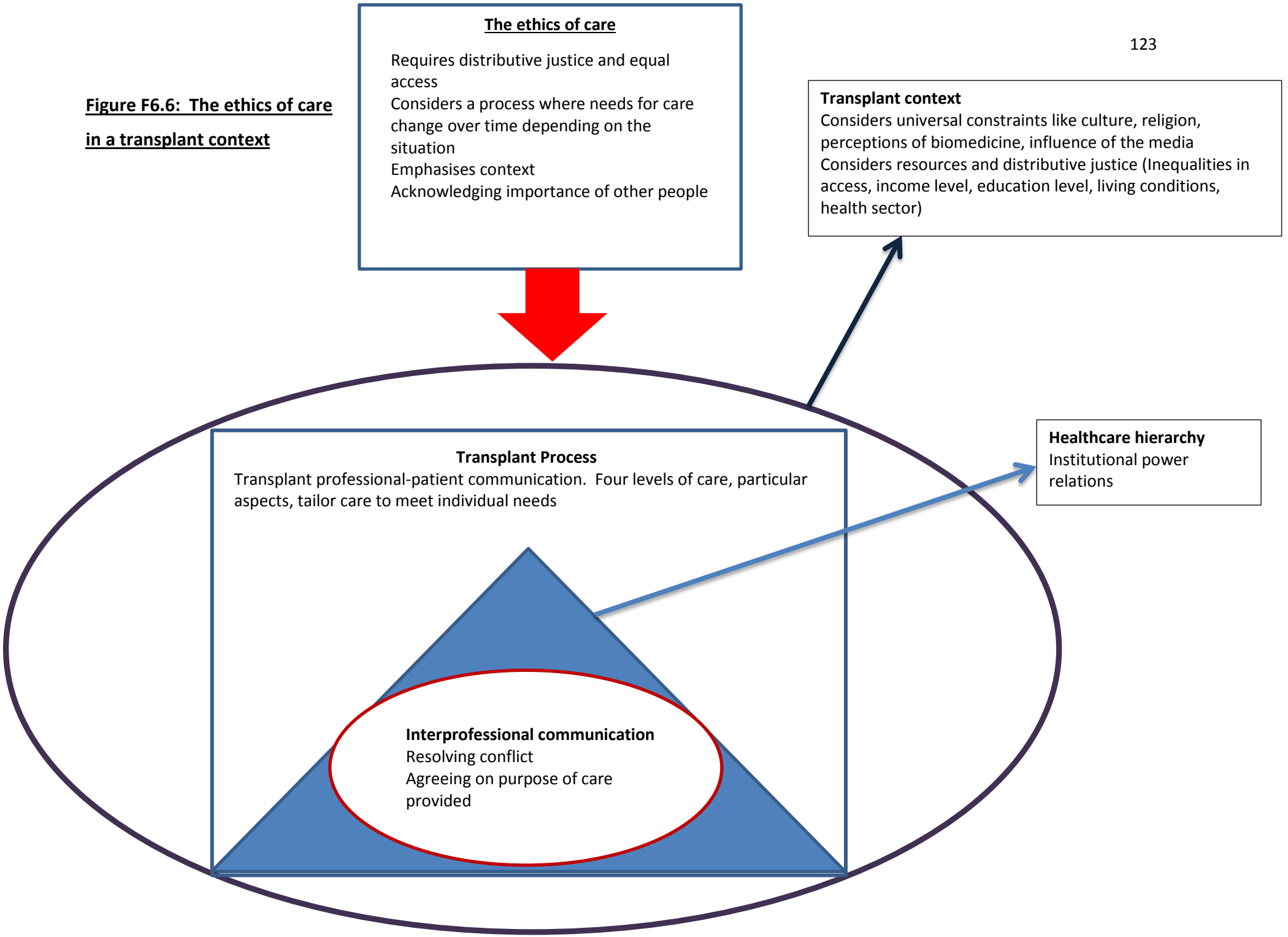
Here we see transplant as a process, which is important in terms of Tronto (2010). This is interesting in light of my thesis which will argue that desperation to receive an organ is a primary factor influencing health professional–patient communication. Heinemann argues that a consideration of local and moral sensibilities about what care should entail are important for those seeking a transplant – and this speaks to Tronto's notion of plurality in the care process.

6.7. CONCLUSIONS ON THE ETHICS OF CARE

Figure F6.6 depicts a model of the ethics of care in a transplant context, drawing together a number of the main themes considered in the literature review into a framework based on ethics of care principles. It has been argued that the ethics of care must consider universal factors (Tronto, 1993) which in this literature review are aspects of cultural and religious practices, suspicions of biomedicine, the influence of the media and the situation of inequalities in which people live and access healthcare. These all serve to create a context which should be appreciated and understood in order to apply the ethics of care in a transplant setting. It has also been argued that at an institutional level care must be considered as a process (Tronto, 2010) and that particular aspects, like managing patient uncertainty and information provision, need to be addressed. Power (Tronto, 2010) is factored into the model primarily as a function of the health hierarchy, where power asymmetries between care givers and those receiving care pose challenges for patient management and communication. The purpose of care (Tronto, 2010) and the role of conflict (Tronto, 1993) are considered in terms of interprofessional interactions. In transplant, this literature review has shown that conflict can occur in interprofessional relationships and that transplant professionals may be at odds with one another in terms of the purpose of care they are providing.

The ethics of care has implications for this discussion of transplant in Gauteng. Firstly, I have demonstrated that access to transplant in Gauteng is unequal, and that those who are able to afford private care also enjoy better transplant prospects. Here, we see the notion of care as a commodity and this commodification of care holds implications for the results of my research. I have also shown that transplant is characterised by power in decision-making, where doctors are the most influential health professionals and male family members have the final say in donation decisions.

Figure F6.6: The ethics of care in a transplant context



I have further shown that a large web of interpersonal relationships form during the transplant process, and these are bounded and defined by the communication within them. My thesis will argue that these relationships in transplant influence both patient care and also care for one's colleagues and fellow health workers. The ethics of care also accounts for uncertainty in transplant and invites consideration of the care needs of a potential recipient and how these might change post-transplant, as presented by Heinemann (2014). My thesis will show that this type of particularity of care often depends on the phase of the transplant process, and is demonstrated to varying degrees across it. Through considering challenges to the ethics of care, I will also argue that a failure of care in transplant could lead to moral distress.

6.8. LITERATURE REVIEW – SUMMARY AND CONCLUSION

This literature review has provided a large amount of information and discussed a number of studies which are relevant to my research. The literature review started by exploring differences between international and South African transplant, and I considered some factors which influence the South African transplant context such as scandals, the role of the family in making decisions, the importance of public awareness, the influence of religion and ancestral beliefs and suspicions of biomedicine. Through an exploration of the differences between international and South African transplant programmes, I argued that some of the main barriers to transplant identified in the South African literature had been overcome internationally, and thus a grassroots exploration of transplant was required in order to identify other factors which could account for South Africa's low transplant rate.

Because this exploration necessarily took place within health institutions where transplant takes place, the second section of the literature review explored some essential characteristics of South African health institutions. These included the health hierarchy and features of moral distress. It was shown that the health hierarchy mirrored societal hierarchy with social factors like wealth, gender, power, income and education level permeating health institutions along the same lines. I argued that

practicing within the hierarchy, combined with systemic resource challenges which were identified in Chapter 2, created an environment where moral distress could occur.

Chapter 4 of the literature review considered the transplant process. I argued that because this takes place within health institutions an appreciation of their hierarchical structure was necessary in order to contextualise the transplant process.

In subsequent chapters, the literature review was further narrowed to consider health communication. In my study, communication takes place within the healthcare setting and transplant communication is bounded by the transplant process. Both transplant professional–patient communication and interprofessional communication were considered. I argued that both are essential for an appraisal of communication throughout the transplant process.

Finally, the literature review covered the ethics of care and I argued that this is an appropriate framework for understanding research results because of the way it advocates concepts like process, context, time, interprofessional relationships, conflict resolution, notions of power and the importance of resources - all important to the realisation of caring institutions. In terms of methodology, this literature review has considered the findings of both qualitative and quantitative studies in healthcare and in transplant at an international and local level. It has shown that qualitative studies produced the most helpful results when considering issues such as communication, hierarchy, moral distress and uncertainty management. I utilised qualitative methods for this reason.

Throughout this literature review, a number of gaps in both international and South African transplant research were identified. Internationally, I argued that the concept of moral distress has not been considered at any point in the process other than pre-transplant. When it came to uncertainty management in transplant I argued that whilst the experiences of recipients had been previously researched, this was not the

case for transplant professionals and donor families. My research proposes to address these shortfalls.

Locally, I argued that research considering interprofessional transplant communication using qualitative methods has not previously been undertaken in South Africa. Given the scale of interaction required and the possibly serious results of a miscommunication, obtaining relevant evidence seems particularly important. Similarly, teamwork in transplant, whilst undoubtedly significant, has not previously been explored in a South African setting. The literature review also showed that in the South African setting transplant communication has not been researched from a perspective of transplant professionals themselves and no South African research has previously documented the transplant process as a whole. It was noted that research relating to follow-up of donor families was especially scarce in South Africa. My research hopes to address some of these gaps in South African transplant literature.

CHAPTER 7 -

Methodology

7.1. INTRODUCTION

This chapter aims to describe the process which was followed in my research. It begins by examining broad methodological choices and providing a general overview of the research design. The chapter then details each component of my research, describing specific method choices. Ethical considerations specific to individual arms of the research and ethical considerations which were general to the whole sample are then discussed and subsequently data treatment, analysis and rigour are examined.

The purpose of my study was to explore organ transplant and communication in Gauteng. As the literature review has shown organ transplantation is a complex field in healthcare. It involves many individuals with different skills sets, and requires teamwork and team liaison. The overall research objective necessitated an exploration of all the of interaction as depicted in Figure F1.4.

7.2. AIMS AND OBJECTIVES

The overall aim of my research was to explore communication in transplant settings in the Gauteng province.

The specific objectives were to:

- Explore communication aspects of organ transplant in Gauteng from a transplant professional and patient/family perspective.
- Attempt to understand how decisions about organ transplant are made by patients (donor families, living donors) and transplant professionals in the context of personal experiences.
- Ascertain likely barriers to, as well as facilitators of, transplant in Gauteng.

7.3. RESEARCH DESIGN

My research was concerned with exploring communication, a process which is based upon relationships and interactions, and how it relates to organ transplant, a health intervention which, as the literature review has shown, produces challenges due to its complexity and the number of individuals that are involved. Given the relational nature of communication and the characteristics of the health intervention being explored, I made use of both constructionist and pragmatic paradigms (Guba & Lincoln, 1994).

I argue that because communication is personal and contextual, explorations of communication lend themselves to constructionist approaches. The thesis of constructionist approaches is that meaning and truth are relative, and are constructed by humans based on the social and historical context within which they function. The literature review has shown that many aspects of my research context, and of the individuals within it, have been constructed by the South African setting. Similarly, communication is an interchange between individuals who enter into an interaction with their own sense of identity, perhaps a function of their context and worldview. For these individuals, such interactions may have differing meanings. Epistemologically, constructionist approaches acknowledge a link between the researcher and the research participants, who, through a convergence of their different backgrounds and worldviews, construct knowledge through the research interaction (Guba & Lincoln, 1994).

I argue that because organ transplant is a health intervention which faces significant challenges, pragmatic approaches which consider how to overcome these challenges or improve the intervention are also relevant. The epistemology of a pragmatic approach is to gather many different views on a phenomenon and then attempt to reconcile them in order to identify trends (Guba & Lincoln, 1994). Pragmatism requires exploration of a real-world problem, such as transplant, rather than a hypothetical one.

By combining constructionism and pragmatism I propose to account for both the realities and challenges of transplant.

7.3.1. Why choose qualitative research?

Whilst the science of transplantation has been well documented, certain factors central to the process appear to have been neglected. These have been identified in the literature review. My study examined a complex topic within a multifaceted context. Because the phenomena under investigation are not easily quantifiable, and because my research was concerned with perceptions and individual people, I decided that qualitative methodology provided the tools best suited to the nature of my proposed enquiry.

Qualitative research is concerned with perceptions and experiences of social phenomena, from the perspective of the individual, in his or her natural context (Barbour, 2000; Malterud, 2001). It emphasises the presence of multiple (sometimes contradictory) views and voices and the interplay of these (Barbour, 2000). As it allows for the exploration of different standpoints, qualitative methodology appears ideally suited for research on organ transplantation, which involves a multitude of individuals, teams and interactions.

Qualitative research methodologies are not uniformly accepted as a legitimate means of answering research questions relating to healthcare phenomena (Jones, 1995; Malterud, 2001). Jones (1995, p.2) posits that a methodology where: “the generation of hypotheses often replaces the testing of hypotheses, explanation replaces measurement and understanding replaces generalisability” does not sit well with clinical scientists. However, Jones (1995) also argues that qualitative methodologies are useful when exploring questions of belief and understanding, as they offer the researcher a toolkit with which to evaluate aspects that, owing to their abstract and complex nature, are not conventionally quantifiable.

7.3.2. Principles of qualitative research

As qualitative research is based on "systematic collection, organisation and interpretation of textual material derived from talk and observation" it is sometimes faulted for lacking numerical quantification, an essential element for evaluating credibility, objectivity and generalisability (Malterud, 2001, p. 483). However, Malterud (2001) argues that these benchmarks find corollaries in qualitative research in the principles of validity[16], reflexivity and transferability. Also, the means by which the researcher fulfils these criteria in qualitative research differ from those used in quantitative enquiry, due to the differences in the nature of the data set and assumptions about how the questions are going to be answered (Malterud, 2001).

Reflexivity concerns the relationship between the researcher and the research question. To this end, I continually evaluated my relationship with the data and considered potential sources of bias. Malterud (2001) argues that, though the background and experience of the researcher will influence the research questions and chosen methodology, this should be viewed as a demand for reflexivity rather than a limitation of qualitative inquiry (Barbour, 2000; Malterud, 2001).

At the time the project began, I had had little first-hand exposure to transplant procedures. This proved advantageous in that it allowed me to position myself as an outside observer, without being influenced by prior experiences and interactions. However, I had also read extensively on the topic, and had formulated certain hypotheses based on these readings. Many of these hypotheses related to trends generally observed in transplant in South Africa, which have been discussed in the literature review. These hypotheses have undoubtedly informed my research questions, and may have introduced an element of researcher bias into the process.

[16] It may be argued that validity is not a qualitative term, however Malterud (2001) uses it in her article.

7.4. DATA COLLECTION TECHNIQUES –IN-DEPTH INTERVIEWS AND FOCUS GROUPS.

7.4.1. In-depth interviews

I decided to make use of in-depth interviewing and focus groups as my data collection techniques. Interviews took place on either a one-on-one basis, or within a nuclear family. Focus group discussions were guided by common characteristics of the participants. This will be discussed in Section 7.7, below. In-depth interviews and focus groups were chosen because I considered that, given the intricacies of my research questions and objectives, they would provide the most appropriate data collection method within the highly complex research setting.

In-depth interviewing allowed for the discussion of particular, focused topics whilst also providing participants with sufficient leeway to express their views and explore these as they unfolded (Marshall & Rossman, 2011; Miller & Glassner, cited in Silverman, 2011). Given the intricacies of transplantation in South Africa, the possibility of identifying important and unexpected phenomena added to the appeal of in-depth interviews as a study tool. This technique also provided an opportunity to glean an understanding of the cultural frameworks inside which individuals locate their experience (Miller & Glassner, cited in Silverman, 2011, p. 133). Within the unique and diverse socio-cultural structure of South Africa as a whole, identification and exploration of such phenomena was considered vital.

It has been widely argued that the evidence base in healthcare must be extended to include healthcare professional interactions and interactions with patients in their specifically lived context (Barbour, 2000). In-depth interviews serve to perform this function within my research. Jones (1995) notes that incorporating this type of naturalistic, interpretive enquiry into healthcare research can serve to enhance the field.

7.4.2. Focus groups

Focus groups have a number of advantages in health research settings (Green & Thorogood, 2014). Hence I decided to utilise focus groups as one of my data collection techniques. According to Green and Thorogood (2014) in a focus group which has been carefully planned a researcher can not only collect verbal data, but also observe interactions between individual participants. Furthermore, focus groups give participants a unique opportunity to interact with each other, to debate differing points of view and in some cases to refine or clarify shared opinions (Tong, Sainsbury & Craig, 2007). I argue that, because this is a communication study, the focus group gave me a unique window on the dynamics amongst my study participants. I was able to observe who was most dominant and opinionated, who was quieter and how participants communicated with one another. Green and Thorogood (2014) argue that a focus group where participants are already known to each other, what they call a 'natural group', can provide interesting insight into *how* social knowledge is generated. Because of the complex backdrop of my study, where I argue both knowledge and identity are formed by historical factors, I used focus groups – where appropriate – to investigate this phenomenon.

7.4.3. Appraisal of other potential data collection techniques

As my literature review suggests, communication is both a complex human phenomenon and an essential element of health practice. As such, it has been widely studied and a large number of methodological approaches have been utilised (Sparks, 2014). Amongst these approaches, observational methods and conversational analysis (Wessles, Koole & Penn, 2014) have both been used effectively in the South African setting.

In designing my study I carefully considered the ethical implications of my chosen methods and I undertook extensive consultation with transplant professionals and coordinators about the most appropriate data collection strategy. Whilst directly observing or recording actual transplant interactions with patients may have enhanced

the study, I argued – and many concurred - that the interactions themselves were of too sensitive a nature for this to be ethically feasible at this stage. For instance, I grappled with a possible data collection technique where interactions between potential donor families and transplant coordinators could be recorded. However, in these cases the family is in a state of grief, and I posit that observing interactions of so sensitive a nature may have caused additional harm to the families themselves.

It could also be argued that it would have been appropriate to record or analyse interactions between transplant professionals as they took place. I discounted this method as unfeasible for two reasons. Firstly, as my study was the first of its kind in South Africa, I had little previous research to guide me as to the exact nature of communication that takes place between transplant professionals – was it face-to-face, telephonic or through the use of mobile phone technology? Hence, I was unable to accurately target the types of communication which warranted exploration. Secondly, because transplant involves communication across a number of geographical settings, such techniques would not have been feasible in terms of time or budgetary constraints.

In fact, I posit that given the large number of interactions which take place simultaneously – and between different transplant professionals – when coordinating a transplant, a method of direct recording or observation may have resulted in some important factors being left out of the data set. Because my objectives were to explore communication as a whole, I feel that my chosen method was most appropriate given the nature of my research and the paucity of previous studies which could have informed my methods.

7.5. THE STUDY CONTEXT

The objectives of my research are broad, and necessitated detailed exploration of a large transplant system in order to answer the questions they posed. My study considers aspects of specific transplant policies, which necessitates an examination of the views of interlocking networks across a range of diverse sites (Green & Thorogood,

2014). Hence, my research took place at relevant sites in the Gauteng province of South Africa. I live in Gauteng, and chose it as the geographical setting for several spatial and logistical reasons (ODF, 2013c):

- Gauteng has the highest concentration of transplant centres (seven in total) within an individual province in the country.[17] This meant that I was studying the largest and most complex transplant system in South Africa. However, some transplant centres in Gauteng were excluded from my study in order to avoid a replication which could result in bias towards some specific programmes over others.
- Gauteng boasts a number of state-run transplant facilities, providing me with a diverse study sample reflecting most accurately the two tiers of the South African healthcare system.
- Gauteng province performs the greatest variety of adult transplants in South Africa, and has facilities for the transplantation of all major solid organs. This variation allowed me to explore the diversities of organ transplantation with reference to the nuances presented by each organ type within a single setting.
- Gauteng-based transplant centres provide the same degree of living donor transplant facilities as other provinces, which made it possible for me to explore both cadaveric and live organ transplantation.
- Several hospitals in Gauteng are involved in organ procurement through their trauma and intensive care facilities. These institutions are relied upon for the referral of potential cadaveric organ donors. Hence, I was able to consider transplantation as a process which begins at the referring hospital, enabling me to provide a complete procedural overview from beginning to end.

[17] The Western Cape Province has five transplant centres, KwaZulu-Natal four and the Free State two.

7.5.1. Choosing sites

Six sites, which incorporated transplant centres and referring hospitals in Gauteng, were included in my research. From each of these sites, a sample was drawn which reflected the services provided on a site-specific basis. Several categories of participant, sampling strategies and recruitment techniques were employed to obtain the overall sample. This section aims to detail the methodological decisions which were made in doing so. Figure F7.1 depicts participants and sampling methods. Interactions were sporadic, and required a great deal of liaison, administration and travel on my part.

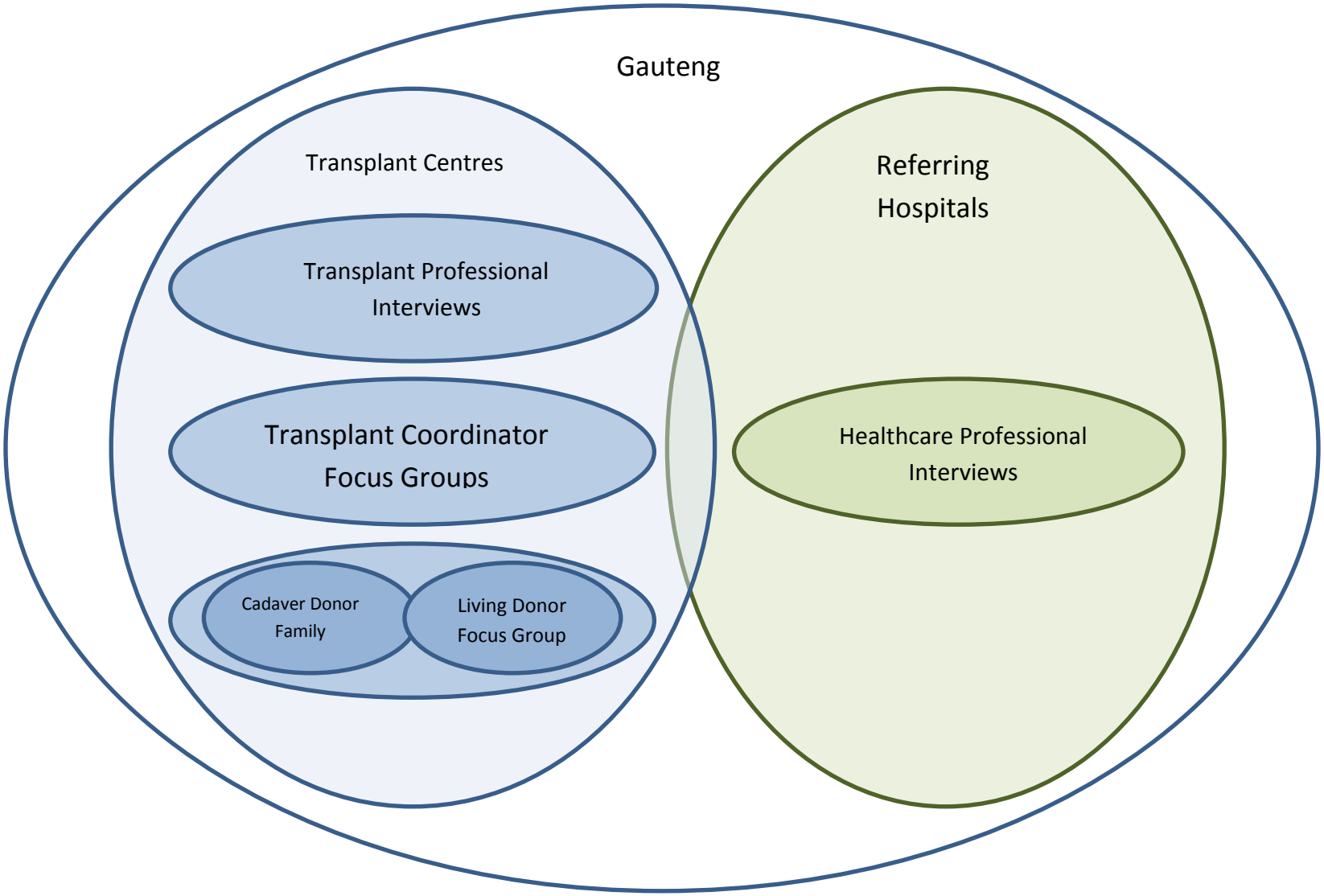
Transplant professionals

Numerous healthcare professionals are involved in organ transplantation. These professionals interact with transplant coordinators, donors, recipients, their respective family members and each other. In order to explore communicative factors in organ transplantation, to identify barriers or facilitators to communication, and to understand the influence of interprofessional relationships and cultural practices on transplantation, in-depth interviews were undertaken with thirty transplant professionals across the study sites. These professionals included surgeons, physicians, nursing staff, and allied support staff who were directly or indirectly involved in transplant programmes.

Transplant coordinators

Focus groups were conducted with Gauteng-based transplant coordinators. Focus groups were chosen because transplant coordinators share similar circumstances which are relevant to the study questions. Focus groups lend themselves to the generation of non-specified or unexpected topics through open talk (Kitzinger, 1995; Marshall & Rossman, 2011). The supportive environment of the focus group setting also provided transplant coordinators with an opportunity to openly discuss their activities and to learn from each other.

Figure F7.1 – Research design – participants and sampling



Cadaver donor families

In terms of patient perceptions, my research protocol proposed to interview families who had consented to donate the organs of a brain-dead loved one and families who had declined to donate. Use of both of these samples was approved by the Human Research Ethics Committee (Medical) at the University of the Witwatersrand on the basis that a strong support system was in place for individuals who found the interview psychologically harmful. Furthermore, similar interviews with families had been undertaken in the Western Cape by Kometsi and Louw in 1999[18] (discussed in Section 4.5.1.3) and this served to strengthen the rationale for a similar study in Gauteng.

However, subsequent to Ethics Committee approval, a number of transplant professionals in the study setting expressed reservations about interviewing families who had declined to donate organs. These were based on two broad arguments. Firstly, access to these families is logistically challenging, as the names and contact details of those who decline to donate organs are not recorded. Reyneke (2014) confirms that this can be a barrier to accessing donor families. There is also an undertaking that the decision made by a family will be respected, and contacting them to discuss such a decision may be deemed inappropriate. Secondly, concern was expressed that if a family perceived my research as *"the transplant people bugging us"* then they may feel compelled to complain, or even to take the matter to the media. Whilst this might be unlikely, mass media coverage of organ transplantation in South Africa seems to have extensively damaged the reputation of this field and hence this was an area where circumspection was required.

Following further liaison within the transplant setting and an intensive discussion of the proposal with key role-players and with my supervisors, it was deemed inappropriate to undertake interviews with family members who had declined to donate organs. I felt that the potential harm both for the individual family members

[18] Reyneke's (2014) study also sampled donor families, however at the time I started this research Reyneke (2014) had not yet produced her dissertation and hence her sampling was not used as a rationale for donor family interviews.

participating in the interview, and for the field of organ transplantation, outweighed any anticipated benefits, and hence pursuing this avenue of my research was considered unwise.

As a result, only families who had agreed to donate the organs of a brain-dead loved one were interviewed. This strategy may have introduced an element of bias into my research, and some may argue that excluding this section of the research as a whole would have been more appropriate. However, I submit that any bias introduced here is not significant. Only two interviews were undertaken and these have been triangulated with a much larger *data corpus* for analysis according to pragmatic paradigms in order to ascertain the views of a large number of role-players.

Living kidney donors

Focus groups were conducted amongst living kidney donors because they make up a much larger pool than living liver donors. From an ethical perspective, focus groups were chosen because living donors are not as emotionally vulnerable as deceased donor families (the decision to donate an organ is not taken at a time of enormous grief) and I felt that an opportunity to share common experiences should be afforded to the participants in a group setting.

Methodologically, I made use of focus groups amongst living donors in order to obtain data where participants came to a consensus about their experiences (Green & Thorogood, 2014). Because there are many complex psychological factors which influence the living donor process, and because the process itself can be lengthy (as described in Chapter 4) I was interested in the background of my participants and the ways in which this influenced their donation decision. By bringing my living donor participants together in a group setting, I hoped for discussion on the main factors influencing donation, and that participants might eventually reach consensus about which of a multiplicity of factors were especially relevant.

7.6. PILOT STUDIES

Transplant professionals

The interview guideline for transplant professionals (Appendix 3) was piloted in an interview with a transplant physician. I conducted the interview in the manner of planned data collection, including audiotaping and transcribing the interview, and making ethnographic notes on my research setting. The interview took place at the participant's office, which was standard, neat and quiet. I sat across the desk from the participant. The interview began as a discussion with the participant and his secretary, who then left the room. The rest of the interview was uninterrupted, and continued for one hour and thirty-eight seconds. Following the interview the participant expressed his overall impressions of the study guideline and the line of questioning. He deemed the interview to be of an appropriate length. The participant also identified several aspects which he considered important to explore in my study. These included a more detailed investigation of racial and governmental factors which influence transplantation. I prompted on these factors when they were brought up in the interviews, however, the study tool was not specifically amended to include them as this may have resulted in leading the participant (Green & Thorogood, 2014).

Transplant coordinators

The question guideline for transplant coordinator focus groups (Appendix 4) was not piloted with a transplant coordinator in Gauteng. The reason for this was that many of the coordinators in the province were invited to participate in the discussion, and piloting with one of them would have served both to decrease the potential sample size and possibly to introduce an element of bias in terms of participant recruitment. A transplant surgeon and an experienced transplant coordinator from another province perused the proposed question guideline, and both considered it suitable in light of my research objectives. I do not consider the lack of a pilot study to have influenced my research process. The stated objectives of my research were sufficiently

addressed in the focus groups, discussion was free flowing and very little prompting was necessary.

Cadaver donor families

The interview guideline for cadaver donor families (Appendix 5) was not piloted with a family who had consented to donate the organs of a loved one so as to minimize potential psychological harm which might result from the discussion of such a traumatic event. However, the interview guideline was assessed by someone who had a background in qualitative research and who had donated the organs of a brain-dead loved one. Particular attention was paid to appropriateness of the questions and prompts, and their potential to cause unnecessary harm. Whilst the questions were deemed to be appropriate, it was suggested that additional prompts were added, as some participants may feel particularly uneasy talking about their experiences. I incorporated these prompts into the interview guideline.

Living kidney donors

The question guideline for living donor focus groups (Appendix 6) was piloted with a living kidney donor known to me. The pilot participant had donated a kidney to his son. The question guideline was e-mailed to the individual, as he was not in the same geographical area as I was. The participant replied with his views on the question guideline, and deemed modification of the question guideline unnecessary.

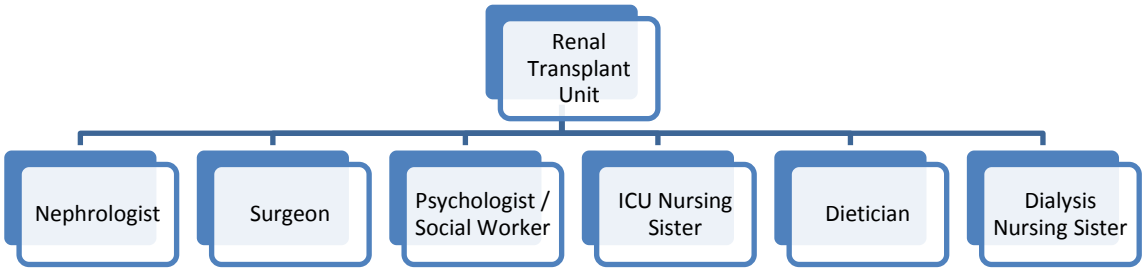
7.7. SAMPLING STRATEGIES

Transplant professionals

For transplant professionals, convenience (accessible sites) and purposive (guided by my research questions) sampling strategies were used (Marshall & Rossman, 2011). This sampling strategy proved particularly useful in identifying areas which needed extra focus. The aim was to try and obtain a sample which reflected the transplant structure in each participating institution, by including transplant professionals who took on different roles at each site. Participants were excluded if they were under the

age of eighteen, or had been working at the institution for less than six months. Medical students and interns were excluded as their rotations through the various units are only of three months in duration. Creating a balance between state and private institutions, to ensure that private institutions were not overrepresented, was also a sampling consideration. The number of interviews conducted at each site varied according to the specific transplant programme which the site offered. This made it possible to form a *data corpus* which reflected the overall transplant system in the Gauteng province. Figure F7.2 provides an illustrative example of how sampling might have occurred at a renal transplant site. Not all professionals from all units were sampled, and some professionals practiced across several sites.

Figure F7.2: Typical sampling from a renal transplant unit – example



Transplant coordinators

Transplant coordinators were identified using purposive sampling, where all coordinators from a representative sample of transplant programmes were invited to participate. The aim was to obtain a sample reflecting every type of organ transplanted in the province, with state and private facilities equally represented. Both procurement and recipient coordinators were included in my sample. All coordinators were over the age of eighteen, so no exclusion on the basis of age was necessary.

Cadaver donor families

Cadaver donor families were identified using convenience and purposive random sampling. The study was facilitated through one of the transplant centres. The aim was to interview two families who had donated the organs of a brain-dead loved one. Given this population's vulnerability to research-related harm, the number of interviews was limited in the interests of causing as little emotional strain as possible. Family members under the age of eighteen were excluded from the study. Although I made provision for a multilingual facilitator to conduct the interviews, both families expressed a preference for interaction in English. Hence I lead the discussions, which was more appropriate given the sensitive nature of the questions and the moderating skills required. Families who had donated the organs of a loved one less than one year before the interview were excluded from the study. This was done because - in consultation with a transplant coordinator and a clinical psychologist with extensive transplant experience – it was decided that families may be too vulnerable and susceptible to research harms before this point.[19]

Living kidney donors

As with the family interviews, convenience and purposive random sampling were used in this arm of the study. The aim was to obtain a demographically varied sample with donation having taken place within a range of circumstances. In South Africa, children (individuals under the age of eighteen) are not permitted to donate organs, so all study participants were therefore adults. Individuals who had donated a kidney outside Gauteng were excluded, as were those who had donated less than a year prior to this interview. Recipients were excluded from the study in order to limit its scope.

[19] Though it does not follow that families would not be susceptible to research harms after a year had lapsed, this was deemed an adequate strategy.

7.8. PARTICIPANT RECRUITMENT

Transplant professionals

Transplant professionals were recruited in a number of ways. In some cases the structure of a unit or programme dictated that only one or two professionals were eligible for inclusion in the study. In other cases, casual conversations with different parties involved in transplant identified potential participants. These individuals were approached telephonically and invited to participate. If an interest in participating was expressed, a study information sheet (Appendix 7) was e-mailed to the transplant professional and a meeting was set up. Interviews were confirmed at least 24 hours in advance.

In cases where several transplant professionals were eligible for participation in the study (generally involving nursing or allied healthcare professionals) I engaged in a method of physical recruitment. This involved visiting the study site and inviting individuals to participate. I would approach the first individual I saw, determine their eligibility, and, if eligible, invite them to participate. If the potential participant declined, I approached the next individual. When an individual agreed to participate, I handed them a study information sheet (Appendix 7) and arranged a meeting. The telephone number of the participant was noted, and I confirmed the interview at least 24 hours in advance.

Table T7.3 depicts characteristics of the transplant professionals who participated in my research and the length of the interview. Table T7.3 shows that there was a large variation in the length of interviews.

Table T7.3: Characteristics of transplant professionals who were interviewed in this study

Participant Number	Gender	Sector	Profession Type	Interaction Length
001	Male	State	Medical	01:00:38
002	Female	State	Medical	00:37:20
003	Male	State	Medical	00:33:57
004	Male	State	Medical	00:53:24
005	Female	Private	Allied	00:53:23
006	Male	Private	Medical	00:36:45
007	Female	State	Allied	00:33:34
008	Female	Private	Allied	00:40:19
009	Female	Private	Allied	00:36:29
010	Female	Private	Allied	00:38:03
011	Female	State	Allied	00:12:58
012	Female	State	Allied	01:17:44
013	Female	State	Allied	00:16:51
014	Female	State	Allied	00:35:27
015	Male	Private	Medical	00:44:53
016	Male	Private	Medical	00:20:39
017	Male	Private	Medical	00:47:40
018	Female	Private	Allied	00:20:31
019	Female	Private	Allied	00:29:51
020	Female	Private	Allied	00:28:33
021	Male	Private	Medical	00:42:38
022	Female	Private	Allied	00:45:44
023	Male	State	Allied	00:10:49
024	Female	Private	Allied	00:29:18
025	Female	Private	Medical	00.41.58
026	Female	Private	Allied	00:28:04
027	Female	Private	Allied	00:07:32
028	Male	State	Medical	00:35:14
029	Male	State	Medical	00:40:19
030	Male	Private	Medical	00:07:21

This was because in some cases participants were not busy during interview times and also because some participants were much more vocal in answering questions than others. The shortest interviews were generally cases where participants were very busy or were required to terminate the interview to attend to emergencies. In the

table I have not specified how long each participant has been working in transplant or their years of experience because, as these factors are added, participants become identifiable. The ethical challenge of protecting participant confidentiality will be discussed shortly.

Transplant coordinators

Transplant coordinators were invited to participate in one of two focus groups, depending on their geographical area, by e-mail. E-mail addresses were obtained from the relevant transplant units. These e-mails were sent to each coordinator individually, so that other potential participants could not be identified. The study information sheet was attached to the e-mail (Appendix 8) and the e-mail contained information about the group, including the date, time and location. These logistics had previously been discussed with key coordinators, who indicated the most appropriate day and time to me. Venue suggestions were also made. A study information sheet was attached to the e-mail.

Of the fifteen coordinators invited to participate in the groups, eleven agreed to do so. (However, one of these eleven was unable to attend the group due to transplant commitments, so the final sample consisted of ten individuals). Those who had expressed willingness were sent a reminder e-mail 24 hours before the group took place. Transplant Coordinator Group 1 (TCFG1) lasted for 1 hour, 16 minutes and 41 seconds and Transplant Coordinator Group 2 (TCFG2) lasted for 1 hour, 9 minutes and 58 seconds. A table detailing participant information and demographics has not been included in this section because the coordinators who participated in my research are highly identifiable by these characteristics and I feel that protecting their confidentiality is important.

Cadaver donor families

Family members were recruited with the assistance of a transplant coordinator at the study site. It was essential that a coordinator was the first point of contact with the family, as passing on personal details to me without family consent would constitute a

breach of confidentiality. The coordinator contacted families telephonically, explained my research and asked whether they would be willing to participate. If willingness was expressed, the coordinator arranged a time for the interview and provided the family with my contact details should they have any comments or queries about the meeting. I did not have any direct contact with participants until the day of the interview as it was deemed more appropriate to have a single point of contact rather than multiple individuals approaching a family who had agreed to participate.

Recruiting the two families required to constitute the sample proved to be a significant challenge. A number of individuals were unwilling to take part, and the coordinator had to ring twelve families before the sample was achieved. Whilst the coordinator was not permitted to ask the reasons for non-participation, she speculated that families do not wish to re-live highly traumatic situations and just want to "*get on with [their] lives*". Table T7.4 depicts some characteristics of the families who participated in my study.

Table T7.4: Family interviews

Family #	Participant Number	Gender	Time
Family 1	DFI1P1	Female	00:47:53
	DFI1P2	Male	00:47:53
Family 2	DFI2P1	Female	01:07:45
	DFI2P2	Male	01:07:45

Living kidney donors

Participants for the living donor focus group were recruited according to the same methods used for the family interviews. Although opinion as to the optimal number of participants in a focus group differs, Krueger and Casey (2000) argue that a discussion with six participants tends to yield rich data whilst still being manageable in terms of facilitation. Hence, the aim was to recruit six living donors for my study. However, as with the family interviews, recruitment proved particularly challenging. The transplant coordinator made several phone calls to potential participants, and eventually

identified three who expressed a willingness to participate and who met the inclusion criteria.

The low recruitment rate is noteworthy. When I enlisted the coordinator to assist, I asked that a list be kept so that participants' responses and participant numbers could be tracked. However, I made many requests over a number of months for statistics as to how many people were telephoned and how many had refused to participate and no information was forthcoming. All I have been able to determine is that a 'significant number' of calls were made to donors. I cannot speculate on the reasons why potential participants may have refused to take part as it is unethical to ask this question of potential research participants in a South African setting.

Two of the participants were living related donors, having donated a kidney to a family member – to a child and to a sibling - respectively. The other participant was a non-related living donor, and the recipient was described as a "*friend from work*". The inclusion of a non-related living donor in the sample proved highly successful, as non-related living donation poses a unique set of communication and ethical issues. Table T7.5 depicts some characteristics of the living donor focus group participants.

Table T7.5: Living donor focus group participants

Participant Number	Gender	Donor Type	Time
DFG1	Male	Living Related	01:04:09
DFG2	Female	Living Related	01:04:09
DFG3	Female	Living Non-Related	01:04:09

7.9. INTERVIEW SETTINGS

The variety of participants in my research also meant a variety of interview locations. In some cases participants suggested a venue, in others I did. Interviews took place in the following settings: individual offices, tearooms, private wards, patient meeting rooms, unit manager offices, shared offices and one interview took place outside.

Each of these settings lent different characteristics to the interview. Focus groups took place in meeting rooms, and were carefully structured to account for group dynamics.

7.10. INTERVIEW GUIDELINES

Transplant professionals

The interview guideline for transplant professionals was developed based upon the literature review (Longman, 2013; Lingard et al., 2012; Samela et al., 2005; Zwarenstein, Rice, Gotlib-Conn, Kenaszchuk & Reeves, 2013). Transplant professionals were questioned on their perceptions of communication with each other and also with patients across the transplant process, because neither of these phenomena had been researched in detail in the study context. I also asked participants how they understood each other, in order to prompt a discussion on how different levels of transplant professionals communicate within the team. Participants who were located in referring units were similarly asked about this communication process, because poor communication at the point of referral is often considered a barrier to cadaver organ donation. Participants were asked about the effect of the time factor on communication particularly in those stages of transplant, such as harvesting a donor organ, where time is a critical factor and therefore can be a source of much stress. Finally, participants were asked their opinion regarding the influence of religious and cultural practice in transplant, because South African transplant literature suggested that these were commonly cited as barriers to donation.

Transplant coordinators

The question guidelines for transplant coordinator focus groups were based on literature review which suggested that coordinators were the centre of the transplant process and that their job required extensive, careful communication, often under highly stressful and pressurized circumstances (Payne, 2015; Naude et al., 2002). Participants were asked general questions about their experience of being transplant coordinators because this has not previously been researched across the transplant process. Within this question prompts were based on exploring relationships with the

multi-disciplinary transplant teams. Coordinators were specifically asked about the role of language in interactions with cadaver donor families because literature suggested this may be a barrier to obtaining consent. Finally, coordinators were asked about the role of religion and cultural factors in transplant, because literature suggested these could be a barrier to organ donation in my research setting.

Cadaver donor families

The interview guideline for cadaver donor families was based on literature review (Bellali & Papadatou, 2006; Cleiren & Zoelen, 2002; Merchant et al., 2008; Moritsugu, 1999; Pearson et al., 1995). In order to try and understand how decisions about organ donation are made in relation to personal experiences, participants were asked what it was like to donate the organs of their loved one. Prompts here included emotions during the transplant process, impressions of communication with transplant coordinators and other health staff at the time of referral and also lasting impressions of communication which stood out for the family. Cadaver donor families were also asked about the views of their community, religious or cultural group in terms of organ donation, because literature has shown that these factors can influence predispositions to donating organs.

Living Kidney Donors

The question guidelines for living kidney donors was based on transplant literature (Fellner & Schwartz , 1971; Troug, 2005; Veriava & Swanepoel, 2011, slide 5). Participants were asked about the process of donation, how they found out about it and their process of decision-making. These questions were important for understanding how donation decisions are made in relation to personal experiences. The next question concerned impressions of organ donation within the participant's community, religion or culture because these factors may be barriers to organ donation. Finally, participants were asked about communicating with transplant professionals, emphasising the role of language and understanding which have been identified as barriers to effective health interactions within the study context.

7.11. INTERACTION FORMATS

Transplant professionals

I ensured that I arrived for interviews at least fifteen minutes in advance, in order to find complex locations and to address any unexpected circumstances. There were numerous cases where participants were late for the interview due to other commitments. I either waited for the participant, or rescheduled these meetings, depending on the situation. Several of the participants in my research perform highly demanding clinical and patient-related tasks, which must take priority over research interviews. I was aware of this, and the possibility of waiting, or rescheduling interviews, was built into the data collection timeframe.

I occasionally made notes during the interview, though these were kept brief in favour of portraying an interest in what a participant was saying. This was achieved through active listening, paraphrasing, reflecting, body language and eye contact, hence establishing a rapport between the participant and myself (Guion, Diehl & McDonald, 2001).

After thanking the participant for the interview and leaving the interview location, I recorded my observations about the interview location, the participant and the interview itself. Participants were sent a formal thank you letter by e-mail.

Transplant coordinators

Transplant coordinator focus groups were conducted following the guidelines of Krueger and Casey (2000). This involved clearly delineating my role and that of the research assistant, familiarity with the data collection tool, paying attention to seating and body language and using techniques to facilitate discussion, such as pauses and probes.

In their guide to focus groups, Krueger and Casey (2000) argue that the demographic characteristics of the moderator (in this case myself) and the assistant moderator

(hereafter referred to as the research assistant) may have an impact on the dynamics of a focus group discussion and should be considered with care.

I am female, under the age of thirty years and a fluent English speaker. I also speak second language French and Afrikaans. I decided to moderate the discussions myself because I was familiar with the topic at hand, and had established a relationship of trust with a number of the participants over a period of approximately two years. Familiarity with my research questions, objectives and topics also ideally positioned me to probe certain points which were deemed highly relevant, whilst still allowing the discussion to flow freely (Krueger & Casey, 2000).

A research assistant was employed to offer support during the first focus group but not during the second. This was because there were a large number of participants in the first group, and a more manageable number in the second. Furthermore, significant travel was required for the second group, and this was impractical for the research assistant. The research assistant was female, under the age of thirty years and spoke both English and Afrikaans fluently. She was highly qualified, with a financial background and extensive experience in consultancy work. The research assistant was able to appreciate the importance of her role in facilitating audiotaping, transcription, and logistical troubleshooting whilst withholding her personal views and opinions of the topics under discussion. Added to this, the research assistant also possessed excellent social skills, and was able to make participants feel comfortable as they entered the venue and had breakfast before the group commenced. The research assistant made extensive notes on her perceptions of the group dynamics, and did not participate in the discussion (Krueger & Casey, 2000).

There were specific characteristics of the participants which I considered when making choices about group facilitation. These included the following:

- All participants in the groups were English speaking, some were also proficient in Afrikaans, isiXhosa, isiZulu and Sesotho.
- All participants were over the age of thirty.

- All participants were female.
- All participants were registered nurses.

Given that all participants were English speaking, it was not necessary to enlist the services of an interpreter to conduct the discussion in a language other than English. Hence, English was chosen as the official language of the groups. The research assistant was available to translate Afrikaans phrases or terms that were used during the first group, however this proved unnecessary. Both I and the research assistant were younger than the participants, and this assisted in establishing an easy relationship amongst the group as there was no sense of the participants being subordinate to the research team. All those present were female, and I think this may have led to more open discussion. As the participants were all registered nurses, it would not have been appropriate to have another medical professional present, as this may have also led to power asymmetries amongst the group. Hence, the research assistant did not hold a healthcare qualification.

Where possible the research team set up the venue before participants arrived. Dictaphones were placed at either end of the table, signaling from the outset the intention to record discussions. Number tents were also positioned on the table to aid in transcription and to take into account the dynamics which I had previously observed in the group. For instance, participants who seemed quieter were seated opposite me in order to facilitate maximum eye contact.

As they entered the venue, I greeted the participants and introduced them to my research assistant. The participants already knew one another. In the first group, participants were invited to have breakfast and many took the opportunity to catch up and chat with the research team. In these interactions, the research team ensured that discussion was kept to general topics and steered away from transplantation as far as possible (Krueger & Casey, 2000). All consent forms were distributed, signed and collected from participants before the groups officially began.

When everyone was seated, I began the discussion. Dictaphones were turned on and these were checked to ensure functionality throughout the discussion. I welcomed participants and thanked them for attending. Ground rules for the group were established, and participants were advised as to the group format. In Group 1, each time a new participant spoke, my research assistant recorded their number and wrote down the beginning of the sentence. I did not make use of notes, as these can interrupt the flow of the discussion and can make participants feel uncomfortable (Krueger & Casey, 2000).

After the groups, I sent participants a formal thank-you letter via e-mail. These were followed up three weeks later, inviting any comments or questions. None of the participants had any comments or questions.

During the first focus group, the research team noted some dynamics which could possibly have caused tension between certain participants. However discussion was generally convivial. Some were argumentative, and this made for a deep conversation where participants generally addressed each other, and I had to occasionally prompt or steer the dialogue in a different direction. Although participants expressed intense frustrations with certain aspects of their work it was also clear that they were enthusiastic about transplant and its merits. One participant found discussion of transplant disturbing due to personal experiences. Following the group, the participant was followed up telephonically and offered counselling, which was declined.

During the second focus group I did not observe any unusual dynamics between individual participants, all of whom knew each other well. There was a good deal of laughter during the group, and the participants were not as argumentative as those in Group 1. The participants in the second group expressed similar frustrations to those in the first, though they also seemed more satisfied with the support systems which were in place to facilitate their job performance.

Cadaver donor families

Prior to the interview, I was briefed on the details of each family by the transplant coordinator. I took this opportunity to memorise the names of the potential participants and the name of the loved one who had been the organ donor. Families were greeted and brought through to the interview room by the transplant coordinator, where I was introduced to them. They were invited to help themselves to refreshments, and some small talk ensued. When all individuals were seated I commenced the information and consent process. The study information sheet (Appendix 9) was distributed and participants were given an opportunity to ask questions about my study. Attention was drawn to the fact that the questions were sensitive, and may cause emotional stress. It was emphasised that the interview could be terminated at any time, and that questions which were deemed inappropriate would be skipped. Families were also advised that the transplant psychologist was on hand should they require therapeutic intervention. Consent documents (Appendices 10 and 11) were signed, and the participants also filled in a contact sheet (Appendix 12) for thank-you letters and further correspondence. I then turned on the dictaphone and began the interview.

At the end of the interview, participants were thanked and asked if they would like to see the psychologist. All these requests were declined. In the hours following the interview, I sent a thank-you note to the families via e-mail. This was followed up with another note two weeks later which invited questions and served to thank the familes for their contribution once again. In both cases, the families sent encouraging replies, stating that they valued the opportunity to contribute and the chance to tell their story.

The first interview took place with a family who had donated the organs of their teenage son who died following complications from surgery. The interaction was highly emotional, with participants expressing frustration and disappointment in the donation process. At the end of the interview, I felt it essential to share some of their

views with the transplant coordinator as soon as possible. To this end, I requested that I be permitted to breach confidentiality and disclose part of the interview, in order that remedial action may be taken. The family agreed to this request and follow-up with the coordinator suggests that remedial action was initiated soon after the interview.

The second family had donated the organs of an aunt following complications related to lupus. Motivated by a Christian desire to do good and to prolong the life of another, the possibility of donation had been discussed with the deceased prior to her death. This interview was not as emotionally charged as the first, and no issues which required immediate action were forthcoming.

Living kidney donors

As with the transplant coordinator discussions, these focus groups were conducted according to the guidelines proposed by Krueger and Casey (2000).

Participants were greeted by the transplant coordinator who introduced me to them and to each other. Name tags were provided. Participants were invited to have refreshments, and conversed with each other freely. It was not possible to sit participants in a deliberate fashion as I did not have any prior knowledge of individual characteristics.

When everyone was seated, the study information sheet (Appendix 13) was distributed and an opportunity to ask questions about my study was given. It was emphasised that the focus group could be terminated at any time, and that questions which were deemed inappropriate could be skipped. Potential participants were advised that the transplant psychologist was on hand should they require therapeutic intervention. Confidentiality implications of participating in a focus group discussion were explained. Participants were required to sign consent documents (Appendices 11 and 14) and they also filled in a contact sheet (Appendix 12) for thank-you letters and further correspondence. I then turned on the dictaphone and began the discussion, using the same format as was used for the transplant coordinator focus groups.

At the end of the discussion, participants were thanked and asked if they would like to see the psychologist. All requests were declined. A thank-you note was sent to each participant via e-mail, and this was followed up with another note two weeks later which invited questions and thanked donors for their contribution once again.

No notes were taken during the discussion. However, I recorded my impressions immediately afterwards. Participants appeared to get along well, and the discussion was free-flowing. One participant experienced some emotional stress when recounting her story. The other group members also made gestures of support, such as hand-holding. Participants were offered reimbursement of their travel expenses, and one accepted.

7.12. ETHICAL CONSIDERATIONS

7.12.1. Research approval

My research was approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand. I submitted my study to the ethics committee in two phases. The first phase was the transplant professional interviews and coordinator focus groups (Appendix 15) and the second was the donor family interviews and living donor focus groups (Appendix 16). I decided to divide the ethics applications because the ethical issues encountered when sampling health professionals were different to those when sampling donor families and living donors, and will be discussed in more detail in this section.

7.12.2. Confidentiality

Three of the seven transplant centres in Gauteng are located in state hospitals. One of the seven centres has the capacity to perform heart-lung transplants. The characteristics of these transplant units vary between hospitals. Most have an office which is staffed primarily by transplant coordinators. Although integral to the team, medical professionals (surgeons and physicians) and allied professionals (nurses, social workers and psychologists) are often based in their own departments and feed into the transplant programme only when their services are required.

Given there are so few permanent staff members, characteristics such as language or hospital name become significant identifiers in a transplant unit. Furthermore, only a few healthcare professionals with specialist skills undertake transplants in each centre. For instance, a hospital with a transplant centre may only have one harvesting surgeon and one transplant surgeon. These individuals are identifiable by hospital name, specialty or other physical and professional characteristics. Fortunately, the structure of most transplant centres is homogenous. Each centre has a number of coordinators, medical and allied professionals whose function and role remains the same, no matter what transplant unit they are affiliated with.

Writing this thesis demanded careful measures for protecting the identities of study participants. The prerequisite of confidentiality has posed challenges when balancing ethical investigation with the requirements of rigour, which demand detailed descriptions of study sites. I believe that all steps should be taken to ensure that research is as ethical as possible. Thus, in order to maintain the confidentiality of participants, descriptions of research settings (Sections 7.7, 7.8) are deliberately vague, and any identifying characteristics have been omitted from them. There is some precedent for omitting this type of identifying information in order to protect participant confidentiality. Runkel (2013) undertook her study at a private hospital in Gauteng and has omitted the name of the institution from her research report in order to enhance confidentiality. Some of the transplant centres in Gauteng were not included in this study, and some referring hospitals were not included in this study.

7.12.3. Informed consent

Written informed consent was obtained from all the study participants before the interview or focus group discussion began. Informed consent is constitutionally mandated in South Africa, within the right to Freedom and Security of the Person (Constitution of the Republic of South Africa, 1996). It is realised as a legal requirement of all healthcare provision in the National Health Act, No. 61 of 2003, which outlines specific parameters for informed consent and provides consent

regulations for research with human participants. According to this Act, written consent must be obtained from all potential participants once they have been informed of my research objectives and possible consequences of participation or non-participation (National Health Act, No. 61 of 2003). The consent document used for my study consisted of two sections, the first expressing agreement to participate in the interview, the second permitting tape recording of the interview (Appendices 10, 11, 14, 17, 18,).

7.12.4. Ethical issues unique to research participant groups

Transplant professionals

The main ethical challenge which these interviews posed for me was the mandate of maintaining confidentiality. Although healthcare professionals are not a vulnerable group[20] in my research context, a number of those who participated are highly identifiable due to the characteristics of their work in transplant. Throughout the process, from recruiting healthcare professionals to finishing the interview and subsequent follow-up, participants were ensured that confidentiality would be maintained. This was possible, firstly, through keeping all the participant's details separate from the data and then keeping this data in a secure, locked area; and secondly, by dividing participants into two categories – medical professionals and allied professionals. Writing this report without reference to the specific job titles of the participants was necessary to further protect their identities and to maintain confidentiality.

Transplant coordinators

As with the healthcare professional interviews, the main ethical challenge which these focus groups posed was that of maintaining confidentiality.

When it came to writing up my research, I considered whether or not transplant coordinators were easily identifiable on an individual level. It is argued that they are

[20] A vulnerable group is typically defined as one which lacks certain human rights or liberties which render them vulnerable to exploitation. They are generally thought to include the impoverished, illiterate, children, prisoners and the elderly – amongst others (Zion, Gillam & Loff, 2000).

less identifiable than other transplant professionals in this study because several coordinators are employed in different capacities at numerous locations. For instance, a centre may have only one social worker, who would be highly identifiable. However, the centre will employ five or six coordinators – some of whom work across other regional locations - making them less so. Hence, transplant coordinators are specifically identified according to their job title in this thesis. The specific roles of coordinators – that of either donor coordinator or recipient coordinator – are not specified.

Potential breach of confidentiality by another participant was addressed throughout the focus group process. Participants were reminded that their confidentiality could not be guaranteed because individuals cannot be prevented from discussing the group with others. Before the group commenced, participants were specifically requested to refrain from this, and the implications of participating were reiterated. Coordinators were also given the opportunity to excuse themselves from participating should they feel uncomfortable about confidentiality implications, and were made aware that they could leave the group at any time.

Cadaver donor families

The main ethical challenge posed by interviewing family members was the risk of psychological harm and how this might be mitigated. I addressed these challenges on two levels. Firstly, during the interview process I made use of several consent and interview techniques specified by Rosenblatt in his article entitled *Ethics of Qualitative Interviewing with Grieving Families* (1995). These included using non-verbal communications which display empathy, engaging in active listening as well as getting "processual consent" (p. 148). Processual consent took place throughout the interview, and it involves giving participants several chances to terminate the discussion or to indicate their willingness to answer certain questions. Whilst all participants were forthcoming about their perceptions and experiences, emotional stress was evident. At these times, I made sure I displayed empathy and gave the

participants space to collect themselves. Although participants were given numerous opportunities to end their interviews, all were refused.

Secondly, I had enlisted the services of a clinical psychologist, with extensive expertise in organ transplantation, as a referral healthcare practitioner in the case that participants exhibited psychological distress. Participants were made aware that assistance was available at the beginning of the interview, and it was subsequently offered three more times (straight after the interview, in thank-you correspondence and in follow-up correspondence). All offers of counselling and support were refused by participants, and as they were consenting adults, I felt it would be inappropriate to question these decisions.

Living kidney donors

The main ethical challenge in the living donor focus group was the protection of participant confidentiality. Participants were assured that I would not divulge their identities to anyone other than my supervisors. However, participants were also warned that confidentiality could not be guaranteed as I could not prevent individual participants from discussing the group with others. At the beginning of the group, I requested that participants keep the content of the discussion to themselves.

The living donors who took part in this group are not individually identifiable, and hail from a large living donor population in the province. Hence, the backgrounds of participants have been described in more detail than was the case with transplant professionals and coordinators, who were more identifiable.

7.13. DATA

7.13.1. Data treatment

In order to prepare interview data for analysis, I transcribed the interactions with participants from audio to written form. According to McLellan, MacQueen and Neidig (2003) careful documentation of research processes is necessary to ensure robust

qualitative enquiry. This section will provide a detailed account of the transcription process.

As detailed in Section 7.4 above, data collection took the form of numerous interactions with participants. These were over a period of one and a half years. Given the length of the data collection phase, I transcribed interactions immediately after they had taken place, rather than waiting for all data to be collected and then transcribing the data set as a whole. It was decided to transcribe interviews verbatim, promoting reliability and trustworthiness of my study (MacLean, Meyer & Estable, 2004). I transcribed all the interactions myself, as they were in English and translation was not required.

I made use of several approaches until finding the one which proved to be most effective. The transcription process had two phases. The first was listening to the interview in a slow mode and typing simultaneously. The second was re-listening to the interview and checking the accuracy of language, spelling and punctuation. This was to ensure that the apparent meaning of the participant's speech was not lost. I then read over each transcript.

Oliver, Serovich and Mason (2005) argue that transcription of data presents an opportunity for reflection on the research process and allows one to adapt the process to account for unanticipated issues in the transcription. I found that the interactions were lengthy and transcriptions sometimes took several days to complete. Green and Thorogood (2014) suggest that in some cases where data sets are very large, it may be necessary to transcribe data collected at the beginning of the process in full and thereafter only transcribe certain sections. At one stage, I investigated the possibility of such a transcription technique in order to expedite the process. However, this was discounted as I found the action of typing was much more helpful for familiarising myself with the data than listening to it or reading it. Furthermore, I was concerned that selecting specific areas of data to transcribe could lead to "premature" theory construction and was thus best avoided (Silverman, 2010). Hence, the entire data set, including asides or apparently irrelevant speech and slang, was transcribed.

7.13.2. Reliability of transcription

As I transcribed the entire data set myself, there was no need to meet with other transcribers and translators in order to ensure that the transcriptions were consistent across a transcription team. However, I had an independent research assistant check 10% of the total data set for transcription accuracy. Transcripts were deemed to be accurate, and did not require significant re-transcription or revision.

7.13.3. Data saturation

Questions as to 'How many interviews are enough?' endure in qualitative research. The general consensus is that sampling should cease when data saturation is achieved. Data saturation occurs when interactions are not producing anything *new* in terms of themes and ideas (Green & Thorogood, 2014). In their paper entitled *How many interviews are enough? An experiment with data saturation and variability* Guest, Bruce and Johnson (2006) methodically group and analyse in-depth interviews, making detailed observations about the emergence of new themes and ideas during the process. They conclude that saturation occurs within the first twelve interviews. However it is acknowledged that this is dependent on the data set and the type of study.

The participants sampled in my study represent various medical and allied health professions, as well as members of the lay public. Each of these individuals holds different views about transplantation, based on their professional background and/or personal experiences. Whilst most participants expressed similar views on specific issues, many also contributed new ideas to the discussion. Hence, data saturation, *per se*, was not achieved in my research sample as new ideas were continuously forthcoming – even after interactions with 47 individuals. However, saturation was achieved across some stratifications, such as unified perceptions of communication at various points in the transplant process, across institutions or where healthcare professionals shared views on a specific topic. These views were then confirmed by the transplant coordinators and the donors. However, every interview or interaction

produced new data and I eventually decided to cease sampling because, along with my supervisors, I felt that a rich data set had been generated, which answered my objectives and where the main points of the transplant process which I addressed in Chapter 4 had been covered. Also, time and financial constraints prevented me from sampling further.

In terms of the living donor focus group, it could be argued that data saturation was not reached because only one group with three participants took place. Similar studies have included a larger number of groups in order to address this limitation, and these studies argue that at least three focus groups per area of interest is necessary (Tong et al., 2008; Tong et al., 2007). However, as shown in Section 7.8, it was challenging recruiting even three donors in my research setting, and this was a strong disincentive to the prospect of recruiting further groups. It could be argued that I should have approached another institution and asked for assistance with recruitment from a different patient cohort, however this was difficult because the other potential institutions were not as willing to provide the necessary resources for recruitment. Ultimately, I did my best with the sample I was able to recruit, although a larger sample could have added to value to my data set.

7.14. THE DATA ANALYSIS PROCESS

7.14.1. Theoretical background

According to Ritchie, Spencer and O'Connor (2003) qualitative analysis requires a mix of creativity and methodology. They argue that there is no single correct analysis method and that considerations of the research objectives and data set are important.

I made the decision to use thematic analysis across the data set. There were several reasons for this choice. Firstly, because the study was exploratory it was essential that the analysis method allowed for revisiting, reworking and refining throughout the process (Braun & Clarke, 2006). Secondly, and for the same reason, I required an analysis approach which would allow for the identification of common sense data characteristics – like participant perceptions of phenomena they encountered in

practice (Ritchie et al., 2003). Thirdly, my project made use of numerous data sources - transplant professionals, transplant coordinators, cadaver donor families and living donors. Given that my main aim was to explore transplant communication in Gauteng it was important that the analysis framework allowed the integration of data into a logical set of findings (Ritchie et al., 2003). For instance, Fereday and Muir-Cochrane (2008) made use of thematic analysis to integrate a set of raw data from research interviews and focus groups with a set of institutional documents. Whilst I did not integrate the data set with institutional documents, I did integrate the data produced from the four different sources in terms of a pragmatic approach.

7.14.2. Data analysis - Braun and Clarke's (2006) thematic analysis

Analysis for my project involved a continuous process of engagement with the data from the time the fieldwork first commenced. Considering the data regularly during the entire research process assisted in developing methods, concepts and testing findings (Silverman, 2010). Braun and Clarke (2006, pp. 16 - 23) advocated six phases of data analysis which were used in my study. The process which was followed is depicted in Figure F7.6:

a. Familiarising myself with the data
b. Generating initial codes
c. Searching for themes
d. Reviewing themes
e. Defining and naming themes
f. Producing a research report

7.14.2.1. Familiarising myself with the data

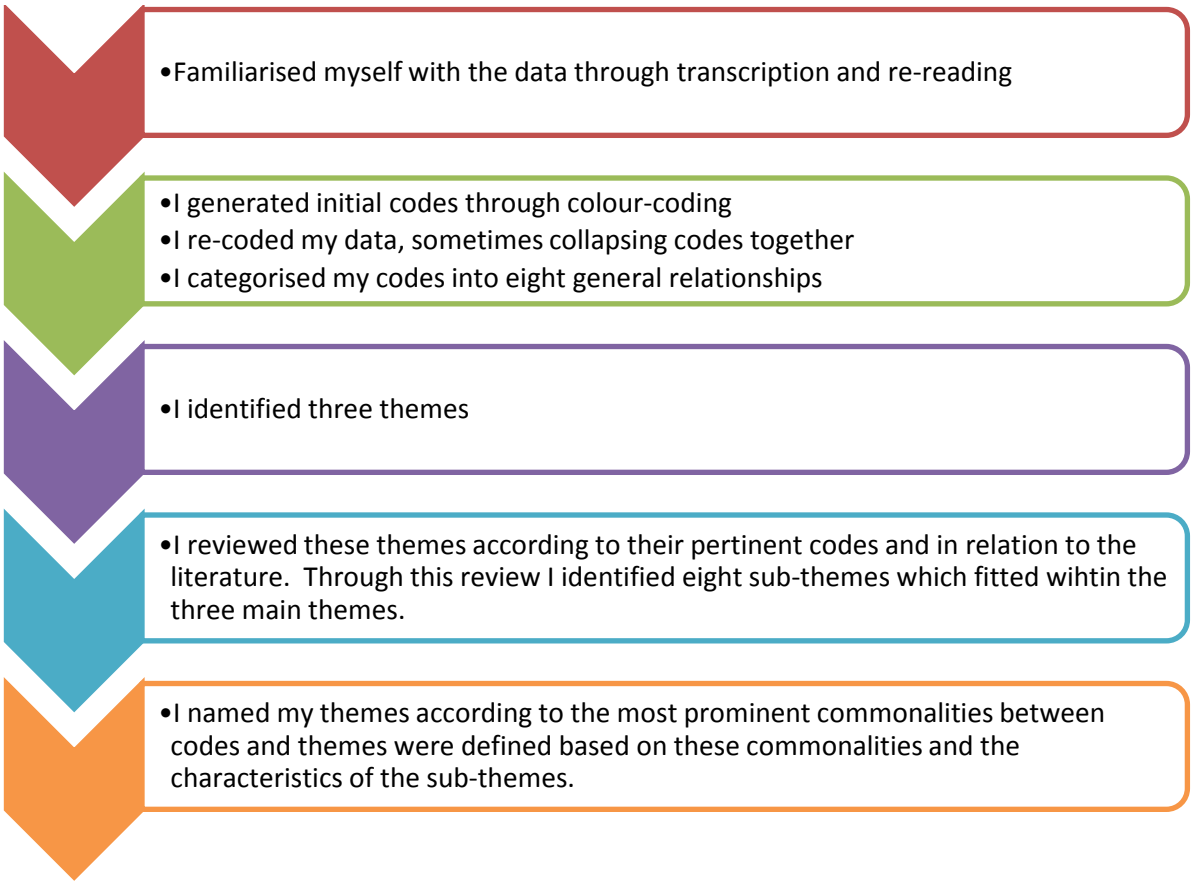
This initial analysis period involved me familiarising myself with all the data. This was done through the data collection and transcription process, all of which I undertook

myself. I then engaged regularly with the data, primarily by reading and re-reading it over a period of time.

7.14.2.2. Generating initial codes

Interviews were coded in batches. The first ten interviews were coded simultaneously, and possible definitions for these codes were devised. The remainder of the data set was subsequently coded either according to the initial code definitions or into new codes which emerged.

Figure F7.6 – The analysis process



At the point when I started generating codes, I realised that differing perspectives on similar issues were emerging, based on the context of the participant. For instance, the notion of follow-up post-transplant emerged as a code; however this was viewed

differently by transplant professionals and by donor families. In order to account for this difference in perspective and viewpoints, the donor family interviews and the living donor focus group were coded separately. This form of non-cross-sectional analysis (Ritchie et al., 2003) allowed me to generate a new set of codes, specific to the views of the donors. Subsequently, I sought to identify corresponding codes across the two data sets. In most cases correspondence was found. However, in the case of donor family follow-up, correspondence was not in evidence, because while donor families spent a long time discussing follow-up in their interviews, transplant professionals and coordinators did not mention it at all. Because of this large disjunction in the data set I argue that cross-sectional analysis has produced some of the most surprising research results.

I then recoded and refined the coding of the entire data set. Here, some articles from the earlier coding session were recoded or were coded into more than one category. Ultimately, thirty-seven codes were identified. I continuously questioned my relationship with the data (Silverman, 2010). Questions and generalisations started to emerge, as well as some conflicting viewpoints and a number of outlying views and opinions.

7.14.2.3. Searching for themes

The initial search for themes involved examining the relationships between different codes (Braun & Clarke, 2006). I identified eight main relationships amongst the thirty-seven codes which reflected the characteristics of the data. These relationships are depicted at the beginning of each results chapter. The relationships were based on which aspect of the transplant process the code was pertinent to, on the kind of communication and its participants, and on the role of contextual factors which emerged in the data.

Numerous smaller links between codes were identified through sorting codes according to the eight relationships and it soon became evident that codes linked together and that these began to suggest the larger sub-themes of my research. A

consideration of these sub-themes led to the emergence of three themes in the data – context, transplant professional–patient communication and interprofessional communication.

7.14.2.4. Reviewing themes

Once I had identified my three themes and the numerous sub-themes within them, I went back to the academic literature relevant to my study and examined the themes and sub-themes in relation to it. I started to identify aspects where my findings were different from those presented in the literature, and where findings converged or supported each other.

7.14.2.5. Defining and naming themes

The defining and naming of themes took place over time and with a great deal of input from supervisors and academic peers. Although the content of themes did not change after comparison to the literature, the naming of themes was revised to better encompass all the sub-themes and codes which had been generated in the analysis process. The broad definition of themes was as follows:

- Context – Universal factors (Tronto, 1993) of the environment in which transplant takes place
- The decision – Communicating with patients (recipients, donors and their respective families) across the transplant process
- Interprofessional communication – Communication between transplant professionals and coordinators.

7.15. ENSURING RIGOUR

Rigour is an essential element of qualitative enquiry, answering challenges as to its credibility, objectivity and generalisability. Green and Thorogood (2014) have identified five elements to promote rigour, which were considered in this project:

- *Transparency* requires a clear and accurate description of my research process, from conception through to completion.
- *Maximising validity* requires a sophisticated reading of the data, considering alternative interpretations and providing sufficient contextual information for a reader to draw his or her own conclusions.
- *Maximising reliability* relates to replication of research and the likelihood that this would produce similar results.
- *Comparison* of cases within the data set is vital for producing valid and refined theories about the topic under study.
- *Reflexivity* involves recognising the researcher as part of the process, and identifying the potential influences thereof.

I made use of several techniques in order to improve rigour in my study. Some were ongoing throughout my research process and others took place at certain points. In order to fulfil some of the requirements of reflexivity, I actively engaged in reflective journaling. Observations of, and perspectives on, my study were recorded, and the potential influence of researcher subjectivity upon these observations was consistently scrutinised. In order to address the challenges of trustworthiness, I engaged in peer debrief with my peers and expert researchers throughout the process. This continuous dialogue served to critique certain readings or interpretations of data, proved useful for generating novel ideas and theories and afforded an opportunity to openly discuss my personal views and concerns as these occurred during the data collection phase. Individuals from the fields of philosophy, bioethics, anthropology, psychology and sociology were consulted.

Transferability in qualitative research is similar to the notion of generalisability in the quantitative paradigm. In both forms of enquiry, this is related to sample size and participant selection. Malterud (2001) argues that even with the most scientifically stringent choice of method, study findings can never be generalised on a universal basis. Just as a quantitative researcher may base sample size and selection on an

analysis accounting for a specific degree of generalisability on the outcome, so qualitative researchers are tasked with considering the extent to which their findings will be transferable to other settings (Malterud, 2001). However, qualitative methodologies do not aim to present findings which are valid for population groups at large, but are rather situational descriptions, recollections and observations (Malterud, 2001).

The transferability of my research hinges upon its substantial sample size, a geographically, socio-economically and demographically diverse study population and the variety of data gathering methods used, all of which have been discussed in substantial detail in this chapter. Transferability also lends itself to internal and external validity. External validity examines the contexts in which findings can be applied. Internal validity is concerned with the study results and whether these have served to adequately address the specific study questions (Malterud, 2001). It appears from my results that some of my findings may be applicable to other developing world contexts which host transplant programmes. This is especially relevant because a number of the contextual factors which have been found to influence transplant in South Africa are also evident in other countries. However, my research may most accurately be applied to other South African provinces which have transplant programmes. The internal validity of my research also seems to have been achieved, as the study sufficiently addressed my research objectives and also identified unexpected trends.

It has been argued that careful and uniform reporting of qualitative research studies can also help to improve rigour (Tong, Flemming, McInnes, Oliver & Craig, 2012; Tong et al., 2007). In light of these arguments and in order to enhance the rigour of my research I have described and explained my methodology in particular detail in this thesis. I have paid careful attention to explaining every aspect of my data collection process thus promoting research transparency and the concept of transferability.

I undertook *member checking* where results and themes were discussed with some participants and their views were sought (Green & Thorogood, 2014). However,

according to Green and Thorogood (2014), member checking requires circumspection because it relies on the notion that respondent agreement with the research interpretation confirms a valid finding. However, the findings of qualitative studies are subjective and do not purport to be absolute truths upon which there is universal consensus. Hence, I treated these feedback sessions in terms of overall agreement, not based on individual sentiment. I also presented sections of my findings in various forums attended by health professionals, some of whom were involved in organ transplant. These sessions invoked substantial discussion and served to confirm some research results and analysis, especially those related to hierarchy and continuity of care. This engagement with peers and participants assisted me in promoting reflexivity, as I was able to discuss my attitudes towards the topic with others, some of whom expressed differing personal positions and opinions.

7.16. SUMMARY AND CONCLUSION

This chapter has described the process followed when undertaking the fieldwork and analysis for my study. It has addressed my methods in substantial detail in order to promote transparency and trustworthiness. It has examined methodological choices in detail and located these within the paradigms of pragmatism and constructionism. Data analysis methods have been described and finally the chapter has addressed the concept of rigour and how it was promoted in my research.

CHAPTER 8 – RESULTS

The Gauteng transplant context

8.1. RESULTS SECTION STRUCTURE

This chapter is the first of three which will present an overview of my research results. Three main themes were identified in the data analysis, and one chapter has been devoted to each:

1. Theme 1: The Gauteng transplant context
2. Theme 2: The decision – grief, expectation and uncertainty
3. Theme 3: Interprofessional communication and transplant

The presentation of several sub-themes in this and subsequent results chapters has posed several challenges for me. Numerous sub-themes have been included in a particular section, but overlap with other themes or sub-themes of my study is inevitable. In the discussion (Chapter 11) all these factors will be drawn together.

Excerpts from participant interactions have been used to illustrate themes and sub-themes. These are typed in *italics* and important aspects of the quotes are presented in **bold**. Where participants used emphasis in their speech this has either been underlined or UNDERLINED AND CAPITALISED if the emphasis was particularly strong. The numbers at the end of each quote refer to the interaction from which it was sourced and correspond to participant lists in Tables T7.3, T7.4 and T7.5. In some cases quotes are presented in a table. This is generally done in order to illustrate different viewpoints between participants or to illustrate a perceived problem and its corresponding solution.

Because extracts are drawn from interviews which were transcribed verbatim, there are often linguistic inconsistencies which are reflective of those in everyday speech,

which is generally not as precise as written English. Within the quotes a number of typically South African words are used by participants (like "ja" which means yes and is derived from the Afrikaans language). Words which might identify a participant as speaking a particular language, and hence pose a potential for breach of confidentiality, have been removed from quotes. However words in common parlance like "ja" have been left in because I do not deem them identifying.

8.2. INTRODUCTION

Context can be broadly defined as: "The circumstances that form the setting for an event, statement, or idea, and in terms of which it can be fully understood" (Oxford English Dictionary). As discussed in Chapter 1, South Africa is unique, complex and diverse, all factors which help shape its context. Gauteng is characterised by the same inequalities, asymmetries and extremes which are common to the rest of the country.

Context, in this thesis, refers to the larger setting in which transplant in Gauteng is accessed. A basis for this chapter is the need to acknowledge universality (Tronto, 1993) when considering care. Good care requires an appreciation of universal factors which form the circumstances and views of role-players in caring relationships. This chapter will discuss universal aspects which converge to create the context for transplant in Gauteng and which will subsequently require acknowledgement in understanding further research results within an ethics of care framework.

Findings presented here are important for exploring the influence which personal experiences have on transplant, a specific objective of my research. Furthermore, the literature review noted that an exploration of context is vital for a comprehensive understanding of phenomena such as uncertainty (Brashers et al., 2003), healthcare hierarchies (Jewkes et al., 1998) and moral distress (Austin et al., 2005; Varcoe, et al., 2012; Roels et al., 2010).

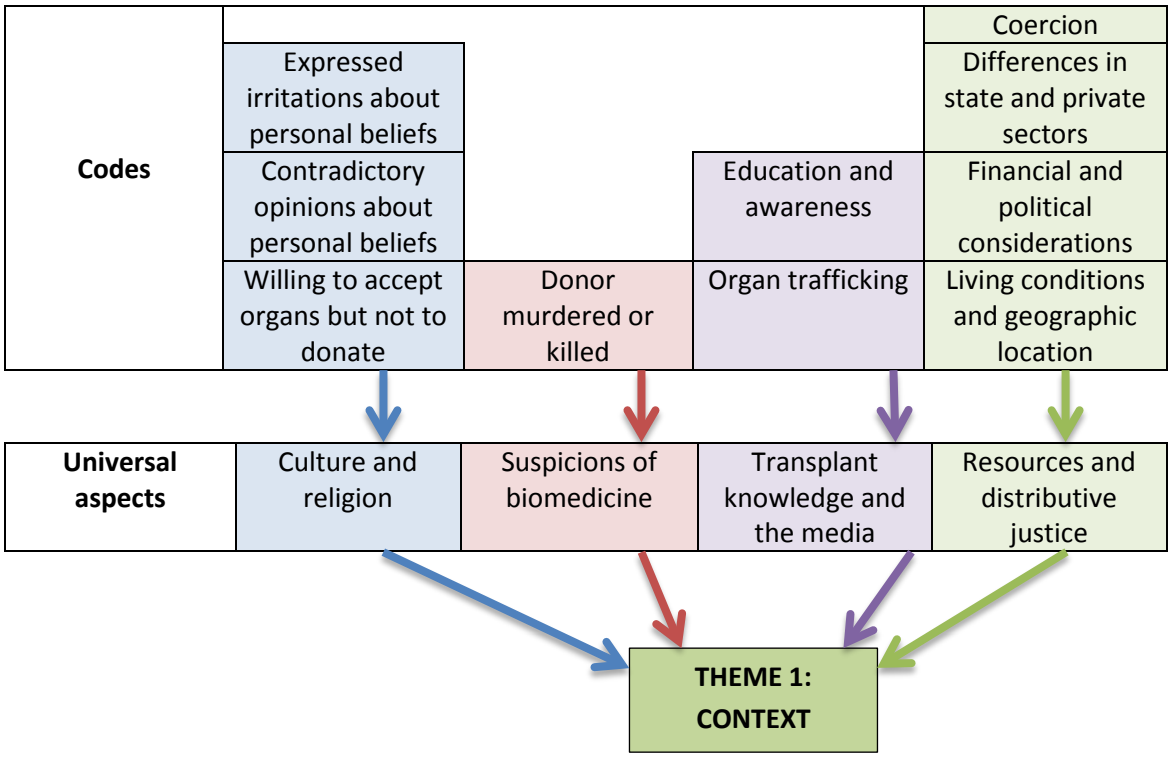
By identifying similarities between codes (Figure F8.1) I identified four universal aspects which shape the transplant context in Gauteng. These, listed below, are then

presented in Figure F8.2, which develops the model (Figure F6.6) presented at the end of the literature review:

1. Culture and religion
2. Suspicions of biomedicine
3. Transplant knowledge and the media
4. Resources and distributive justice.

Figure F8.1 - The Gauteng transplant context

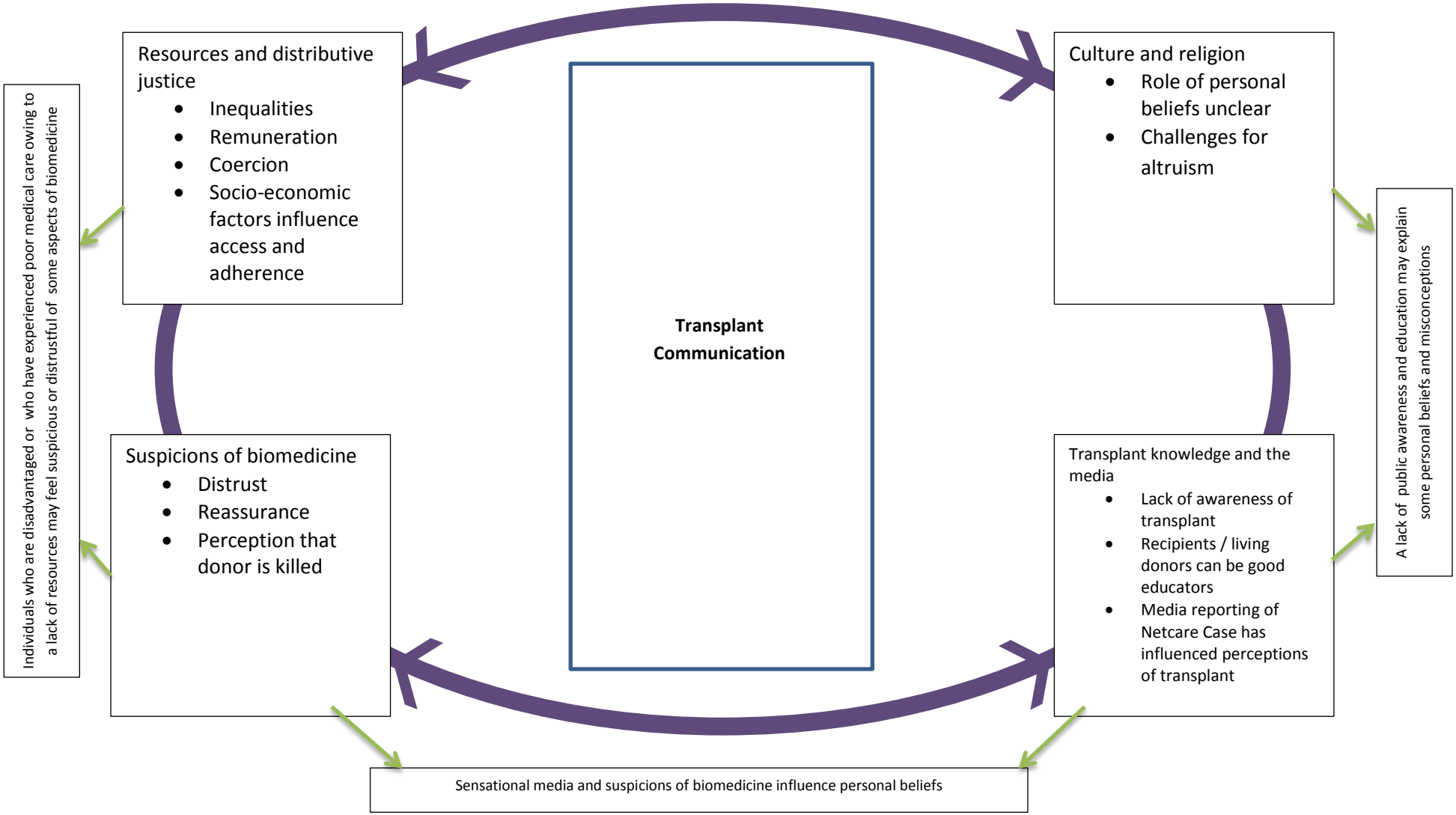
The overall theme of context in transplant identified four sub-themes which can be related to universal constraints in the ethics of care. These included culture and religion (personal beliefs), the influence of perceptions of biomedicine, influence of the media and resource constraints related to distributive justice. The link between initial codes, sub-themes and the main theme is depicted.



- Culture and religion – Codes arose from a direct question about perceptions of cultural and religious factors in transplant. The sub-theme related to participants' perception of cultural and religious practice and its influence on transplant amongst the general public.
- Suspicions of biomedicine – Only one code was strongly linked to suspicions of biomedicine. This was a perception amongst participants that both health professionals and the general public believe that a cadaver organ donor is killed for his or her organs.
- Transplant knowledge and the media – Participants in my study specifically linked trafficking and its portrayal in the media – which is why trafficking was not grouped with suspicions of biomedicine – although incidents of trafficking could perpetuate these suspicions. These observations arose primarily in response to questions about cultural and religious practices.
- Resources and distributive justice – Four codes were grouped together because the data addressed larger questions relating to resources, finance, equality and poverty. All of these had implications for distributive justice and hence were grouped together. There was no direct question about these aspects, however, they emerged as a significant feature of the data.

Figure F8.2: Model for the Gauteng transplant context

This figure illustrates the Gauteng transplant context. It demonstrates that contextual factors not only affect transplant communication, but also shows how they are interlinked – with each aspect of context affecting the others and all adding to the overall complexity of the Gauteng transplant context.



8.3. CULTURAL AND RELIGIOUS CONTEXT - PERSONAL BELIEFS AND PRACTICES

8.3.1. A note on terminology and writing style for this section

A number of studies have suggested that factors such as 'culture' and 'religion' could be indicators of transplant preferences (Bhengu & Uys, 2004; Bidigare & Oermann, 1991; Blok, 2006; Etheredge et al., 2013; Kim, Fisher & Elliott, 2006; Muller, 2013; Terrell et al., 2004). Many of these studies - including those undertaken by myself - used statistical analysis to generalise the attitudes of groups of people, typically reporting similar findings. Based on these studies, participants in my research were asked specifically about their views on religious and cultural practices and the influence they may have on transplant in Gauteng; in fact, exploring these was originally proposed as a research objective. My research results suggest that personal beliefs and practices are considered influential. However the findings are complex and often cannot be attributed to religion or culture alone. Rather, personal beliefs appeared to be a small part of the larger transplant context.

For this sub-theme I have relied heavily on quotes from participants to illustrate their points. This allows the reader to engage directly with the findings, and removes the possibility of bias which may have been introduced by aligning the interview questions with findings from previous studies. Furthermore, interpretations of key concepts, such as culture, are not offered, rather allowing the participants' own interpretations to stand. I also decided to keep this section brief, because many of the findings were similar to those of previous studies which were discussed in Section 2.6 and I considered it more important to present new findings in this thesis. However, it must be noted that the vast majority of participants expressed opinions about personal beliefs in organ transplant, and this is significant because it suggests that personal beliefs are deemed important by participants.

8.3.2. Personal beliefs and transplant

Personal beliefs are an always-present factor influencing the decisions individuals make. Transplant decisions are no different, thus personal beliefs and practices form part of the transplant context. Over three quarters of the healthcare professionals who participated in interviews felt that factors such as diversity in religious and cultural beliefs influenced transplant in Gauteng. However there was no consensus on these points.

Diverse personal beliefs and practices in the general public were sometimes considered a barrier to organ donation, and were a source of frustration for some participants. Perceptions were based on religious and cultural practices, mistrust of biomedicine and limited public awareness of organ donation. However, opinion was divided in these instances, with as many healthcare professionals feeling that beliefs were not a significant contextual factor in the transplant process, as those who felt that they were.

Over three quarters of the transplant professionals shared their views on universal aspects such as diverse cultural practices and religious beliefs and their implication for organ transplantation. Once again, the results showed the sample was divided, and no consensus was reached. The quotes below illustrate that personal beliefs may be a barrier to transplant because they can prevent individuals or families from considering organ donation:

> *It's huge, it's massive, I mean your religion and your culture defines who you are. And you believe it. Whether or not it makes any sort of sense is another issue. You believe it and I mean, you know, we've got a very interesting country here because you come across all sorts of cultures and all sorts of beliefs, and to the people who believe those things, they believe it.* ***So some of our patients believe it. You must go to your maker as you were born, whole. You know, and you may not desecrate the body, and well, you can stand on your head, they will not give those organs (003)****.*

> *Or even after passing on, donating to the community, because they[21] don't believe in that. They believe that you must be whole because your ancestors won't accept you if you are being cut into pieces* ***(008)****.*
>
> ***Religion is huge, and so is culture. Obviously they're two different aspects, but ja it's huge. Within the donation process there are certain religions that will <u>not</u> donate. So like the Muslims will <u>not</u> donate at all.*** *Then there are also, within different cultures, there are certain cultures who will not donate unless they have spoken to their ancestors or it's just generally not their policy* ***(021)****.*
>
> ***I think it's mostly a problem of, especially in the African population, it's culture.*** *The African population is an extended family. I don't own my household. It's owned by my family. It's my mother, my father, my sisters, my brothers. And when a decision, a very big decision, has to be made, that's where all of them come in collectively and make the decision, and that's what is causing the delay* ***(TCFG1P3)****.*

It was clear in the second donor family interview that religious beliefs had influenced the context in which a transplant decision was made. The family was Christian and believed that the circumstance in which they made an organ donation decision was engineered by God and that donating organs was God's will:

> ***God*** *wouldn't have put all these things into place if it wasn't meant to be* ***(DFI2P1)****.*
>
> *Friends of ours came along as well. We all got together around the bed,* ***we did a prayer session (DFI2P1)****.*

The excerpts above suggest that a range of different beliefs and practices amongst the general public shapes the context in which donation decisions are made. In turn, this is perceived to influence willingness to donate organs. Certain groups were seen as more amenable to donation than others.

Antithetically, two thirds of participants appeared cynical about universal factors like personal beliefs and practices in the general public; these were seen as a

[21] In this extract "they" refers to the general public.

source of frustration with implications for consent rates. Personal beliefs were considered to be a convenient excuse not to donate organs at certain times and under certain circumstances where families may invoke maxims which precluded organ donation. At other times, such as when an individual received an organ him or herself, all such reservations appeared to fall away and the fortitude of expressed beliefs was seen as short-lived in the prospect of a life-saving intervention:

> *Ok, I think that my impression at the moment, because we have a less than 1% donor rate in South Africa, and the majority population group in South Africa are Black, so the ruling belief is that Black people don't donate because of their ancestors and cultural things. I personally think that that's been* ***a smokescreen to excuse failure of promoting transplanting and organ donation****, and I think that it's more a reflection of lack of education, in other words, the transplant fraternity educating the public, right, rather than cultural beliefs* ***(001)****.*
>
> *The opinion I have now might be very different to the opinion I have in twenty years time if something goes wrong and I need transplant. But I don't think that people are very devoted to whatever path they choose. But you know how far does that devotion stretch when it comes to your own life? I think that people are very quick and easy to say, and* ***blame a lot of religion or culture for a lot of their behaviours****. But when you're in a situation I think you think very differently. I wouldn't want a transplant to keep me alive. But in twenty years time maybe I would, I don't know* ***(009)****.*

This cynicism was also expressed by transplant coordinators in both focus groups:

> *Culture, yes I do see,* ***culture actually to me is just like a curtain that people are using not to give****. More than anything else it's the education that is not there. So the easiest thing is to say: "No, culturally, uh-uh, we can't do this."* ***(TCFG1P2)****.*

> *Oh! Well actually they[22] do say, some of them, they say: "After I've received a kidney or any organ, definitely I'll go and have that ritual there so as to appease the ancestors that I've got somebody else's organ in me so that they accept. So that when I die, they can accept me when I go to them.'* ***As it is, I'm busy saying: "Guys, OK, suppose they didn't say yes, they didn't accept it, when you appease them they didn't accept it – I don't know how they show that 'we have accepted'. What will you do? Will you say: "Doctor, take it out because my ancestors don't want it?" And they say: "No, no, no, no, no, I'm not going to say that. I have my kidney now, so I'm not going to allow anyone to take it away from me. So those ancestors can just stay away from me if that is what they want."*** *It's like a thing of, if they don't accept, it's their indaba, I'm going on with my kidney. To me, it doesn't make sense, well to them it does, because that's what they believe in and I've got to respect that. But they do, some of them do the rituals so as to appease the ancestors* ***(TCFG1P2)****.*
>
> *So, and it's different, and it's not just…* ***We often talk about culture, I would say it's not culture anymore****. It's white, black, orange, purple, green, everybody has issues or preconceived ideas about organ donation and to get through those, it's more than a challenge, it's sometimes impossible* ***(TCFG2P1)****.*

One third of the participants expressed frustration that families appear unwilling to donate organs on cultural or religious grounds, yet seem willing to receive an organ in spite of these personal beliefs. This willingness to receive a transplant seems related to the perceived value of one's own life. The immediate prospect of death, or protracted illness, brings the value of life into sharp focus, to such an extent that individuals who would not previously have contemplated donation would now readily receive a transplant. The first quote presented here is key because it shows how beliefs can be overcome in the face of life and death:

> ***So you may get a patient who you would expect because of a religious affiliation to have doubts about transplant, and yet they don't.***

[22] "They" refers to potential organ recipients in the pre-listing phase.

> ***Interestingly. And I think it's because people are confronted with life and death, and they find they can transcend or negotiate or sort of try and ascend that particular religious belief****. I have never come across someone who said sorry, but because I am a such and such I won't (receive an organ). … But for me I've found that, you know, I've had people from deep rural areas who've only ever heard of transplant, but if they're very sick and they want to live then they want it* ***(004)****.*
>
> ***Once there's a need you won't find somebody saying, I'm not going to take the kidney because it's against my culture****. No. We find very little difference in the recipient attitude to needing [an organ]. So once they get onto that side of the scale, all those cultural religious things just fall away completely* ***(002)****.*

Transplant coordinators in the first focus group also noted this trend as a source of frustration:

> *Also, you had that situation where the family didn't give consent for the operation (donation) but then the daughter asked:* ***"Well can't you transplant a brain?" So very quick to say: "No"****…* ***(TCFG1P4)****.*
>
> ***But that's the phenomenon we have in South Africa where it's like: "No, we're not prepared to donate, but how about can you transplant a brain?"*** *It's that same concept of: "I'm in kidney failure, I want to accept an organ, but I'm not quite ready to donate an organ to society"* ***(TCFG1P6)****.*[23]

[23] The notion of reciprocity and altruism in a South African setting is sometimes framed with reference to the concept of *ubuntu*. In this thesis I have been advised not to consider the notion of *ubuntu* in substantive detail because, having read in-depth about the theory, I am of the opinion that *ubuntu* has been adopted sometimes disingenuously as a subject of South African political discourse, and that exploring *ubuntu* fully and doing the concept academic justice is beyond the scope of this thesis – and similarly is not at the core of my argument or strongly evident in my research results. *Ubuntu* is a moral undertaking, driven by values such as generosity, forgiveness and love. Not to have *ubuntu*, then, is a moral deficiency (Bell, 2002). Furthermore, *ubuntu* is a set of personal values which is realised through our interactions with others (Munyaka & Motlhabi in Murove, 2009). *Ubuntu* demands of African people solidarity with one another, especially in times of duress. It places a near moral obligation to help those in need of help: "when some are in need others must play their part in contributing to their good and that of society", and this can be done "through practical communal action to help alleviate human suffering" (Munyaka & Motlhabi in Murove, 2009, P. 75).

Aspects such as suspicions of biomedicine, a lack of transplant knowledge and the effect of the media may also influence personal beliefs and practices, thereby contributing to the universal context of transplant in Gauteng. If individuals are not provided with accurate information, it may be easier to justify donation decisions from the context of personal beliefs, whereas, in reality, misconceptions or a lack of knowledge about transplant may influence the decision-making process. This will be discussed in the following two sections.

8.4. SUSPICIONS ABOUT BIOMEDICINE

Over half of my participants discussed factors of universality that could be linked to suspicions of biomedicine and to misconceptions about transplant; and which may shape the transplant context in Gauteng. Some healthcare professionals were perceived by my research participants as having the impression that organ donation was akin to killing, or was associated with criminal actions, such as the theft of body parts:

> *The biggest obstacle I think, with a lot of staff members, is **the feeling that they are killing the person by referring them for organ donation**. And I think it's a very hard… **(024)***
>
> *Personally I feel that, for me as a person, it's like, you know….. Yes, professionally it's something that needs to be done, we all understand, **but as an individual, at some stage you feel that the person is being robbed of his or her parts.** That's how I feel. I feel it's actually imposing on those people **(022)**.*

Transcriptionists from both focus groups agreed that those healthcare professionals, who held the attitude that a cadaver donor was actually being killed, constituted a significant barrier to transplant. The excerpt below details the experience of organ harvesting in theatre, where nursing staff mouthed the word ''*murderer*'' to transplant coordinators:

> *We have the exact same concept when we take the patient to theatre, when we take a donor to theatre. We have the Mexican wave – I can't say the Mexican wave – we have the African wave. It's like, OK, we are taking a*

> *patient who has been declared dead to theatre, and* ***we are treated as murderers when we are in theatre (TCFG1P6)****.*
>
> *They (nurses in theatre) actually say it, with their mouths… (They mouth the word: "murderer")* ***(TCFG1P2)****.*
>
> *Ja, with their mouths… (Interrupted)* ***(TCFG1P6)****.*
>
> *They actually say it* ***(TCFG1P2)****.*

A perception that organ donation actually involved the killing of the patient was also seen as an obstacle amongst the general public. The excerpt below expresses a sense that the general public felt transplant involved killing someone for his or her organs:

> *… the public to accept that you are not* ***actively killing the patient for their organs (001)****.*

Allied professionals who participated discussed their perceptions of cadaver donor families, noting that the impression that a loved one may have been killed by medical professionals for their organs, was sometimes evident. When a donor family encountered a transplant coordinator in the ward, and they had never seen the coordinator before, the perception appeared to be heightened:

> *I feel for them that, for sure, they feel not nice that now* ***[the doctors] killed my person because they wanted the kidney****, it's what they (the family) are saying* ***(006).***
>
> *… sometimes they (the family) find that who is that (the transplant coordinator)? We've never seen this person next to our loved one and yet today they are here, they want to harvest the organs? Why? Some of them even have, they make crazy assumptions,* ***they're like: "You killed him so that you can take the organs!" (011)****.*
>
> *Something drives them (the family) to say: "No,* ***what if you killed our family member?*** *What if you did it to give whoever? Because we don't know you and you don't know us and we can't prove that what you are telling us is true"* ***(011)****.*

Participants said that such perceptions of organ donation may be born out of distrust for the medical system, and that reassurance was required in order to mitigate this.

Distrust	Reassurance
So there's this misconception that something somehow goes wrong when you never live to see another day because ***people in hospitals they kill you (011).***	*We try to reassure them that: "No man, it's not like that, we are not killers, we are hospital"* ***(011)****.*
… you can't write rules for these things, but there are certain trends. I think some of that is ***born out of distrust for the medical system, which you can understand****… **(016)**.*	(Reassuring patients that) *''No,* ***nobody's been killed****…"* ***(TCFG1P2)***
… that when one takes organs: "Where are you taking them? Are they going to be used for muti[24] *purposes?" … Because I think maybe in [this province] is that* ***whenever a person dies it's you that killed him (TCFG2P4)****.*	

The second donor family focus group also expressed some sense that their loved one was being killed by healthcare professionals. The quotes below recount experiences in the post-consent period, where there is a rush to organise the

[24] *Muti* refers to a medicament derived from animal or plant material and used in traditional medical practices (Sobiecki, 2012). These medicines are believed to be therapeutic, though unlike allopathic medicines they are not regularly subject to rigorous clinical trial processes.

donation. A medical professional entered the ward and started drawing blood from the donor:

> *Ja, for me it was tough. Because I see this lady walking in, as white as a ghost, black hair, black dress, and she's just pulling blood all the time. And that's when I walked out and I said: "No, this is not for me."* ***(DFI2P2****).*
>
> *She basically looked* ***like the angel of death****…* ***(DFI2P1****).*
>
> *I actually stood there looking at her, and it was running through my mind: "Gosh,* ***you are like a vampire, you just drink up as much as you can****"* ***(DFI2P1)****.*

Distrust of biomedicine is a contextual aspect relevant to South Africa which has been substantially documented. It is discussed in this thesis in the literature review in Chapter 2.

8.5. TRANSPLANT KNOWLEDGE AND THE MEDIA

General public awareness about organ donation was seen as a universal factor contributing to the context in which transplant is accessed in Gauteng. Participants had a lot to say about this aspect. A number of healthcare professionals felt that the educational level of an individual may influence their attitude towards organ donation, and that educational level may explain some of the personal beliefs discussed in the previous section. Individuals with a lower level of education were perceived as experiencing challenges when it came to understanding organ donation:

> *The other thing that really does make a big difference is the education level of the person. So* ***if you've got someone who's very set in their religious or cultural beliefs and their education is less than university, maybe less than high school, I think you've got no chance (003)****.*
>
> *Again I think that with the non-medical people there are differences and I think they do sometimes have difficulty grasping the concept, there's no question about that. And again I think it does go back to level of education.* ***So you know, if you've got somebody with a very low level of education,***

> ***who maybe hasn't even had a secondary education, I think the concept for them is very difficult to grasp, they don't understand the things, and they may then rely on elders and ancestral beliefs and things like that which may definitely come into play (015)***.

The overwhelming majority of healthcare professionals and transplant coordinators from both focus groups felt that there was a lack of public awareness about organ donation. This was seen as contributing to low donor numbers:

> *So I think that the cultural perception and the religious perceptions are being promoted to excuse* ***failure of a good, motivated educational programme to the public (001)***.

> *More than anything else it's the education that is not there. So the easiest thing is to say: "No, culturally, uh-uh, we can't do this." But …* ***they don't understand because there's no education about it (transplant)****…* ***(TCFG1P2)***.

> *And, I think also, if I can just add on to that, education also makes a huge difference* ***(TCFG2P1)***.

Lack of information about organ donation was also expressed in the living donor focus group, where one participant had no knowledge of organ donation prior to becoming a living donor:

> ***But we lack information on kidney donation, we lack so much information… (DFG003)***.

> *… Actually from my side,* ***I didn't know anything about kidney transplants, kidney donations****. But my sister once took me to the hospital, I went with her for dialysis, so that's when I found the information about kidney donation* ***(DFG003).***

Some healthcare professionals felt that using the lay press to publicise organ donation was an effective educational tool to combat a lack of awareness. However, other participants and TCFG1 felt that those recipients or living donors

who had been through the transplant process were better advocates of organ transplant than the media or other 'outsiders':

Lay press perceived as a powerful educational tool	Recipients and living donor perceived as a powerful educational tool
… I must say the Organ Donor Foundation and the National Kidney Foundation have had donor drives and there's advertising things and that does help ***(003)****.*	*I think those families, for example, mothers who give to their daughters, are the most powerful advocates for transplant. Because the impact that they have is way beyond any advertising campaign, it's way beyond what any doctor can say to a patient* ***(024)****.*
And then don't forget the avenue of the lay press. That avenue is tremendously important, because, when I mention socially at a dinner party that we did a heart transplant people say: "You don't do those things anymore do you? We haven't heard about that for so long." Because it's become so much an everyday operation that people don't talk about heart transplant as existing at all. So the Organ Donor Foundation, through media like the lay press, like Carte Blanche[25], like those kind of shows will do their best to get the message over to the lay public that transplantation's alive and well ***(014)****.*	***But it needs to be done by the people that they respect****. So whether it's a Zulu community it needs to be done by one of the elders, one of the men who will give consent. In the Jewish community it needs to be done by the Rabbi and in the Muslim community it needs to be done also by the elders. And it's really important that we are speaking to the decision–makers, and educating those decision- makers and that they are filtering it down and then that gets filtered down to families and generations* ***(021)****.*
	But maybe one must also, well two things, start from a recipient side. And I've been saying that, if we've harvested now today at this hospital, then after a week you must take a recipient there, obviously not the same recipient. But go and say: "This is what it's all about. And remember that that person didn't die in theatre, his time of death is declaration time." Because that was one thing I also didn't know before I started doing organ donation… ***(TCFG1P4)****.*

8.5.1. The media, organ sales and trafficking

Internationally, transplant has become tainted with concerns of organ sales and trafficking. These span countries and ideologies and challenge the conventional notion of organ donation as an altruistic undertaking. South Africa has not been

[25] Carte Blanche is a South African current affairs television show.

exempt from these forces and a small number of participants shared their views on this. Participants felt strongly that the Netcare St. Augustine's Hospital Trafficking Case, and the way it was reported in the media, had negatively influenced perceptions of transplant in Gauteng. One medical participant described personal experiences with illegal organ transplants and trafficking, acknowledging the role of desperation in the decision to purchase an organ on the black market:

> ***Some of our desperate patients have asked straight up, how do they buy an organ?*** *And you know, you can go to China, India, you can buy an organ. I've had the misfortune of treating one or two [recipients] from central Africa who were transplanted in another country and arrived back severely ill et cetera et cetera. With no support system, and they hadn't been educated or anything…. So there is certainly, I've certainly experienced exploitation first hand* ***(003)****.*

Medical professionals seemed forthright in reproaching those involved in the case:

> *Now our great transplant surgeons, who are* ***far from the most ethical group of doctors in this world, as you know from all the sales of organs, especially in South Africa where they are trying to wriggle out of it****, that's important…* ***(027)****.*

Medical professionals were also concerned about the impact which this scandal had on donation rates. The quotes below illustrate some of these concerns and consider the consequences of media reporting, indicating an ensuing situation of distrust which may have discouraged organ donation. Similarly, the case was also mentioned in the living donor focus group where it was perceived as corruption, a word strongly associated with factors of untrustworthiness and unreliability:

> *So, ja, we've had these sort of debates,* ***but what didn't help, for example, was the newspapers saying that people, doctors in South Africa were involved in buying and selling people's organs*** *because you know people are very afraid of the muti trade in South Africa. Where people are mutilated and their organs used for…. And you know it's aligned with that sort of thing, so people, it's a hop, skip and a jump for them. They imagine*

you're the grave robbers of old, going around and collecting and doing who knows what. So I think more than anything that hurt us. … ***We had people phoning [the hospital] to ask that their child or whatever donated and did [the hospital] sell these organs and could they have reassurance that this didn't happen to their loved one?*** *We had people actually phoning us and saying… And you know we had one or two phone calls that you know, it was disgusting what we were doing. We had nothing to do with this but you know, you are tarred with the same brush. So it's not to be underestimated, the impact of something like that* ***(003)****.*

The one aspect is public perception, and I think ***in general our cadaveric donation rates are appalling and they used to be very good. And I think there has been some damage from the scandal that we had. I think that has definitely damaged public perception****. And I think if the parties who were involved should be held accountable for anything they should be held accountable for how much it has damaged the public image.* ***So I think people used to feel very safe previously about giving their organs. Now there is a perception of: "What are you going to do? Are you going to sell them? What are you doing with them?" So I think we've lost the trust that we had, from what we've done as a professional body****. So that's my impression of what's going on out there* ***(024)****.*

… because ***there is a lot of corruption going around, especially those days when they harvested all those kidneys in Durban****. But ja, that is the only negative and actually it hurt me at that time, you know* ***(DFG001)****.*

The quotes above suggest that the Netcare St. Augustine's Hospital Trafficking Case, and sensational reporting of it in the lay media, may have created a context of distrust which has then become a barrier to transplant in Gauteng.

8.6. RESOURCES AND DISTRIBUTIVE JUSTICE

The results of my study suggest that universal factors like resource constraints, financial considerations and socio-economic status have significant implications for transplant services in Gauteng. These issues appear to permeate all levels of

transplant, from the system itself through to individuals. This section considers four aspects of resources and distributive justice which have been identified as shaping the transplant context, starting at a provincial level and moving on to personal considerations:

- Inequalities between the state and private sectors
- Remuneration in the private sector as a possible perverse incentive
- Possible coercive factors in living donor – recipient relationships
- The influence of socio-economic factors on access to transplant and adherence post-transplant

8.6.1. Inequalities between the state and private sectors

Twenty healthcare professionals mentioned the influence of finance and resource constraints in the Gauteng healthcare system. Resource considerations impacted transplant at two service delivery levels:

1. Access to transplant for state and private patients
2. Systemic human resource constraints

8.6.1.1. Access to transplant for state and private patients

Medical professionals commented that transplant is perceived as being very expensive and is not always seen as an optimal use of provincial resources, when basic needs are not being met in other health interventions:

> *… I have had many discussions with many other [healthcare professionals] who just think **transplantation is a waste of time and money**. It's expensive, half the recipients die, this is the impression. Organs are wasted. It's not a cost efficient or a very successful programme, which is nonsense **(005)**.*
>
> *There are also groups of people who believe that **transplantation should not occur in South Africa at all because it's technically a third -world country, it's an expensive sub-discipline here and it shouldn't happen**. Certainly we should not be promoting transplantation when their own ICUs,*

> *and their own units and departments, are not well-equipped, well-staffed or whatever **(001)**.*

Given these conflicting objectives, transplant services have not been readily provided in the state sector, or they have been provided in a haphazard fashion. Several participants – practicing in both sectors – and the living donor focus group acknowledged resource constraints in the state sector:

> *So it may seem a little harsh, but the fact of the matter is that **we have people outside who are dying without [receiving medical management] (003)**.*
>
> *Or what they do is they go to government for their work-up. And in government the delays are even longer because you have to book the chest x-ray, then you have to book the ultrasound, then you have to book the cross-matching. So **the process in government, although it is available, is very very long (024)**.*
>
> *It's scary to see how children [are] also suffering, you know, with the kidney failure and stuff. **And I don't know if the government hospitals are doing enough to treat those children**. Because if you look and see the background of the children, there's no money. And I don't know how the situation is in state hospitals. But that really is a big issue **(DFG001)**.*

Concern about inequalities in access to transplant for state patients compels me to consider distributive justice. South Africa's justice system was extensively discussed in Section 1.3.1 of the literature review where it was demonstrated that the government is responsible for a progressive realisation of the right to access health services. Figures illustrating that there has been no significant increase in access to Renal Replacement Therapy (RRT) demonstrate that government commitment to transplant may be questionable. Thus, I must consider that a lack of political will to support transplant may partially account for the limited service provision in the state sector, as one third of the healthcare professionals who participated in my research felt:

> *Why aren't we doing it (transplant) in South Africa? Because we have a so-called 'previously disadvantaged group'. Certainly the* ***politicians will live on this for the next 200 years, it brings them money and power, and I'm not interested in either their money or their power (027)****.*
>
> *And I feel that another challenge for this, '****cause our very own politicians and senior people are very cultural themselves. Maybe the reason for not promoting it so much is because they themselves feel conflicted in terms of their own beliefs*** *that are getting in the way. Because I don't think organ harvesting is a new thing* ***(011)****.*

The quotes above suggest that provincial resource constraints and politics may combine to create a context which constitutes a barrier to accessing organ transplant in the state sector.

Access to transplant in the private sector also appeared to depend on context, such as an individual's employment status. Employment often includes membership of a medical aid scheme which gives access to private health services. To this end, it would appear that wealth is less a factor of access to private care than whether or not one is employed:

> *There are a lot of people who are not, it's not entirely class, it's to some extent class- based, access to it (transplant), obviously, because it's high-end technology. The fact that more people in this country are now having access to medical aid means that it's not entirely class-based. You have to be employed or have someone in your family who is employed. But there are a lot, a lot is probably the wrong word,* ***a lot of working-class people … who are getting transplants because they have a medical aid****. So it's not just the rich who are getting them. But you do have to be employed* ***(004)****.*

However, one of the participants in the living donor focus group, shared perceptions that those who required transplant services were very ill, and hence may have poor employment prospects. This would then preclude them from access to private transplant services:

> *Because I saw her, she was suffering from that machine. Staying four hours, going three times a week.* ***Not getting employment, because there was no employer who was going to hire such a person because she had to go three times a week for dialysis (DFG003)****.*

DFG003 also mentioned that employment was a pre-requisite for membership of a medical aid scheme, and obtaining satisfactory medical care without one was particularly stressful. The participant was concerned about the quality of care he might receive in the state sector and feared that if he was unemployed his access to satisfactory management would be restricted:

> *Because again, in the public hospital, like for instance that time I was not working, the time I donated my sister a kidney I was not having a medical aid. So the questions I was asking myself again was: "If ever something goes wrong about me, meaning I am going to go back to the public hospital", and public hospital they are going to tell you: "You have to be on the waiting list for a certain time, because of the shortage of machines for dialysis."* ***So, you know, at least if you have a medical aid, you know private, it's the best thing that you are going to get…*** *You see* ***(DFG003)****.*

The quotes above suggest that access to transplant services can be shaped by a number of factors. Some of these, such as resource constraints, are quantifiable. Others are more subjective - such as the extent to which the cultural beliefs of politicians can determine the nature of the healthcare services which are available. It appears that those who are in employment are most likely to belong to a medical aid scheme which gives them easier access to superior transplant facilities in the private sector. Those who are not employed are compelled to use the limited transplant services found in the state sector.

8.6.1.2. Systemic human resource constraints across sectors

Irrespective of practice sector, many participants experienced the effects of understaffing in their institutions. This impacts upon the ability to provide care. One participant noted that there were not always enough teams to transplant all

the organs from a single cadaver donor which means that some organs which could be used are lost to potential recipients:

> *We sometimes have a clash or a discussion when we only have one team available, and we've got [two organs] available. And where the organs are of good quality we have to make the call [as to which organ] we will take…* ***(014)****.*

> *… at times when there has been* ***too few staff and you know there might be a delay of several hours****…* ***(029)****.*

Staff shortages within institutions were also mentioned and these sometimes affected the quality of care patients received. The excerpts below suggest that in resource constrained settings, the provision of care was rushed and haphazard:

> *Mmmm there's very few [speciality name] trained staff in the unit, there's only about four [speciality name] trained staff. And the other, there's a lot of … very young [staff] … and I don't know what their basic training is before they walk into a unit. … Because there, there's a definite skills shortage. I mean if I look at everyone who's on duty today, I'm only comfortable having three of the staff who are on duty today looking after [a transplant patient]. Which is a problem… And from a skill point of view there is a major, major, major lack* ***(009)****.*

> *We are already very short-staffed, so time is very tricky. So already with the pressures that we're dealing with, actually by the time we get there* ***instead of giving those patients … the extra time that they actually need you end up doing things quickly (012)****.*

8.6.2. Remuneration in the private sector as a possible perverse incentive

Healthcare professional participants were often practicing across two sectors, and had experiences of both. The results of my study suggest that in the private sector remuneration structures for medical professionals act as tacit perverse incentives

which prevent the referral of both potential recipients and potential donors into the transplant system. Each of these will be discussed in turn.

8.6.2.1. Financial incentives preventing the referral of potential recipients in the private sector

It was felt that physicians were sometimes unwilling to refer patients with chronic, transplantable conditions for transplant listing as this would result in a loss of income. This observation was based on the fact that medical professionals are often paid according to the number of patients under their care, thus, there was an incentive to have as many patients under one's care as possible. The lengthy excerpt below shows some of the financial complexities inherent in the referral process and has been adjusted to protect the identity of the participant:

> *But I think there's also a significant proportion of people who sit in private units for a long time without being worked-up for transplant. And some of the criticism that has been levelled at that is that **chronic patients are cash-cows**. So the medical aid pays the [physician a certain amount of money] per month just to have a chronic patient sitting in a unit. … So a lot of criticism has been levelled at people who don't refer for transplant because it's not a financial option. … And I think the other criticism that colleagues have levelled at medical aids is that the remuneration for looking after transplant patients is a lot less than the remuneration for looking after chronic patients. So, for example, the medical aid doesn't pay [the physician a certain amount of money] per month to look after a transplant. But they will pay [the physician a certain amount of money] per month to look after a chronic patient **(024)**.*

As kidney transplantation is the most common organ replacement practice in Gauteng, I specifically asked this participant about perceptions of nephrology, where sentiments were reiterated:

> *I think, for example, the criticism that's been lodged at a lot of [nephrologists] who have a lot of chronic patients is that, if [they are] paid R 1600 per month, [they] need to see that patient a least once a month. And*

> *often that doesn't happen. Patients will say: "I sit here, I can see that the doctor's getting paid, and I never see the doctor". … but I do think, if [a medical professional is] going to charge then [they] must be sure what [they] are charging for and [they] need to offer that patient the service that [they] are charging for…* ***(024)****.*

The observation was then confirmed by an allied healthcare professional who had experience interacting with dialysis patients in the private sector:

> *… [the hospital has] got nephrologists that look after [dialysis patients] and then they monitor them…* ***The routine is that every three months [the dialysis patient has] to go and see the doctor (026).***

8.6.2.2. Financial incentives preventing the referral of potential donors in the private sector

Some possible reasons why healthcare professionals are unwilling to refer potential donors are presented in the following chapter. However, it appears that one contextual factor influencing referral is linked to the notion of resources and relates to the remuneration structure of medical professionals in referring units. Like those who may refer potential recipients, medical professionals in referring units are paid per number of patients under their care. Pay is also based on the type of care being provided. In the technology-intensive settings from whence donors are referred, utilising resource-intensive, expensive measures over a period of time was seen as lucrative. Referring the patient as a potential donor would put an end to this revenue flow:

> *You see unfortunately the way remuneration works in the private sector in this country, it rewards that kind of behaviour. If [a physician can] keep a brain-dead patient alive in ICU for a few weeks it's extremely lucrative. It rewards [that person] financially as the treating physician.* ***It doesn't reward [that person] financially to refer that patient as a potential donor.*** *… The way it works is, for each patient you see in [a referring unit, as the doctor], for each patient you see, you get paid a certain amount per day from the medical aid, from the funders. And if they're on a ventilator it's*

> *even better, you get paid more. So if [a medical professional] sees the same patient everyday that's a way of making money. So [they] get paid per day* ***(005)****.*
>
> *I must say the overwhelming obstacle to donation is this perception that* ***it's very demanding to look after a donor who's dead anyway. And you put all this effort in and often there is a bit of concern in terms of reimbursement****, so you know if I - because it is true you know, the medical funders, you know if you are said to have demised at 3.15 in the morning and you happen to do something to the patient at 3.20, they will not reimburse* ***(003)****.*

This idea that a medical professional may lose out on income by referring potential recipients and potential donors is perhaps an incentive not to make these referrals, as illustrated by the quotes above.

8.6.3. Altruism and possible coercive factors in living donor – recipient relationships

The results of my research suggest that a number of universal but subtle coercive factors affect the transplant context in Gauteng, raising questions about the role of altruism in the transplant process. Incentives take many different forms, from indirect pressures in families and relationships, to expectations of monetary reimbursement. Here, it seems as though organs are seen as having a value rather than being seen as agift.

As discussed in Section 2.2.1. of the literature review, altruism is a fundamental principle underpinning the donation of organs by living individuals. However, altruism is often questioned, and doubts about whether an altruistic donor has genuine motives are frequently expressed. Like trafficking, coercion in organ donation appears to be linked to recipient desperation for an organ. It is most frequently seen in living donor-recipient relationships in the way some donor families may expect compensation from the recipient who is / was desperate to receive an organ. Unlike trafficking, coercive factors are local and do not always involve money.

Only five healthcare professionals who participated in my research shared their views about coercive relationships in transplant. However, these are relevant because they were discussed in great detail in transplant coordinator and living donor interactions. Concerns about transplant incentives included:

> *Or sometimes, there's another one who was given an organ by a girlfriend, a non-related living donor.* ***You'll find that the boyfriend doesn't want the girlfriend anymore. Sometimes <u>we</u> even tell him: "But, I mean that one gave you a kidney?" They say: "It's not because she gave me the kidney, I must now be forced to love her. If I don't love her anymore I don't****" … I mean that mindset must come that he or she gave [an organ] willingly, not forced. But now that one I'm talking about she was getting the pressure from the family they were now like, they don't want to see her anymore, you know it's no more the part of the family.* ***So she was very stressed (006)****.*
>
> ***But you always find that there's some hidden agenda between the donor and the recipient. The donor always expects, somehow, somewhere, or at some time, to get some little incentive in return****. We had a donor some years back who usually, like if the weather was like this, would call the recipient for a certain recipe of muffins. And they lived quite a long distance apart. And the recipient would have to bake those and take them to the donor. So I think it really shows the community that we are, that people are not willing to give in return for nothing. They always feel like: "I give you this and in return you give me that…"* ***(TCFG1P3)****.*
>
> *"****Can we negotiate?" "Is there a benefit? "Is there a benefit for me****?" Ok, we live in a society where it's: "Ok, what's in it for me?" as opposed to: "What's in it for <u>us</u>?" as a society. And families will blatantly say to you: "So, there's nothing for mahala[26] in Africa"* ***(TCFG1P6)****.*

Participants in the living donor focus groups did not directly discuss coercion, though they made (perhaps unthinkingly) statements that tally with those presented above. There may have been a notion of pressure from medical

[26] *Mahala* is a slang terms meaning that something is free of charge.

professionals, who were giving encouragement in the decision to donate, when it may be argued they should have been more objective:

> ***And then even the doctors, they said I'm "doing the right thing."*** *Ja* ***(DFG003).***
>
> *The psychologist part, ja, I think all of us went through that. The money questions or that someone is putting pressure on you to donate a kidney* ***(DFG003)****.*

Living donors also discussed the relationships with their recipients post-transplant. Though no obvious coercion was noted, subtle factors like asking recipients for transport may be indicative of a power asymmetry:

> *And I can remember when my cross-match was successful and it matched with (my recipient)* ***she brought me a bunch of flowers*** *and she was so happy about that* ***(DFG001).***
>
> *That's right, I don't know, the bond is stronger now, from my end. I mean,* ***I asked him to bring me here, no problem (DFG002).***

Questions about the extent to which genuine altruism can motivate living donors are prevalent. A medical professional shared views on altruistic donors noting that they were considered mentally unstable:

> *I mean, we've now had in recent years, a lot, quite a few altruistic donors, which is not something I ever saw before. I never saw…* ***We used to just refer them to the psychiatrist and say: "You must be crazy!"*** *(laughs)* ***(003)****.*

Recognition that altruism may be limited was also reflected where the notion of compensating a family for donation was discussed. One medical professional who participated felt:

> *…that* ***the family should be thanked in some very generous way*** *– I'm not saying how – but the family should be thanked for this marvellous gift* ***(027)****.*

This was echoed in TCFG1:

> ***But I think that's the reality of the times and I don't want to sound like I'm pro incentivising, but I think the reality is people cannot bury their loved ones. And if you look at a lot of the overseas programmes there are financial incentives for the family****, I don't know if you can call it incentives, but there are schemes that assist donor families. And in this country, unfortunately, a lot of people don't have the funds, and I think it's the way of our society, you know, the cops stop you: "How much can I give you so I don't get the receipt?" It's become a way of thinking in this country* ***(TCFG1P1)****.*

8.6.4. The influence of socio-economic factors on access to transplant and adherence post-transplant

Geographical proximity of potential recipients to a transplant centre was noted as a factor influencing whether they would be listed, and ultimately receive, a transplant. As noted in the literature review, transplant centres are primarily located in urban areas. These areas are often home to wealthier people who may have easier access to health services. So, those in urban areas and in closer proximity to the facility were sometimes perceived as being favoured. This could have consequences for those who lived further away from transplant centres. Being unable to speedily present for transplant, the organ may be given to another potential recipient or there may be a delay:

> *… we understand if* ***you're in another province*** *and there's no ways you can get here. … Then it's also a bit tricky because* ***it's a rarity that they have their own transport*** *and they can't just get in their nice car and drive to the hospital…* ***(003).***

> *Sometimes the patient from [names geographical location] will be asked to come and then the time it's late, then they have to, maybe… Ja I remember there was a patient whom we called and* ***because he is from far, they had to tell him: "No, no, no, we've got another one (recipient)****" … it affects even the patient that comes from far, and he comes here, and the kidney has been given to somebody…* ***(006).***

> *Because sometimes it's not only the staff that can delay that process, the patient themselves... Because remember sometimes when they phone you, they will tell you maybe at 08h00 that they: "Have just received a [an organ] that is matching you". Then you need to come, wherever you are. Remember the … operation will be done in [Gauteng], maybe you are in [another city]. So it's not going to be easy for you* ***(018)****.*

Along similar socio-economic lines, many healthcare professionals who participated in this research felt that adherence post-transplant could be affected by contextual factors which influenced the lives of recipients. It was stated that the management team need to question recipient adherence within a contextual framework:

> *"Oh he's defaulted again", you know as if the patient is inherently defaulting.* ***But when you investigate why, there will be a social reason*** *or there will be some reason why the patient has not been able to be adherent to their programme* ***(001)****.*

> *Those who don't [comply[27]] the issue [is] socio-economic. That the patients that I've come across maybe they'll say: "I didn't have money to come to the hospital on that particular day, no one woke me at home" … In transplant most of the patients that I've seen is the ones that's got social problems: "****No one working, I didn't have money to come to the hospital because no one working. I don't have my grant****" (013)****.*

This type of socio-economic context is problematic because non-adherent patients run the risk of rejection of the organ; this would be a waste of a donor organ, a scarce resource. In this case however, recipients have already received their transplants, and it is vital that medical management revolves around facilitating adherence amidst changing circumstances.

8.6.5. Sub-theme summary – Socio-economic context

This was a lengthy sub-theme and a brief summary at this point may prove useful to the reader. This sub-theme has predominantly considered the influence of universal contextual factors such as financial forces and resource constraints on

[27] The notion of 'compliance' is outdated, however this is the terminology used by the participant.

organ transplant in Gauteng. A small number of political and legal factors have also been identified. Resource constraints shaping the Gauteng transplant context are apparent across both private and public sectors; however serious economic disparities prove a barrier to transplant for the unemployed. This limitation in access may be driven by a lack of political will to accept transplant as a viable healthcare intervention. However, there is a perception that politicians will accept a transplant for themselves should it be necessary (Section 2.6.3.2). Other universal contextual factors such as geographic and socio-economic factors also influence the transplant context in the way that they shape the type of transplant care people are able to access.

8.7. SUMMARY AND CONCLUSION

This chapter has demonstrated the complexity and paradox of the Gauteng transplant context as shaped by a number of universal considerations. These findings have ethical implications, because they suggest inequalities and injustices which pose challenges for care. Personal beliefs do not appear to be conclusive barriers or facilitators of transplant in Gauteng. Rather, personal experiences, feelings about biomedicine and media coverage of transplant converge to form a context which may shape a donation decision.

The financial context is undoubtedly influential, facilitating or restricting access to transplant in sometimes surprising and unexpected ways. It seems as if considerations of greed and trafficking have clouded perceptions of transplant in Gauteng, and these form an integral part of the context in which decisions are made. Hence, when it comes to transplant education and public awareness the media is advocated as a positive tool, whereas in reporting trafficking it is felt to be negative. The media is thus a double-edged sword which can be used to shape context by promoting transplant or stigmatising it.

Finally, the social and geographic context of patients is found to either facilitate or hinder access to transplant, with disadvantaged individuals less likely to receive an organ than their wealthier counterparts.

Lack of public awareness and education may explain some personal beliefs and misconceptions about transplant. Because the general public may not be aware that organ donation is an option, or may not understand the intricacies of the transplant procedure, personal beliefs about transplant may never be tempered by a level of education and understanding which allows for a balanced decision. Professional misconduct by healthcare professionals, sensational media reporting of it, and suspicions of biomedicine could also influence personal beliefs because it is possible that misconduct and inaccurate or sensationalised information can create an environment of distrust. Individuals who are disadvantaged, or have experienced poor medical care based on a lack of resources, may feel suspicious or distrustful of some aspects of biomedicine, based on a perception that it is difficult to access, that there are not enough staff to provide care and that hospitals are only places for people to die.

CHAPTER 9 – RESULTS

The decision – grief, expectations and uncertainty

9.1. INTRODUCTION

My research argues that there are a large number of often conflicting expectations at play in the transplant process, and acknowledging these is vital in transplant communication. These expectations are shaped by situation, emotion and uncertainty. In this chapter I will show that the type of interactions taking place (those between transplant professionals and patients) require an acknowledgement of particularity (Tronto, 2010) in order to facilitate good care.

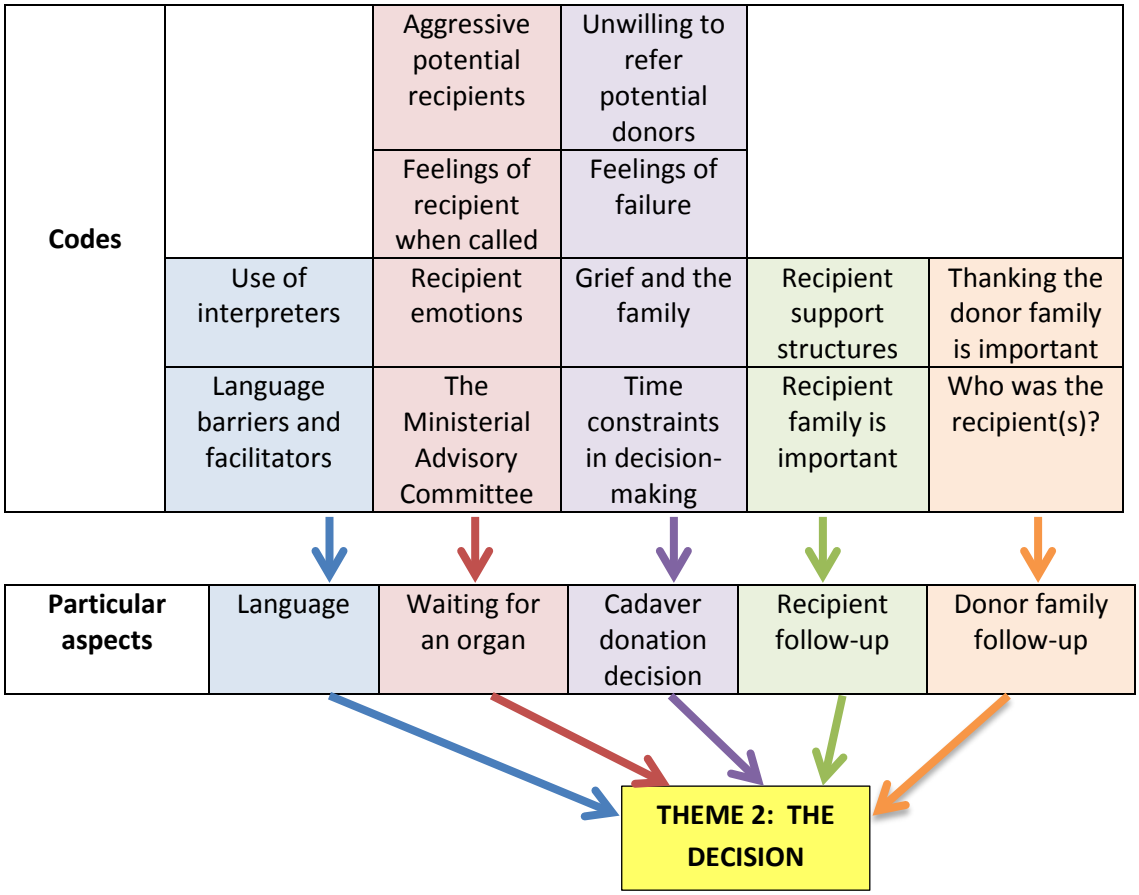
Organ transplantation is a major process, involving a large number of people. It takes place on the boundary between life and death, and entails a mingling of bodies and DNA. It involves recognising that one life must be lost in order for another to continue. A potential recipient and his family are desperate for an organ, whilst a donor family is grieving a loss. The healthcare professionals who are involved in the process also need to grapple with their own beliefs about donation and the ethical requirements of their practice.

This chapter considers communication between healthcare professionals, donor families, living donors and recipients through the process of transplant (Figure F9.1). It will begin by considering particular issues such as language and the use of an interpreter when communicating with patients or donor families. Thereafter it will discuss transplant professional–patient communication at various stages of the transplant process (Figure F4.1). Complexities in the pre-transplant process will be considered first. These include aspects of listing potential recipients for organs and the wait for a transplant.

The decision of a family to donate organs will now be considered.

Figure F9.1: The decision – grief, expectations and uncertainty

The overall theme which considered the decision either to pursue transplant as medical management or to donate organs throughout the transplant process produced five sub-themes. In terms of the ethics of care framework, this was the theme where particular aspects of care which required sensitivity in communication and insight into uncertainty were identified.



- Participants were not specifically asked about their perceptions of language but a number mentioned it. Language factors were related to differences in home tongue and the use of interpreters.
- Waiting for an organ was a combination of all codes which had been grouped together because they applied to all potential recipients.
- Cadaver donation decisions were derived from codes grouped together because they explored processes pre-transplant during the phase of procuring donor organs. The codes here were generated from questions asking opinions of referral from transplant professionals and coordinators, and from questions asking donor families about their experience.
- For recipient follow-up, codes were grouped as they related to transplant professionals' perceptions of these factors. The data emerged in questions about communicating with patients.

- Donor family follow-up combined codes which related to this phase. The codes were generated from questions posed to cadaver donor families.

This will include referral of potential cadaver donors into the transplant system and communication with a family who is faced with a donation decision. In the post-transplant process, recipient follow-up will be considered, and finally, findings related to donor family follow-up post-transplant.

9.2. THE ROLE OF LANGUAGE

Healthcare professionals, recipients and donor families - often with widely differing backgrounds - come together at the point of the donation decision. It is therefore apposite to explore here the vehicle for their communication, language, as a prequel to the following results.

The healthcare professionals who participated in my research spoke a range of languages. Some were only familiar with two, but many spoke four or even five. Participants were asked about their perceptions of communicating with patients and surprisingly few mentioned language at all, with less than one third giving their views on the subject. Those who did discuss language did not seem to consider it a barrier to transplant as they would enlist the services of a family member or healthcare professional to interpret if necessary.

Only two medical professionals mentioned language:

> … ***you definitely do want to speak to them in their own language*** *and not in English. Or Afrikaans, I mean that is quite out of the question* ***(027)****.*
>
> *From patients, well, I mean,* ***there's a couple of reasons patients may battle with communicating with us. One is obviously language (003)****.*

However it was also noted that some successful transplants had been performed where the patient was illiterate and the outcome had been good:

> ***We have in fact transplanted people who are completely illiterate who have actually done very very well, some of them even better than the fully literate ones****. And it really is a case of involving the family. And sometimes we take over patients, so there was one young man, shame he passed on*

> *now, but he was both deaf and dumb, so that was a bit tricky. Um, but you know we developed a mechanism with his mother, for example, where she would phone and we would explain it to her, etc. But you know the problem with that is always that, you know, Mum maybe is not always around, so there's that* ***(003)****.*

Allied professionals and transplant coordinators were more vocal about language factors, but appeared to agree that it is not a barrier to transplant as a third party may always be enlisted to assist if necessary:

> *For me it's not that difficult because I can speak all the languages, whether Afrikaans, Shangaan or whatever… So for me it's not that difficult,* ***that's why sometimes they call me … to translate*** *if there are patients, like a South African patient who has to go through transplant, I go there and help with translation. So it's not that difficult. But for the doctor it might be difficult because it's hard to try to explain to someone that he has a [name of organ] problem when the patient doesn't even know where the [name of organ] is, what are you actually talking about?* ***(008)****.*
>
> *Because some of the doctors don't know the African languages, they don't speak them,* ***so they also need someone to actually translate****. … And some family members don't speak English at all, they don't. So you'll find that most of us working here know about three to four or five languages and are actually there to assist them and say: "No, they are saying this…"* ***(011)****.*
>
> *"Ja, where most of us,* ***fortunately most patients understand you know, either English or they understand Afrikaans****" (028.)*
>
> *Language hasn't been a big barrier* ***(TCFG1P1).***
>
> *I have a few times,* ***when I've really had a family that can understand no Afrikaans or English. I've used the staff in the wards****. You get to know the staff that you can trust and you get to know the words that you can pick up, you know, odd words* ***(TCFG2P2)****.*

In those instances where the participant mentioned working with interpreters, I asked about their impressions of this experience. Two allied professionals and

TCFG1 felt it was satisfactory and helpful, though they did express doubts about the information that was given:

> *Um, well I don't know because **I don't understand what she's saying, you know. You're hoping that she's saying what you're saying**. Um, I haven't had any issues with regards to that **(010).***

> *Well **you never know how much information gets lost, that you don't know**. And also the consultation will be much longer. But other than that I don't have a problem with that, obviously they help us a lot. But ja, I just hope that the information gets carried over **(023)**.*

> *From a procurement point of view I find **if I'm with a family and I don't speak their language, it's so much easier to have somebody translate for you**. But you also have to be very careful that you choose people to translate that are pro organ donation. Because I don't speak the language, which is my shortcoming, I might say this, and the translator could be saying something completely different. And that is a concern **(TCFG1P5)**.*

Only one allied professional was particularly critical of the usage of interpreters in transplant:

> *Mmmmm, **I don't find it satisfactory, I must say**. And I think that's probably, if you're looking at communication and improvements, that would certainly be one of the areas that would require improvement. It's not something that's dealt with, maybe sensitivity is the right word, that it should have. So I think they're not trained interpreters and maybe each of the clinics should have an interpreter that is trained in issues of transplant who can be used **(004)**.*

Furthermore, a number of allied healthcare professionals and TCFG2 felt that provided patients or their families could speak basic English, an interpreter was not necessary and the consultation could take place in English:

> *I generally find that **if there's a working proficiency in English it goes ok (004).***

> *Most of our patients, even our black patients, speak English really well* ***(021)****.*
>
> ***So there's no one in South Africa except perhaps the ouma and the oupa op die plaas[28] that can't have a conversation in English****. It shouldn't be a big factor anymore. I think it would be nice to be able to speak to somebody in their own language, I'm not always convinced it's going to make that big a difference. I know I'm probably going against what you trying to prove here…* ***(TCFG2P1)****.*

Amongst my research participants a number had acted as interpreters in transplant interactions and the notion of cultural brokerage (Penn & Watermeyer, 2012a) as a means of bridging the language and background divide came through strongly. In the excerpt below a participant explains how a health professional may ask a direct question of the patient, but the interpreter goes further, for example querying the patient's responses, based on a knowledge of his or her cultural background and practices, which the health professional does not possess:

> *But if I'm translating to you, if you ask a direct question (to the patient), and then me, I go further. … you could have maybe asked twenty questions and I ask [the patient] one question because* ***I know what is expected of him and what he knows****. … And for [patients] to lie to me it won't be easy because I know what is happening. If [the patient tells the health professional] that: "I'm not allowed to eat pap" or whatever, [the health professional] won't know [and will] just say: "Ok."* ***Whereas me, I'll ask: "Why aren't you allowed to eat pap?" Because I know that you should eat it****. If you don't eat pap what do you eat? Pasta?* ***(008)****.*

In the quote above the participant's words demonstrate the bridging function of the interpreter, who comes into the consultation knowing what is expected of the patient from a medical standpoint and also is familiar with the patient's background, knowledge and belief system.

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[28] *Ouma* and *oupa* are Afrikaans words specifically meaning grandmother and grandfather. However, these terms are often used more generally to refer to elderly people. '*Op die plaas'* is Afrikaans for 'on the farm'

Communication between transplant professionals and patients or families takes place within the context of language. The communication itself will now be considered, as indicated in Figure F9.2.

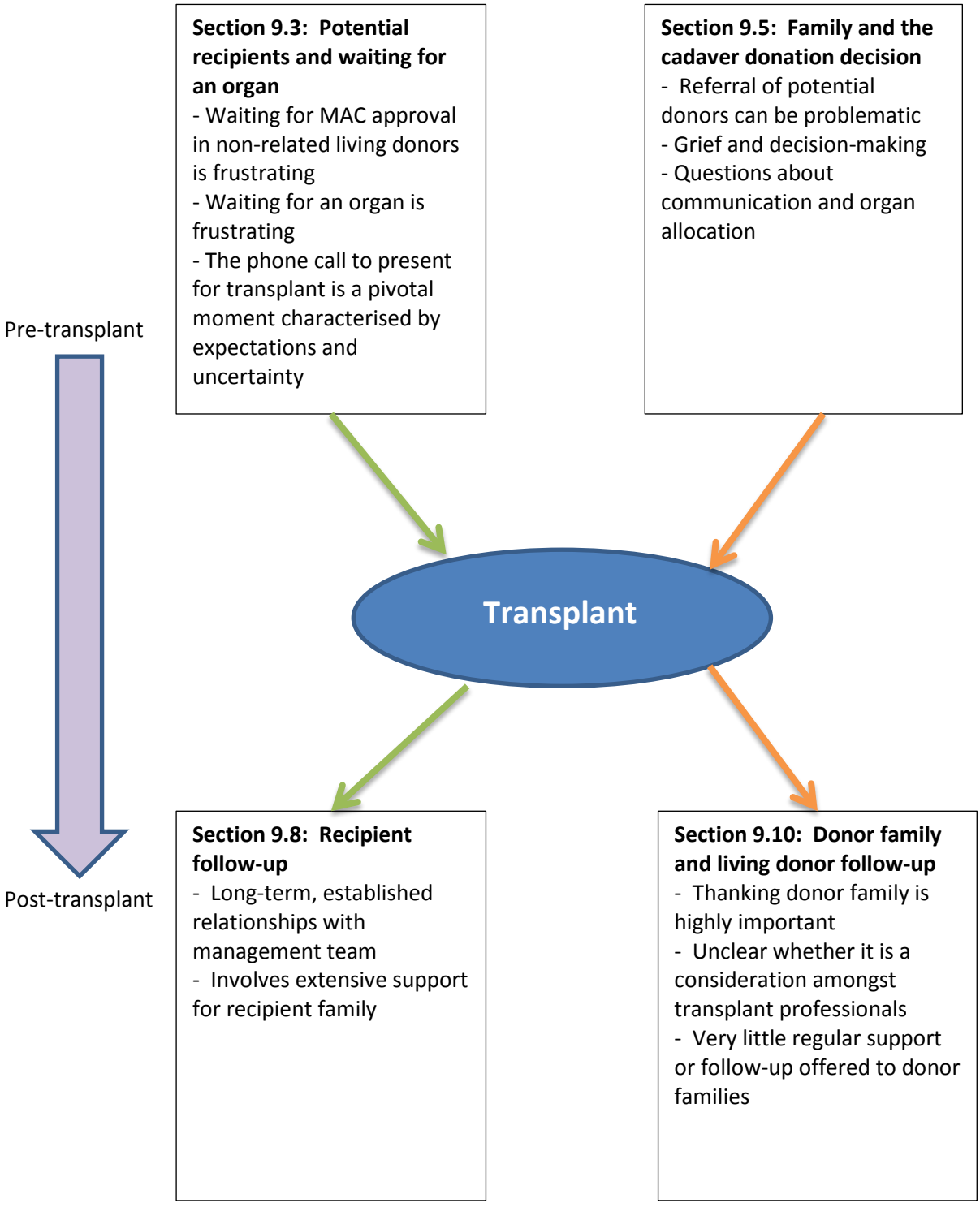
9.3. POTENTIAL RECIPIENTS AND WAITING FOR AN ORGAN

As described in the literature review, the waiting period for a donor organ can be lengthy and emotionally complex. The potential recipient may feel hopeful and optimistic that an organ will become available. However, there is also a constant fear that this will not be the case (Martin et al., 2010). The potential recipient may also experience frustration about waiting time, which compounds feelings of desperation in the face of illness and death (Hashmi & Moss, 2008). Such a complex emotional situation poses a number of challenges for transplant professionals who are required to manage potential recipient and family expectations by acknowledging particularity in their outlook and circumstances. The management needs to take place over a period of time and in a professional manner. My analysis has identified three important aspects of recipient expectations, and each will be discussed in turn in the following sections:

- The Ministerial Advisory Committee (MAC): 'infuriating', yet essential
- Communicating with frustrated potential recipients and their family members
- Calling a recipient to present for transplant

Figure F9.2: The decision – grief, expectations and uncertainty

The figure below depicts aspects of the transplant decision. It illustrates the pre-transplant aspects of decision-making along with their post-transplant consequences. Note how each role-player enters the transplant process with different emotions. These role-players come together in the transplant situation. This chapter will show that post-transplant, these role-players once again separate.



9.3.1. The Ministerial Advisory Committee (MAC): infuriating, yet essential

A potential recipient cannot receive an organ from a non-related living donor until the case has been reviewed by the MAC. A number of medical professionals in my research had experience with the MAC. All voiced strong opinions regarding its functioning. It was felt that the MAC was essential to the transplant process because it helped ensure ethical practice and prevent organ sales or trafficking:

> *Well personally **I think it's very necessary because, to be honest, some of our colleagues are, to say 'slap-dash' in their approach to making sure it is safe to transplant people, is an understatement. Certainly some of my colleagues have put people up for transplant that I wouldn't have sent for a haircut, you know**. It is very necessary. It was also very necessary socio-politically because we needed to reassure the public that we are not grave robbers, we are not profiting from illegal organs (referring to the Netcare scandal) **(003)**.*
>
> *… **they do fulfil the mandate in making sure it is all above board**, and I think that having the external audit is a very good thing **(024)**.*

However, the MAC was perceived to function at a sub-optimal level and medical professionals expressed intense frustration due to long turnaround times which were considered to disadvantage not only potential recipients, but also potential donors:

> ***We've had huge trouble**… **(027)**.*
>
> *(The process is) **laborious, infuriating, and very frustrating for the donor and the recipient (024)**.*

The extended waiting time for MAC approval was described as:

> *… **devastating from an expectation point of view**. So very often, some patients say: "I can't go through this again, so just leave me on the cadaver list, I can't do this" **(024)**.*

One of the living donors who participated in my research considered the time frame for approval from the MAC as the only negative aspect of being a living non-related donor:

> *The only thing that is a bit **negative about the whole thing is taking a long time**… **(LDF001)**.*

Furthermore, there are considerations of who would pay for the living donor work-up. In the private sector these are covered by the medical aid fund of the potential recipient, provided transplant actually takes place, at which point costs are refunded. However, if the MAC does not permit the transplant, medical aid will not cover these costs and this can have serious financial implications for the family:

> *So it's financially very costly, because the way the healthcare funders work, for example with [medical aid schemes], they will pay for the donor work-up, but only if the donation happens. So you can have someone who goes through the whole investigation, **all those tests have to be paid for, CT scans, the ultrasounds, the blood tests, which cost an absolute fortune… That has to be paid for upfront. And then if it goes to the Ministerial Committee and they say: "No", that's it. All the money that the family have spent investing in that is negated**. So financially it's very risky for the family **(024)**.*

One medical professional acknowledged that the MAC is a small committee and hence it may be operating within substantial human resource constraints*:*

> ***Now the ministerial committee consists of two people in South Africa**, both doctors. The minister or whoever else looks at them, probably throws it in the dustbin. So two doctors **(027).***

It could be argued that this sub-theme focussing on the MAC belongs better to the third theme, that of interprofessional communication. The MAC submission process does involve communication between transplant professionals (the transplant centre and the MAC). However, I decided to discuss the MAC in this chapter because a number of participants commented on potential recipient expectations in relation to the MAC. The notion of potential recipient expectations

is discussed more substantially in the following sections. Separating this sub-theme from others would have interrupted my argument that potential recipient expectations shape the nature of transplant professional–potential recipient communication.

9.3.2. Communicating with frustrated potential recipients and their family members

Both allied professionals and transplant coordinators had experienced aggressive, demanding behaviour from patients awaiting transplant and their families. The desperation and uncertainty was a highly stressful and anxious time, and it is clear that this lead to difficult communicative encounters involving potential recipients and their families:

> ***And the desperation that you know you're going to die*** *(the recipient is going to die), you are young. We all are going to die. But then I decided I will donate [an organ] to her. … And she was desperately in need of [an organ], and the transplant list is so long, she was on the list for about eight years, seven years. And there wasn't [organs]* ***(LDF001)****.*
>
> *I think the stress on the waiting list is under-rated... You know, that wait, the possibility of are you going to live? Are you going to die?* ***(TCFG1P6 interjects****: That's hope and desperation). You know,* ***I think modern medicine has brought about extreme fears on the waiting list (TCFG1P1)****.*

One third of allied professionals discussed unpleasant behaviour amongst potential recipients' families, stating that they could be difficult and did not seem to trust those caring for their loved ones:

> *But you get* ***some parents who are extremely difficult*** *and will question every single thing to every single person* ***(009)***.
>
> *And* ***some families, they fight****, they are like: "Why did you do that? You should have consulted us first" … they're like: "****What are you hiding?****"* ***(011).***

*I've found that they feel you are trying to **chase them away to hide something (009)**.*

Transplant coordinators maintain the transplant waiting list, negotiate the procurement of organs, and are the point of contact for listed patients. They therefore have intensive communication with potential recipients and their families. Coordinators were unanimous in the perception that potential recipients were especially difficult and demanding. Potential recipients would wonder why they had not received a donor organ, accuse coordinators of failing to do their jobs properly and threaten to report them to the media. Coordinators and DFI1 felt that potential recipients conveyed a sense of entitlement, claiming a right to receive a donated organ. The following excerpts illustrate the demands and expectations of potential recipients listed for kidney transplantation:

> ***TCFG1P6**: I'll get recipients phone me, on the waiting list, and the [name of town] recipients [are] exceptionally, quite volatile. I don't know if its service delivery protests or Julius[29]… But I would receive calls at least twice a week from recipients who were on waiting lists, and not even in the top fifty: **"Hey! Sister, where is my kidney?"*** (Said in an African accent, at which point all participants start speaking at the same time):
>
> - ***TCFG1P3**: Or they want to receive….*
> - ***TCFG1P3**: **"HEY! Where's my KIDNEY!!!!???!!!"** (Shouted)*
> - ***TCFG1P5**: And there were forty million deaths over Christmas: "Where's my kidney???"[30]*
> - ***TCFG1P6**: Jaja! Exactly. How many calls did we get in January?*
> - ***TCFG1P5**: I got about seven*

[29] Julius Malema is a South African politician, activist and president of the Economic Freedom Fighters (EFF), a political party.

[30] This section of dialogue is the transcript of a very heated discussion in TCFG1. The use of extra punctuation marks is deliberate in an effort to portray the vehemence with which participants made their statements.

- ***TCFG1P6**: **"I have just read that they had the highest death fatality on the road, <u>where's my kidney?</u>"***
- ***TCFG1P4**: Ja, we have that as well.*

***TCFG1P6**. Ja, it's amazing. **We have a society that says: "Eh! It's my right"** (*Said in an African accent*). Transplantation is not a right, it's a privilege.*

***TCFG1P5**: It's a gift.*

***TCFG1P6**: It's an absolute gift.*

***TCFG1P3**: Ja, but I think once the person is on the list and they know, it's like: "You promised" and we're like: "No, now you are on the waiting list and when a kidney becomes available we'll give you." And then they cannot wait, the 'when' becomes an issue with the recipients. They think it's going to happen very soon.*

*… maybe it is an indication of what our society is like today, **where everybody believes they are entitled to certain things (DFI1P2)**.*

Transplant coordinators who participated in the second focus group concurred. They especially agreed in the case of renal patients:

***TCFG2P2**: Kidney patients are difficult patients…*

***TCFG2P1**: They're **demanding**, they're…*

***TCFG2P2**: They're **extremely difficult** patients.*

Coordinators from both focus groups also mentioned that they were considered incompetent because patients had not been transplanted. This perception of coordinators failing to fulfil potential recipients' expectations often resulted in a threat to report the coordinator to the media or to their institution, illustrated by the two following excerpts:

***TCFG1P6**: I've also had the chutzpah [31] of: "**<u>No, you're not doing your job correctly! Because I haven't been transplanted!</u>**" (Lots of interruption)*

[31] A Yiddish term meaning insolence, cheek or audacity.

- ***TCFG1P1**: Ja, you see*
- ***TCFG1P5**: I mean, "**what do they pay you for?**"*

***TCFG2P2**: …but the whole culture in South Africa is changing. So we're getting more: "**You will either do it as I want it or I will contact the Beeld or Department of Health or I will phone your doctor or I will phone your hospital manager if you don't do as I say you must do**". So that has definitely come in the last three, four years…*

***TCFG2P1**: Ja.*

***TCFG2P2**: That culture has totally changed. So you get more and more patients, **I call them 'mean patients', rude, obnoxious people** come in and I don't necessarily always have the tact to handle these sorts of patients. You didn't see it [previously], these patients were, they came in, they accepted what you do for them, they said: "Thank you." And it was OK, and then it suddenly changed, it is three years now, **if you don't do it their way then they will see to it that you are reported all over the place**. It doesn't make the process quicker for them, instead it actually harms them, it makes it slower.*

I asked coordinators how they dealt with patients who had the expectation of receiving a transplant. TCFG1 stated that giving a potential recipient an idea of the length of the transplant list, and indicating their position on it, helped illustrate prospects of receiving a donor organ:

*… I actually took the transplant list, I printed it out and I went to the patient and I'm like: "This is the transplant list. You can see how many people there are, and this is your name, there. So now you know how long you may have to wait." Because, unless they see it on paper, they're like… Because the transplant list, even to the nurses and the doctors, it's like an imaginary document. They don't know how big it is, what it looks like. **But when you show it to them, now they know exactly where they stand (TCFG1P3)**.*

One transplant coordinator mentioned how the situation with difficult patients became more pleasant once they had received an organ. Allied staff also observed a change in attitude post-transplant:

> *Because most of these patients after, they will come back to you, and they will ignore the fact of how their behavior was. And they will go on as if nothing ever happened: "**You're forgiven now, I've had my kidney, you're forgiven now**" and now we go on again… **(TCFG2P2)**.*
>
> *Like [TCFG2P2], you know, these patients love her so much because, like, they know that she is the one who's giving them the kidney. I don't know but they love her. They will say: "Can I see [TCFG2P2]?" And then you can see in their face when they see [TCFG2P2] **they just appreciate her, they thank [her] that: "You've done a good job, you've done a great job" (025)**.*

9.3.3. Presenting for a transplant

Half of the medical and allied healthcare participants cited phoning a potential recipient to present for a transplant, and subsequent interactions at the transplant hospital, as aspects where careful communication was required. These situations were imbued with strong emotions for management teams, potential recipients and their families. It appears that the understanding of the transplant process is tested to the limits at this juncture because when called, the potential recipient feels hopeful of receiving an organ, but there is no guarantee that he or she will do so.

Participants commented on the emotional stress of waiting for the phonecall to present for a transplant and it was noted that potential recipients expressed their frustration at waiting for the phone to ring:

> *Now, can you imagine being told you need [an organ] transplant, and **you wait nine months, and every time your phone rings you think: Maybe it's the hospital…** – have you ever thought about that? I've thought about that a lot. So when the time comes, depending who's closest to the potential recipient, you make the phone call. And they're often very emotive phone*

> *calls, a lot of tears on both sides of the family, you know: "Are you sure? Is it going to happen?" and us getting pretty emotional as well…* ***(014)****.*
>
> *I always tell them, to give them hope, that they must wait because they will never know. Because* ***maybe they might get a call that same day****, that the [organ] is there, they have to go and have a transplant done* ***(026)****.*

These findings suggest that this phonecall triggers several emotional reactions in potential recipients. My participants noted that these emotions are a mixture of hope and excitement about receiving an organ, with fear and apprehension about poor outcomes if the transplant is unsuccessful:

> *So look I'd imagine, you know, certainly the patients have told us that* ***they're both SUPER excited but also terrified when they get called (003)****.*
>
> *You know, when they are pre-op, most of the time* ***they are scared, they are not sure. They are excited at the same time*** *because they have been waiting for this organ for such a long time* ***(018)****.*
>
> *But still, I think most of, in fact all of them, are so* ***overwhelmed by the 'what if' factor****…* ***(021).***

Participants stated that their role in pre-operative care was to manage potential recipient and family emotions in a supportive manner through their communications:

> *… and often* ***my job pre-operatively is to alleviate fear****, I mean that's really my thing. Patients understand what they're coming into. … These are massive operations. We tell them the first hurdle in survival, is getting through the procedure. They're horrific procedures, and they require teams with a lot of skill, etc. But* ***I take great pleasure in at least alleviating some of the fear*** *by, I mean at the end of the day, the patient should be happy to be having a transplant because it's a potentially lifesaving procedure* ***(016)****.*
>
> *So what I try and do is* ***manage that situation and manage the anxiety****. So the patient is obviously very overwhelmed by their emotions, so I spend a lot of time talking with the family, making jokes, assisting the patient…* ***(021)****.*

Healthcare professionals in my study acknowledged the prospect of grave disappointment when a potential recipient received a 'false call' and did not in the end receive the donor organ*:*

> *…and then the patients are obviously quite well worked-up from the point of view that they know that* ***just because they are called up for transplant doesn't necessarily mean they are going to get it (009).***
>
> ***We warn them upfront all the time that there could be false calls, so they're aware, we drum it into them. But it's traumatic****. I've had one patient who … was called in three times and in fact was once anaesthetised and we couldn't use the [organs]. And it's just, I mean, we were heartbroken. … [The patient] was, I wouldn't say suicidal, but extremely traumatised by it, as were we all* ***(020)****.*

9.4. CONCLUSION

This section has examined aspects of the pre-transplant process for potential recipients, identifying some complex ethical and communication issues. It has been shown that uncertainties for potential recipients pre-transplant revolve around whether and when a donor organ will become available. The phonecall to present for transplant is a harbinger of a new range of uncertainties about the future and the success of the transplant.

9.5. THE CADAVER DONATION DECISION

9.5.1. Referring potential cadaver donors

The first step in the pre-transplant process of obtaining cadaver donor organs is the referral of a potentially brain-dead patient to the cadaver procurement coordinator. The majority of medical professionals and all allied professional participants based in those units which are typically relied upon for referrals, perceived unwillingness to refer potential cadaver donors. Both transplant coordinator focus groups concurred with these views. The results of my research suggest three critical factors may prevent referral from taking place:

- Personal beliefs of staff in referring units

- Discomfort discussing poor prognoses and donation with families
- Giving the family a choice

It could be argued that this sub-theme would have fitted in better in the third theme of interprofessional communication because referral of potential donors involves a conversation between health professionals. However, it was decided to discuss these factors here because DFI1 commented on their interactions with health professionals in the referral process, and in some cases communication at the referral stage does involve the potential donor family. It was also important to discuss referral in this theme, because it helps build my argument in this chapter, that particularity (Tronto, 2010) in communication with the donor family is recognised better in the pre-transplant phase than in the post-transplant phase.

9.5.1.1. Personal beliefs of staff in referring units

Several medical professionals who participated in my study identified the personal beliefs of staff working within specific units as a potential barrier to referral of a cadaver donor:

> *You'll often hear: "I don't believe in transplantation"* ***(002).***
>
> *… remember also there are doctors who don't believe in transplantations, there are neurosurgeons who don't believe in transplantation* ***(014)****.*
>
> ***If you've got an ICU staff who don't believe in organ donation … you're not going to get any referrals (024)****.*

However, it seems that personal beliefs unfavourable to transplant are not always a significant barrier to referral. Some allied participants from referring units said that although they held personal reservations, they understood a professional obligation to refer potential donors:

> *No one has ever said: "I don't want to do this because of this."* ***Many of them are quite professional hey (011)****.*
>
> *Personally I feel that, for me as a person, it's like, you know…..* ***Yes, professionally it's something that needs to be done, we all understand****, but as an individual, at some stage you feel that* ***the person is being robbed of***

> ***his or her parts**. That's how I feel. I feel it's actually **imposing** on those people **(022)**.*

Transplant coordinator focus groups were unanimous that personal beliefs of staff were a significant barrier to donor referral. Nursing staff were seen as particularly influential in the referral process, given their close relationship with the potential donor family:

> *And you're called in as a coordinator and you've got the nurse outside shaking her head and saying: "Oh! I don't know why these people are coming here, because it's not something that we do". … **And not being shy to say that: "I'm in the medical field and I don't believe in organ donation**" you're already dealing with a family that's treating you as suspicious and as the outsider. And I also found, not only nurses, I also found doctors who would say to the family (and it's happened in my presence): "I'll call the coordinator in to speak to you although I don't believe in organ donation, I think let them have their say anyway" **(TCFG1P1)**.*
>
> *Because we'll find that, even in ICUs, we'll find the sisters even now, sort of refusing with the family of the donor…: "Really, do you think this person is really dead?" You know **(TCFG2P4)**.*

9.5.1.2. Discomfort discussing poor prognoses and donation with families

One quarter of medical professionals who participated in my study mentioned that the referral of a potential cadaver donor could be construed as an admission of failure on the part of the attending clinicians, and for this reason some were unwilling to refer:

> *I've lost a patient and I don't want to admit that **(002).***
>
> *So they've **failed** with this patient. They've **failed** to cure this patient and to save the patient's life **(005)**.*

This feeling of failure could cause referring units to direct maximum life-sustaining resources towards a likely futile case and:

> *… flog their brain-dead person* ***till they're no longer a potential donor (014).***
>
> *…* ***often keep these brain-dead patients alive for weeks just so that they don't have to confront the family*** *with the fact that the patient is brain-dead and not going to survive, they say: "No, he's alive, he's alive" until the patient dies of something else, an infection or…..****(005)****.*
>
> *"… not really my… Part of my job and if it was* ***I would probably avoid it a bit****" **(030)**.*

Transplant coordinators concurred that accurate information about a prognosis was not always given to a family:

> ***The direct information, we are still afraid of divulging it to the family*** *until it's really the last minute and that straight line or really everything is falling apart and the vital signs and everything. And the family now: "But doctor, you've been saying that my relative or my son is doing well?"****(TCFG2P4).***

It seems that referral for donation is a highly complex situation which may require healthcare professionals to undertake actions that, because of their own personal beliefs, they do not believe to be in the best interests of the potential donor or their family. They feel that these actions, such as referral of the patient as a potential donor or having a discussion about end-of-life issues, may be upsetting for the family. In light of these complexities it was not surprising that DFI1 were not offered the option of organ donation, and had to request a referral themselves:

> ***Me****: So who was it, or how were you approached?*
>
> ***DFI1P2:*** *Well,* ***we weren't actually approached****…*
>
> ***DFI1P1****:* ***I told the sister****, while we were waiting for the results from the tests, that if it came back what they suspected then they could contact the organ donation people because we would do it.*
>
> ***Me****: And how did they react to your request?*
>
> ***DFI1P1****: There was absolute relief on their faces…*
>
> ***DFI1P2****: Yes,* ***utter relief. Because they didn't know how to broach the subject with us****.*

9.5.1.3. Referral of potential cadaver donors - giving the family a choice

Healthcare professionals who participated in my research expressed concern about non-referral of potential donors and considered this unethical. Non-referral was seen as a denial of family autonomy and the right to make an informed decision:

> *Especially with regards to the donation process if they [healthcare professionals] are not happy with how it would impact on their belief system or their religious beliefs or their culture, sometimes we don't get a referral, which* ***I think is very unfair for the family because they haven't been given the decision. It's almost a decision being made for them (021)****.*
>
> ***We would like to believe that if a person is really brain-dead, that their family get offered the opportunity****. A lot of families say no during their hour of grief, but conversely there are a lot of families who get tremendous consolation in the number of lives they can save* ***(014)****.*

There was also a sense of stereotyping. The quote below suggests that families were not offered a donation decision because of a perception that individuals from certain demographic groups would always refuse. This type of blanket decision-making, based on an appraisal of demographic characteristics, meant that healthcare professionals considered that a referral was pointless:

> *We just leave it alone because we know that the efforts will be futile.* ***And we look at the African language spoken at home. It's quite difficult with some specific ones and we know it's going to be a definite no-no, we don't bother calling them (the transplant coordinator), because we know that these ones (the potential donor family) are never going to agree (010)****.*

Like healthcare professionals, TCFG1 felt that whether a family consented or refused to donate, it was important that they had made an informed decision based on accurate information:

> *… did that family, whatever their decision was, they made an informed decision?* ***They had all the information they needed for either way. And for me that's really important, that they are given the choice (TCFG1P5)****.*

The group also expressed concern that failing to offer the family of a potential organ donor the option to donate, infringed on their autonomy:

> ***TCFG1P5**: … people will say: "What do you do" and you'll say: "I'm a transplant coordinator" and they'll say: "Ah, you know, my son was in a motorbike accident two years ago and nobody even spoke to me about it". And that, it's heart-breaking, he might not have been a suitable donor but….(Interrupted).*
>
> ***TCFG1P6**: **The family were denied that right to make the choice***
>
> *… a lot of patients who are exposed to our health care system are not given the autonomy to make decisions. We, as the medical field, make it on their behalf. This family, we will not allow them the right to make the decision, we will switch off the machine **(TCFG1P1)**.*

The quotes above illustrate complex ethical challenges in transplant. It appears that some healthcare professionals - influenced by the transplant context which has labelled some groups unwilling donors – extend this generalisation to apply to all members of a group. A medical professional who participated in my study felt that blanket decision-making, which assumed certain people would be unwilling to donate the organs of a loved one, was not an accurate reflection of donation preferences:

> *And it has been a source of great shame for me, and horror, that we've been going around for years saying: "Black people don't donate their organs." Black people only donate organs **if they are asked**. And if you approach black people to donate organs, their consent rate is probably 80% that of what the white population is, because they are not asked **(020)**.*

Transplant coordinators felt the only way to address this misconception would be for a paradigm shift in attitudes to transplant to take place:

> ***TCFG1P6**: **Organ donation in Gauteng, in fact I think in South Africa, is treated as an unusual practice**. So it's something foreign, it's something that they do not buy into. As opposed to, if you look at **what happens in Europe and what happens in America and what happens in Australia, it's***

***the usual practice**. An end-of-life decision is usual practice. A conversation with every family, come a decision-making or an end-of-life, happens. It doesn't happen in South Africa, so it's an unusual practice. Dialysis has become a usual practice. Organ donation is an unusual practice.*

***TCFG1P1**. I also think **it's an unusual practice because it is not supported by law**. If you look at other countries there's 'Imminent Death Referrals'. You have to. If a nurse does not refer an imminent death, they can be disciplined by the hospital. The law supports that hospital's attitude towards organ donation which we don't have here….*

9.6. MAKING A DONATION DECISION – CONSIDERATIONS FOR A POTENTIAL DONOR FAMILY

Following the referral of a potential cadaver donor into the transplant process, a period of communication with the potential donor family ensues. Half of the healthcare professionals who participated in my research emphasised interactions with the potential donor family as one of the most sensitive and volatile aspects of the pre-transplant process. Three distinct considerations of the donation decision were identified:

- Communicating with grief-stricken individuals
- The influence of family structure and gender in shared decision-making
- Communicating with a donor family at the bedside – perceptions of professional communication

9.6.1. Communicating with grief-stricken individuals

Across both transplant coordinator focus groups the process of obtaining informed consent from a grieving family was unanimously identified as one of the most complicated aspects of a procurement coordinator's work. The consent process involved prolonged negotiation with donor families and at the same time, mediation with referring units, in an attempt to maintain an atmosphere conducive to decision-making. The coordinators expressed a feeling that referring hospitals were often hostile environments:

> *I think the emphasis on the cadaver donors for me is the fact that **when you get called to a hospital you are going into a hostile environment**. The nurses don't really want to see you, the doctors don't really want to see you, and the family don't know that they are going to see you **(TCFG1P5)**.*

Whilst mediating hostile situations, the coordinator must also portray a demeanour of care, empathy and calm when communicating with the donor family.

> *… empathise with the plight of making that decision to donate **(TCFG1P1).***
>
> *… actually **bond with the family in order to get the message across**. It's not just a matter of words, it's a matter of the emotion that goes with the words **(TCFG1P1)**.*
>
> *… not to preach to [the family], it's **to support them**. And I've almost found that it's like: Ok, sure, you're actually empathising, you're acknowledging, you're respectful… **(TCGF1P6)**.*

Both of the donor families who participated in my research commented on attitudes of empathy displayed towards them:

> *[The transplant coordinator] came in early that morning and the hospital actually referred her to us. **She got us together in the one family lounge and they brought us in some coffee and biscuits and things for the family. Which was wonderful for them to do this the way they did (DFI2P1)**.*
>
> *Look, I think at that time there was a lot of empathy from [transplant coordinator] and… I can't remember that other lady's name. But obviously, I mean, that's part of their training, because they are dealing with people in a highly emotional state. **So ja, there was a lot of empathy (DFI1P2)**.*

Both transplant coordinator focus groups felt that, while empathy was important, a recognition and understanding of the family context, nature of their grief and possible beliefs was helpful in facilitating a conversation about organ donation:

> *Ja, that's what I say, **you've got to be led by the family because people's emotions are at different stages** and how you're feeling may be completely different to how somebody else is **(TCFG1P1).***

> *So when [we] consult somebody who has to make an end-of-life decision [we're] guided by what that family perceives the death to be and how they have identified that person with that body* ***(TCFG1P1)***.

The quotes above illustrate the personal nature of donation decisions within different experiences of grief, and the sensitivity required to navigate transplant communication.

9.6.2. The influence of family structure and gender in shared decision-making

Although South African legislation specifies that a single family member may make a decision to donate a person's organs, in practice this decision seems to be within the ambit of the family unit as a whole. The extent of this family unit tends to vary substantially depending on context. For instance, a number of participants specifically mentioned the dynamics of making an organ donation decision in Black African families:

> *Especially with black people it's quite a protocol. I call it the protocol because* ***she's the wife but she will not take responsibility. She has to go home and consult the uncles. The uncles must consult the other elders****. The other elders must come here and everything must be explained to them before the consent is given* ***(011)****.*
>
> *And the other obstacle in black people is the family structure. So* ***one person who might be the husband, wife, brother, sister, won't have the authority to be able to give the consent by himself. He might be willing, but he will have to consult with the other people****. That can give us two problems. You're consulting with multiple people and to get consensus is virtually impossible, and secondly those people often live in rural areas and can't be contacted. And that's more or less how it works out* ***(002)****.*
>
> *… especially [with] black women, especially when [they] are married, I don't know what happens (laughs) especially to these married* ***women, but because, whenever they are faced with a situation of a dying husband or a husband that has already been declared brain-dead, [they] feel not self-***

> ***sufficient to come up and say: "OK, he's my husband**, I know how he felt, especially when it comes to organ donation, we talked about it…" But [they] will still go back (to the elders) and say: "Ok…"**(TCFG2P4)**.*

Contacting those elders who are authorised to make donation decisions was a source of frustration:

> *Like organ donor families where, you know, you have a mother and a father, who's a school teacher in Johannesburg, but they can't make the decision whether to donate the organs of their children. **They have to get hold of the eldest male member of the family, who happens to be living in KwaZulu-Natal on some hill and we can't trace them (TCFG1P1)**.*
>
> *So you know that everything has been spoiled. And **the gogo[32] might be 96 years old but she still makes the final decision, she's sitting under a tree in Limpopo[33]**, I don't know why they're always in Limpopo, but they are. They sit under a tree in Limpopo and you've got no insight, they've got no… **(TCFG2P4)**.*

The quotes above suggest that family structure and perspectives are considered important in decision-making. Both donor families who participated in my study had discussed their preferences for organ donation before any adverse event took place, and there was generally a consensus in favour of organ donation:

> *So we as a family, we have sort of discussed it, but never actually gone to the point and registered. But we've always, I'd say, between you and I, have **had an understanding that, should something happen that that's what needs to**… But we never actually got to the point to think about it for our kids **(DFI1P2)**.*
>
> *… "I'm your next-of-kin. I'm the only next-of-kin that can make this decision. What do you want me to do?" And she looked at me and she made some more jokes about it and I said: "Ok, seriously, we need to seriously look at*

[32] *Gogo* is an isiZulu word meaning grandmother. However, the term is more generally used to refer to an elderly woman who belongs to the Black African population group.
[33] The Limpopo is one of the nine provinces of South Africa. The Limpopo is considered to be a more rural province than Gauteng.

> *this."* ***And she just point blank looked at me and said: "You donate everything." (DFI2P1)****.*

In both cadaver donor families knowing the preferences of their loved one and sharing a common donation ideology was seen as facilitating decision-making:

> *And obviously you can't talk, so your family has got to make the decision on your behalf. So being* ***grateful that (the donor) and I spoke about it****, I knew the final decision was coming* ***(DFI2P1).***
>
> *I think also, I suppose, the ideal is that an individual has made that decision, and said: "This is my decision", and that, in many respects,* ***takes the burden away from the family*** *to come up with it* ***(DFI1P2)****.*

9.6.3. Communicating with a donor family at the bedside – perceptions of professional communication

Once a family has consented to donate, a process focused on maintenance of the donor begins. Firstly, the organs are tested for their viability. This may involve some removal of tissue from the donor. This process is highly time-dependent as there is a window for optimum donor maintenance.

None of the healthcare professionals or transplant coordinators who participated in my research mentioned communicating with the donor family at this stage, however, donor families emphasised some aspects of this phase which they found unpleasant. DFI1 felt the necessity for testing donor organs after consent was not treated with enough sensitivity:

> *What I do remember that made me a little scratchy was:* ***"We'll have to test his organs first". And I was like: "WE'RE GIVING IT TO YOU, WHAT THE HELL!"*** *But I understand you have to test that it's right and whatever, but maybe that part can get left out. It's kind of not what you want to hear at that point, you're being brave and you're offering up somebody, and you're going to test and see if you can use it? That was just a little, ouch* ***(DFI1P1)****.*

> *… you've now got the family who are making this decision, I don't think they really want to hear that: "We're now going to test first…"* ***(DFI1P2)****.*

The participants recommended that some processes be described in lesser detail, in order to minimise the family's grief:

> *… but maybe* ***just leave out the part that you've got to do the tests*** *and first see if it will be viable and blah blah. When you're really emotional about something, that's not something you really want to hear* ***(DFI1P1)****.*

DFI2 had a different experience, feeling that the process after consent was not adequately explained and that everything happened in a rush, with the family unaware of what was going on. However, it must be noted that time constraints mean these processes need to take place as quickly as possible, and the family did seem aware of these constraints:

> *But the horrible part was that, the blood people first came in to start pulling the blood and things out of her body* ***(DFI2P2).***

> *… it wasn't explained. … That happened to me so fast,* ***it was as if they couldn't wait to get rid of the blood. And it was upsetting****, I didn't enjoy it, or like it at all* ***(DFI2P2)***.

I asked the participants about making improvements in the process:

> ***Me****: So do you feel that that's something that could be improved?*

> ***DFI2P2****: Definitely. Oh yes, definitely.* ***Explain in detail****: That's what's going on, this is what we are going to do, this is the reason why we are taking the blood and that is what we are going to do with it. To me that was such a rush…*

> ***DFI2P1****: Sudden, it was sudden.*

> ***DFI2P2****: Ja. They just wanted to get rid of it and ja….*

The quotes above suggest that each family required a different and particular (Tronto, 2010) level of detail when communicating with transplant professionals post-consent.

9.7. CONCLUSION

The results presented above have highlighted a number of my findings relating to the donor family and the process of making a donation decision. It is clear that interactions at these points are framed by grief and uncertainty, and healthcare professionals are mandated to communicate within this framework. Whilst it is evident that a dislike of communicating with families may prevent referrals, this has been identified as problematic because it is seen to infringe decisional autonomy. Transplant coordinators seem more adept in managing grief and communicating with donor families than other healthcare professionals, perhaps unsurprisingly, since this is part of their role. The coordinator's approach to a family may facilitate communication about transplant, as it seems to take into account the specific family structure and acknowledges the grief the family are experiencing with accompanying displays of empathy.

9.8. RECIPIENT FOLLOW-UP AND SUPPORT

Post-transplant follow-up has been widely studied, and contains several elements of lifelong recipient support. An overwhelming majority of healthcare professionals who participated in my study shared sentiments about recipients. These related to the recipient's understanding of transplant, how it would alter lives and the role of a recipient's family during the process. Effective support required substantial communication between healthcare professionals, recipients and their families.

9.8.1. The extent and detail of recipient follow-up

Three quarters of healthcare professionals who participated in my research emphasised the importance of recipient follow-up. Allied professionals explained the extent of post-operative care provided:

> *… **we are with the patient all the time, every minute**, with our monitoring, support and care we give. It is quite tough because we don't know the outcomes, how the patient will respond on a day-to-day basis. If there's no survival it becomes even tougher… **(019)**.*

> *So the lady (an allied professional) comes back again after they are in the ward to just check on them **every day** until they are discharged. So she educates them about the medication **(018)**.*

After discharge, recipients were encouraged to maintain both physical and telephonic contact with the management team. This had two advantages:

- Continued contact and establishing a relationship of trust
- An opportunity to offer support if necessary

9.8.1.1. Continued contact and establishing a relationship of trust

Rigourous follow-up post-transplant appeared advantageous in keeping the management team up-to-date about the progress of recipients. It also appeared to facilitate a trusting relationship between the recipients and the management team. Both medical and allied professionals commented on the benefits of continued contact with patients:

> ***Most of the time we are quite up-to-date with what is going on with the patients and their conditions**. Even the patients who have been transplanted in 2007 come for their check-ups every six months, [they are presented] at the meetings and we know exactly what is going on **(023)**.*

> ***So we become very familiar with them and we know that** and that's the advantage of having a team all the way through. Because I know every single transplant recipient [under my care] and I know when that patient comes in … with a complication, even if it is ten years down the line, what the issues are. And the problems can be often identified a lot quicker by someone who's familiar with the background **(005)**.*

Transplant professionals felt that, with continued contact between the management team and the recipient post-transplant, a reciprocal relationship of trust developed. This relationship was based on the impressions of recipients coming to trust the staff post-operatively, and the staff in turn, learning to trust the recipients, through displays of diligent adherence to the management plan:

> *And that **you've built that trust up over a period of years**. … You have time to build up a trust because they're usually admitted for quite some time, three days to a week. So you can build up trust and that helps when you're counselling them **(010)**.*
>
> *And also, if the patient has been sick, the nurses and the doctors, we all develop a very good relationship with that patient. **And that's part of the process, is to get them to trust you**, is to develop such good relations with them **(021)**.*

Medical professionals noted the importance of being able to trust the recipients under their care. The second quote here demonstrates a balanced, yet pragmatic, approach to adherence:

> *… our patients have to remain in touch with us, because it really is their lifeline. So **they've got to trust us**, they've got to understand what we are saying… **(003)**.*
>
> *What my line to all my patients is, is that: "Transplantation is so complex, and there are so many variables and so many factors in it, and my ignorance of the subject is so great. So the only way I can do as well as possible is to have my patients do exactly as they are asked". And I explain to them that it is not taking their choices away, it's not taking their rights away, it's not me being arrogant. It's taking a potential failure out of the equation. **If I can trust them to do everything that I think they're doing, it will make things better (020)**.*

9.8.1.2. An opportunity to offer support if necessary

The second advantage of long-term recipient follow-up was in the provision of on-going educational and emotional support, if required. It was noted that transplant is a highly complex procedure with many consequences, some of which may only become evident over time:

> *Perhaps the one thing that might be helpful to you in terms of communication, is, I think, what's not spoken about enough in a general sense, is the enormity of this thing, how big it is. **It's a huge thing to***

> ***receive an organ, to be nearly dying or to think you might die or to be on dialysis and then to get an organ, is big (004)***.
>
> *But usually the patient understands where we're at, but it's kind of like* ***you don't really truly understand what the situation is going to be like until you're really there****. So it's all kind of, the information that we are giving is 'pie-in-the-sky' really, until they're actually there* ***(021)***.

Given the significant adjustment in a recipient's life post-transplant, one third of medical and allied participants felt that on-going education was vital:

> *Orders need to be clearly explained because it can be a little bit complex,* ***it's important that you make sure that the person you are asking to do certain things understands*** *what you want them to do. And that's sometimes where people maybe don't always quite get it* ***(003)***.
>
> *In some instances* ***patients need more [education] because for whatever reason, because they're anxious, because they didn't get it the first time, because they have cognitive deficits due to their condition****. And that's something you have to consider in your research, that organ failure results in neurocognitive deficits and that will affect communication, not amongst professionals, but with patients* ***(004)***.

A consequence of continuing education was seen to be an empowered recipient cohort:

> *So in general I think we work with people who are* ***quite well educated and they understand everything (023)***.
>
> *I think we empower them. We encourage them to be empowered and to take control of their organs, their transplanted organ, and I think they really appreciate the fact that they have a second chance so* ***we empower them to look after that organ and that goes all the way from educating them in terms of their drugs, their lifestyle, travel, occupation, their activities, and we encourage them to read, to become knowledgeable in the field of transplantation****. Many of these patients will know a lot more than a junior*

doctor about the medication that they need to take, or possible side-effects, or potential infections that they may get, or other complications ***(005)****.*

Long-term follow-up also offered an opportunity to provide emotional support which was seen as beneficial in light of the psychological challenges post-transplant:

Some [recipients] experience guilt*… **(016).***

Because ***a lot of them also are in denial: "I've got my new [organ], so how dare I be depressed? How dare I be having relationship issues?"*** *So they don't even address it, so they don't even realise that there's a problem. So [when we] see them when they come for their [follow-ups] then [we] can ask the pertinent questions and then we know do they need further assistance or if they are coping really really well* ***(021)****.*

And we've had an incident where a black chap who got a kidney transplant in fact was ***exceptionally disillusioned*** *by the fact that his organ donor wasn't his comrade. And he had to go through a whole process of ritual cleansing in the process of getting his head around accepting…. **(TCFG1P6)**.*

The excerpts above suggest that transplant recipients deal with highly complex emotional processes, where both continued education and psychological wellbeing have an impact on adherence, and ultimately, on graft survival

9.8.2. Communication and the recipient support system

One of the factors considered when listing a potential recipient for transplant is whether that person has an adequate support system in place. Recovery times are often lengthy and recipients may need extensive care during this period. Hence, it is imperative to include family members in the communication process, to gauge their understanding of transplant and to instil an appreciation of the task which they will be expected to fulfil. Over half of the healthcare professionals who participated in my research discussed the importance of the recipient's family in the transplant process. Families were often seen as anxious about the outcome and felt overwhelmed and unsure about how they could assist their loved one in the surgical and post-operative phase:

> *So I think **the anxiety at that time is there's a lot of willingness but people don't really know what to do**. So it will be like: "Well, you can make food, or you can bring a meal, you can look after the children, because the children are not going to be able to come to the hospital for a while". So it's about bringing them in and making them feel that they have a role to play without it just being like, five hundred people who are descending on the poor person at visiting hours… So it's that kind of way you can work with families **(024)**.*

Establishing organisational routine (Watermeyer, 2012) and familiarising the family with the hospital setting was a method for providing support, as was meeting the family and the potential recipient in the pre-surgical stage:

> "*This is where you are going to be, this is theatre, this is where they are in theatre, **this is where you can sit and wait until they come out**" **(024)**.*
>
> *We usually meet with the family as well, **we speak to them as well and try to support them as well, as best we can**… Answering their questions…* ***(019).***
>
> *… **we visit, we go and talk to them and talk to the family** … we see the family of the recipient. But they look forward to receiving, they are so happy to receive* **(018)**.

However, some participants found the continuous presence of the family problematic:

> ***It's very difficult**. We [allow them into the hospital] 24 hours a day if they want to be here. Which is, in itself, I feel, problematic from many views, because they may never get a chance to just go outside and take a breath. … They want to be here all the time **(009)**.*
>
> ***There is a problem with the families**. Sometimes, the doctors will prescribe anti-depressant pills to the family also. Sometimes they are also depressed because they don't know how to deal with it. They are happy, but the patient is not happy, the mind is not there **(018)**.*

Preparing a family for their role in recipient care was emphasised because it constituted an ongoing and serious commitment:

> ***So even the family, they prepare the family psychologically, spiritually***. *And they know when they sign consent. Because this thing of transplant it's not something that happens today and is done tomorrow. It's a process* ***(018).***
>
> *… ready to take them home because* ***it's quite a big issue for family (021)***.

9.9. CONCLUSION

The findings from this section support those from past research studies, suggesting that relationships of mutual trust and understanding are of key importance in the follow-up process, and that these may have a positive influence on the recipient's adherence and wellbeing post-transplant. It seems that participants recognise the importance of support which the recipient's family can give, and are careful to communicate in a way which will strengthen this support system, by ensuring the family is included in the transplant process. However, the results suggest that it takes time to establish these relationships and that they can be challenging, especially during the surgical stages and the post-transplant phase, when the families may experience heightened anxiety.

9.10. WHERE DO ALL THE DONORS GO? FOLLOW-UP OF DONOR FAMILIES

The previous section emphasised the importance of recipient follow-up. This involved extensive efforts in education and adherence. There was also an emphasis on relationships between the recipients and the healthcare staff, which appeared to be ongoing and served to enhance the quality of care given. The results of my research will now go on to suggest that unfortunately the follow-up care provided to the families of cadaver organ donors is not always of the same standard as that provided to recipients.

This sub-theme will be presented slightly differently to the others in my thesis. I will briefly tell the follow-up stories of the two donor families, highlighting their

expectations and using their quotes to justify these. These stories will also demonstrate whether expectations appear to have been met, and explain why this is, or is not, the case. Finally, the expectations for follow-up from donor families will be aligned with donor family follow-up data from transplant professionals and transplant coordinator interactions.

9.10.1. Donor family stories and expectations for follow-up after donation

9.10.1.1. Donor Family 1

The first interview took place with a family who had donated the organs of their teenage son who died following complications from surgery. During their interview, the family expressed great dissatisfaction with the follow-up process.

The family had previously donated the tissues and viable organs of another family member. A few weeks after this first donation a gesture of thanks was received:

> … ***my parents got a letter, on a letterhead and the whole thing. To say, you know: "Thank you***. *And the tissue… And the corneas… You know, [name of loved one] had been able to help two people on cornea transplant and this and that, and like seven people with skin grafts and all the rest of it. And you know, how grateful these people are etcetera etcetera…* ***(DFI1P2)***.

Hence DFI1 expected that they would receive a similar letter from the transplant unit, thanking them for the donation, explaining which organs were used and perhaps even containing some information about the recipients. However:

> ***So ja, my mom said to me: "Have you guys not received a letter like this?" And we said: "No, we haven't".*** *And I think she asked us twice, over a period of three months or so. And I think, ja, my mom, just beside herself, she phoned, and she said: "What's happening?" You know. And then she phoned me and said she'd: "Spoken to [a transplant coordinator], and [that transplant coordinator] says the letter's been sent" and I said: "Well I haven't received it." And then I phoned [the transplant coordinator] and said: "Look, I believe my mom has spoken to you, and this is how we are*

> *feeling." And [the transplant coordinator] apologised and said, you know: "There was a letter, it has been posted etcetera, etcetera" and she sent me an e-mail copy. Well, the e-mail copy wasn't signed.* ***And to date, I have yet to receive this original letter (DFI1P2)***.

At the time of our interview DFI1 stated that they were still unaware of which organs from their son had actually been used for transplant. The family had made numerous attempts to gather this information, the first attempt in the following quote, which describes a phonecall with a transplant coordinator soon after the donation:

> *Ja, this is the annoying thing. It is that in the first… I was told telephonically that: "His corneas have been used" but we had no confirmation. We were told about the lungs and the kidneys. … I don't know if the liver was used as well (**DFI1P2** interjects: The liver was used, except the pancreas). So, you know, and the subsequent follow-up is that one person benefitted from the lungs and two people from the kidneys. And I'm saying: "Well, was the heart not able to be used? Was it rejected etc.?"* ***(DFI1P1)***.

Subsequent to the first interaction described above, about six months later the family once again tried to find out about the corneas:

> *But you know, what sticks in my mind is that when I had the telephone call with (the transplant coordinator), and that must be going back a good three months, or more…* ***(DFI1P1** interjects: No, it's more than that) and **I said: "Well what about [our son's] corneas?" And [the coordinator] said: "Ok, we'll have to find out about that." And nothing more has come of it (DFI1P2)***.
>
> *So you know, the sense I'm getting is that* ***the organs have gone to different regions and different places and it is not pulled together*** *as a whole to say: "This donor contributed there, there and there". I've (the transplant coordinator) now pulled it together so I can give a complete feedback to the family to say, you know: "This is it here, his lungs went to a 23 year old…" I think that was in the last correspondence…* ***(DFI1P2)***.

Participants were also very interested in how many lives they had saved, and how the recipients were coping. However, they did not feel this information had been conveyed in spite of numerous requests as illustrated by the excerpt below:

> ***DFI1P1**: I can't even remember what (the transplant coordinator) said, I know I asked her just this week…*
>
> ***DFI1P2:** There was detail of about three people. There was a young lady who had received the lungs… But then **the detail got a little hazier with the two recipients of the kidneys**, I think it was.*

Both participants felt that some information from, or contact with, the recipients of their son's organs would assist them psychologically:

> *You know, the point that annoys me intensely is that we've probably had to make one of the hardest decisions. And someone has received something from [our son] that has hopefully allowed them to live a better life or not get into dire straits from a health point of view. **And there's no word of thanks**. There's not a – I'm not looking for someone's name and address, it can be an anonymous letter – that says: "To the Organ Donation Fund, thank you so much I am so grateful that I have this second chance or this new lease on life…" Or whatever it is (DFI1P2).*
>
> *[Receiving a letter from the recipients] wouldn't have been everything, **but it would have helped. Just that little token would have helped**. To know that whilst somebody's light went out, somebody else's is still burning **(DFI1P1)**.*

The letter was considered important because it had the prospect of bringing some closure:

> *We feel like we've done so many people a favour, but in actual fact did we do them a favour? **You kind of don't get a closure on it (DFI1P1)**.*

However, when DFI1 asked the transplant coordinator about receiving letters from recipients, they were informed that writing such letters can be a challenge for the recipients themselves:

> *I think there's also, I mean I don't know if it was in the phonecall that you had or the phonecall that my mom had – I think it was when my mom phoned. You know:* ***"No letters or thanks or whatever" and she was told: "You know, that's one of the hardest letters for someone to write."*** *And I was saying in my mind: My goodness! The hardest thing I had to do was to say: "My son is not here, and I'm allowing someone to benefit…"* ***(DFI1P2)****.*

Finally, the participants described their perceptions of organ donation at the time of the interview. The quotes below suggest that both participants were highly dissatisfied with the process:

> *And that, in a way,* ***that's quite hurtful.*** *Certainly to me and I think to [my wife and family] as well. We've gone through all that emotion, and there's no acknowledgement… (Participant breaks down in tears but insists on continuing the interview…).* ***(DFI1P2)****.*

> *And you guys are in the unenviable position that you have got to deal with both sides. Dealing with people that need, and people that are giving. And somewhere along the line you've got to find a balance to keep both sides happy. And it's very hard.* ***But from my perspective, I feel cheated (DFI1P1).***

9.10.1.2. Donor Family 2

The second family had donated the organs of an aunt who died following complications related to lupus. This was the first experience the family had had with organ donation, and the quotes and excerpts below illustrate their perceptions of follow-up post-donation, when they received a letter of thanks:

> *And I must say, the day that (our aunt) died, Monday morning,* ***I received a phone call from (her physician), giving his condolences, and you don't expect that from a doctor****, you know. They are on their routines, they've got their work to do and they go about their business.* ***But it was very touching to find that this doctor was so concerned about my wellbeing*** *as well…* ***(DFI2P1)****.*

> ***DFI2P2**: **And didn't they send that little tear drop thing? That was a beautiful gesture**, I must say.*
>
> ***DFI2P1: It was within a month. I received a letter from the donor foundation** (**DFI2P2** interjects: It was a little certificate) where they actually praise [our aunt] for her bravery on donating her life for more life and also where I get praised in the letter for taking that decision and helping someone out there.*

The quote below suggests that receiving this letter and gift came as an unexpected and pleasant surprise:

> *But in the box, the day I actually went to collect the parcel from the post-office, it was the last thing that I expected. I received a little box, and I looked at this and I thought: "This is weird" and I thought "Donor Organisation"? … **And I thought: "Wow, ok, this is nice, it's a nice gesture"**. I phoned my dad, I told him about it. When [my husband] arrived home I showed him, I said: **"This is the lovely little gift that we received in memory of her" (DFI2P1)**.*

After the surgical phase of the donation took place, the family reported diligent follow-up which helped promote a feeling of closure:

> ***DFI2P1**: The Monday morning at about 4.45 **I received a phone call from [the hospital]. They said they: "…have just come out of theatre now, [we] have used basically most of [your aunts] organs**, some of it for transplant reasons, and it's in flights now to wherever". And I thought: "Ok, so someone's life will be saved this morning", that's the first thing that went through my mind…*
>
> ***DFI2P2**: There was even a child with cancer that was helped…*
>
> *And when I realised it was final, I said to the sister: **"Thank you for informing me, it was great stuff that they did phone to let us know…" (DFI2P1)**.*

Participants from DFI2 seemed pragmatic about the recipients of the donor organs and did not express the same uncertainty as DFI1 did, about who received the donor organs:

> ***Unfortunately, you don't know who the recipients are****, but it's understanding it's all in confidence, and the recipients don't know who the donors are…* ***(DFI2P1)****.*

When I asked DFI2 about their impressions of organ donation at the time of our interview, DFI2P1 expressed a sense of peace:

> ***I have deep peace in my heart****, knowing that I have received the gift from the donor people saying that lives have been saved* ***(DFI2P1)****.*

9.10.2. Comparing and contrasting stories

The stories above highlight three aspects of donor family experiences which came through in my data:

- Thanks for the donation is very important, and it helps the family psychologically
- Knowing how many lives were saved and how the recipients are coping is important for the donor family
- Knowing what organs were used is important for the donor family

9.10.2.1. Thanks for the donation is very important, and it helps the family psychologically

The families who participated in my research had differing experiences of donor follow-up. DFI1 expected some gesture of thanks, based on a past experience, but did not receive this (or any other follow-up) which left them feeling dissatisfied with the transplant process. DFI2 did not expect thanks, but were pleasantly surprised when the acknowledgement arrived, and stated that it had given them a sense of peace. These stories illustrate how a simple gesture like thanking donor families is essential in terms of their expectations and their psychological wellbeing.

9.10.2.2. Knowing how many lives were saved and how the recipients are coping is important for the donor family

The stories illustrate that families appreciate a summary of the good they have done. DFI2 appeared satisfied with a phonecall explaining this; however DFI1 would have liked more information. The need to know something about the recipients may point to the notion of fairness. Incidents, such as the Netcare Case and the Manto Tshabalala-Msimang Liver Transplant Scandal, indicate that organs are sometimes allocated on a basis of power, wealth and preferential treatment rather than equitability and justice. This seemed an important consideration for the donor families. DFI2 expressed concern that the organs of their loved one may have been given to:

> … ***ministers (DFI2P2)***.

DFI1 discussed this in more detail:

> *Did (the donor's) lungs help another child? Or let's go for the kidneys, you know, maybe it's what I don't want to know.* ***Did (the donor's) kidney go to someone who's been a heavy drinker, an alcoholic, who's effectively abused himself****? You know? Let's put it this way, if I had to be the one dishing them out, I would say: "I'd far rather his kidney went to some young child who did not inflict damage on himself"* ***(DFI1P2)***.

9.10.2.3. Knowing what organs were used is important for the donor family

The stories above illustrate the importance of knowing which organs were used. Although I did not ask families why this was important, it seems linked to a sense of closure and finality which families consider important.

9.10.3. Healthcare professional interactions and donor family follow-up

The previous section of this chapter considered the follow-up of recipients. Three quarters of the healthcare professionals and transplant coordinators who

participated in my research stated how important this follow-up is. However, none of the healthcare professionals or transplant coordinators who participated mentioned, or even discussed, donor family follow-up.

It is true that this was never a specific question or prompt posed to transplant professionals or coordinators: family interviews took place after health professional interactions and the notion of donor follow-up only surfaced at that stage. However, one of the strengths of qualitative research is that it allows participants to discuss issues important to *them* (Barbour, 2000; Malterud, 2001). It could be argued that because no health professionals mentioned donor family follow-up, this is not in the forefront of their minds. This argument may be strengthened by the notion that recipient follow-up was particularly important to participants. The finding that expectations of donor family follow-up do not correlate with an acknowledgement from transplant professionals that this is an issue of importance is worrying because data from the donor family interviews - especially DFI1 – suggests this is a significant aspect of transplant. Both families were highly emotional and I got the sense that DFI1P2 was anguished by the transplant experience and felt a deep sense of dissatisfaction with the process.

Here we see a disjuncture between expectations and objectives. This is disquieting, as negative experiences for donors may result in them discouraging others from donating. If we consider that many professionals think donors and recipients are themselves the best advocates for the process, it would be prudent then to ensure that measures are taken to promote positive and acceptable donor family follow-up. Neither of the donor family participants mentioned approaching the media, though DFI2P1 had addressed a church group on donation, whereas DFI1 had not taken part in donor advocacy. These different reactions could highlight how individual experiences of transplant shape attitudes towards it.

9.11. CONCLUSION

By comparing and contrasting the experience of two cadaver donor families, this sub-theme demonstrates that donor family follow-up may be inadequate in Gauteng transplant. This could have implications both for the psychological

wellbeing of families, as well as for the larger transplant context, where negative experiences may form barriers to transplant in general.

9.12. SUMMARY AND CONCLUSION

This theme examined perceptions of communication between transplant professionals and recipients, their families and donor families. The contrasting journeys for recipients and donor families in the transplant process are most evident, highlighting divergent experiences and differing expectations.

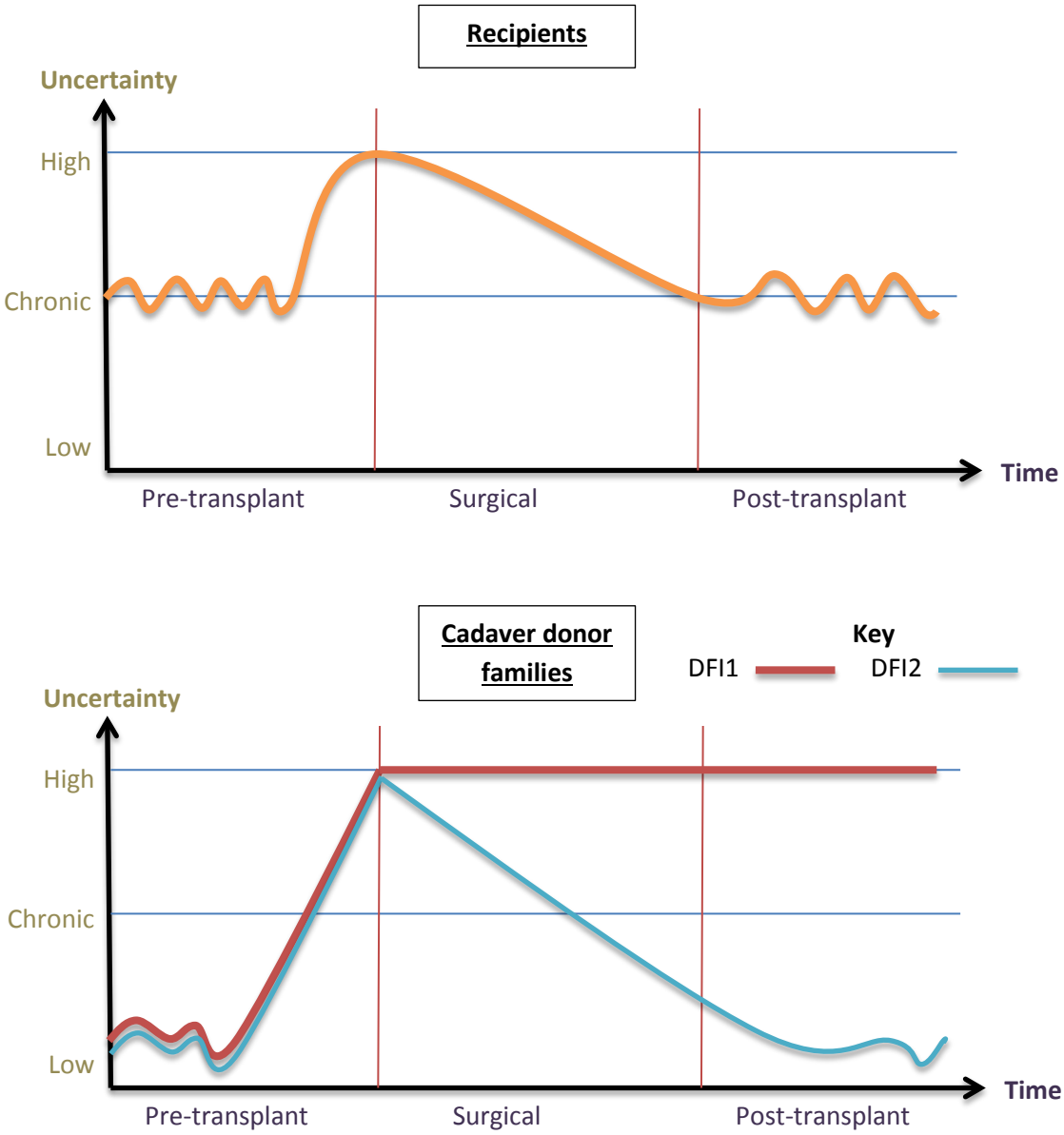
Demands for care in receiving an organ affected transplant professional-recipient communication pre-transplant where desperation and uncertainty were heightened. This communication stabilised and care was characterised through the relationship of trust which developed in the less uncertain post-transplant space. The opposite trend was evident in transplant professional–donor communication which was characterised by notions of care in the pre-transplant phase contrasted with a feeling of a failure of care related to lack of donor follow-up post-transplant. The different experiences of uncertainty for donor families and recipients are depicted in Figure F9.3.

Perhaps the dichotomy of donor and recipient family emotions at the time of a transplant is best expressed by a medical participant who recounted the following story:

> *And we recently had a situation which was heart-breaking, and I was so upset by it.* ***We had a donor in this hospital, with a surgery that was being done in this hospital, so there was a grieving family wheeling their son in to have his organs removed and they were in the same waiting room as the family who were popping champagne… They were celebrating, because their daughter was getting [an organ]****. And they didn't do it purposely, obviously, but to allow those two situations to mix is just wrong you know, it was so sad* ***(020)****.*

Figure F9.3 – Contrasting donor family and recipient uncertainty in the transplant process

The two figures below compare uncertainty in the transplant process for recipients and donor families. The experience of DFI1 and DFI2 are captured to illustrate different experiences and viewpoints. Chronic uncertainty both before and after transplant is emphasised for recipients, whilst the ongoing state of high uncertainty for DFI1 is depicted in comparison to the sense of calm and closure for DFI2. Transplant professionals views of recipient uncertainty found in my study mirror those identified in Martin et al. (2010). Because Martin's study included recipients in the study population, the finding of similar trends in uncertainty may serve to increase the reliability of my research.



CHAPTER 10 – RESULTS

Interprofessional communication and transplant

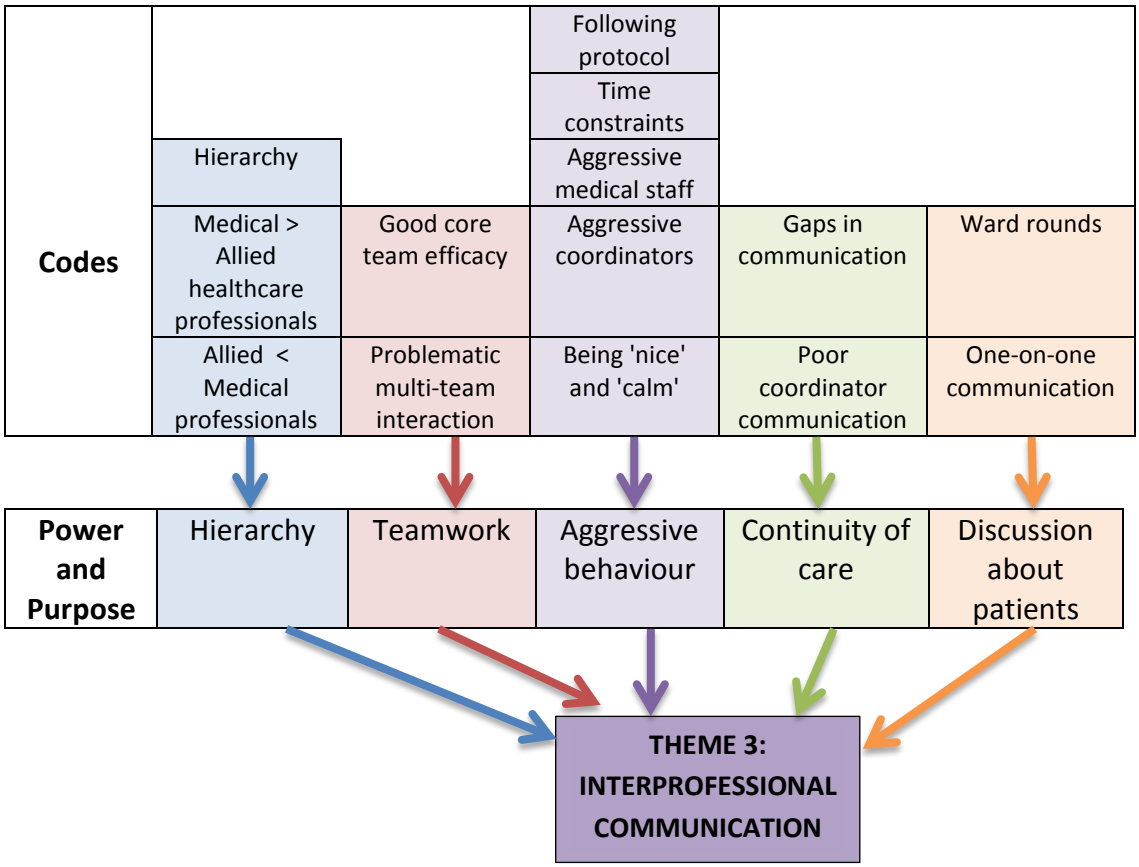
10.1. INTRODUCTION

This theme relates to participants' perceptions of interacting with each other in the transplant context; it demonstrates the way that transplant in Gauteng is shaped by several elements of healthcare interactions and scenarios. These in turn are influenced by personal experiences or preferences. They include observations about communication styles, the perceived value of a healthcare professional within a team and the influence of hierarchy. The sub-themes identified in my analysis process are depicted in Figure F10.1. In practice, these elements translate into barriers to or facilitators of transplant.

Some aspects of interprofessional relationships are identified as facilitators of transplant in Gauteng, as they move the transplant process along. These include a perception of professionalism in spite of personal opposition to transplant, recognition of the importance of teamwork in transplant and observations of cohesion amongst individual transplant teams in Gauteng. Numerous barriers to transplant, which have negative consequences for the transplant process, are also identified. These include communication breakdowns in pressurised situations, inconsistent communication within a framework where professional respect is lacking and interactional challenges between the large numbers of teams who are required to cooperate in order for a transplant to be successful.

Figure F10.1 – Interprofessional communication

The overall theme of interprofessional communication in transplant identified five sub-themes. In terms of the ethics of care, these are related to power and purpose (Tronto, 2010).



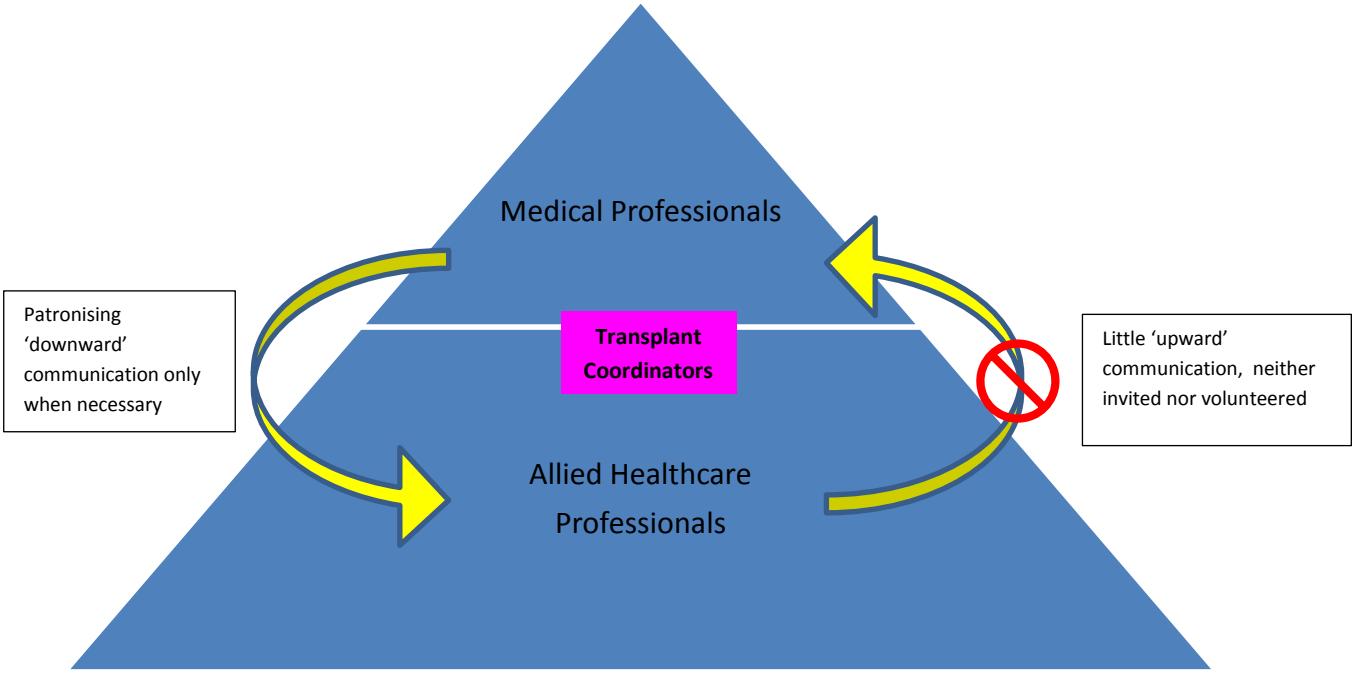
- A hierarchy was identified through grouping codes where a perception of an asymmetrical power relationship between transplant professionals was noted.
- Participants were asked their perceptions about whether team members understood each other. By identifying teamwork as a common element of a number of codes, the sub-theme was identified.
- Aggressive behavior emerged as a sub-theme in grouping all sections of data which provided accounts of unpleasant interaction like shouting or throwing instruments. It also considered coping with this kind of behaviour. Data about aggressive behaviour emerged from asking participants about time pressure in transplant.
- Continuity of care was identified as a sub-theme through grouping all codes where gaps in communication had been identified. Like teamwork, these factors came up when participants were asked about whether team members understood each other.
- Codes where transplant professionals mentioned communication about patients were grouped together because the patient was the common subject of the discussion.

10.2. THE TRANSPLANT HIERARCHY

The data set from this project confirms that a conventional healthcare hierarchy, as described in the literature review, seems predominant amongst transplant professionals in Gauteng. This hierarchical structure appears to substantially influence transplant communication in the province, and results suggest that the hierarchy frames interprofessional interactions. As the framework within which interactions take place, it is necessary to present findings related to hierarchy first (Figure F10.2). At first glance, it may appear that the healthcare hierarchy would fit better into the Gauteng transplant context. However, I have decided to present it here because the hierarchy identified seems most apparent throughout interprofessional interactions within and across healthcare institutions, rather than a factor which is prevalent in the more general Gauteng context.

Figure F10.2: The transplant hierarchy

The figure below depicts the transplant hierarchy as shown in my results. The hierarchy frames transplant interactions and communication in Gauteng. Medical professionals see themselves as being at the top of the pyramid. This position is recognised by allied healthcare professionals. Medical professionals see allied professionals at the bottom of the pyramid. Most allied professionals appear to accept this as their rightful position. Transplant coordinators are placed between the other two groups, illustrating that they appear slightly more empowered than allied staff, but less so than medical professionals.



The hierarchy was described as:

> *… a kind of sub-culture that gets taught to them (medical professionals) when they go to med school about* ***being on a pedestal or being the "knower" compared to the "auxiliary services".*** *So you're often taught that you are the head and the nurses and everyone else are a kind of "sub class"* ***(021)****.*

Eleven of the twelve medical professionals who participated in my research made statements which related to a perception of hierarchy in transplant:

> *You see you have a hierarchy, and a hierarchy usually culminates with the surgeon at the top of the pinnacle* ***(001).***
>
> *So our nurses, our psychologists, our physiotherapists, our dieticians, you know everyone from the* ***chief surgeon all the way down*** *has now been part of the transplant team for some time* ***(005).***
>
> *I do think we're in a better position to do that than the nursing sister, or certainly the nursing sisters I work with, because our understanding of what the patient's about to undergo is far more in-depth* ***(016)****.*

Hierarchy was also clear in the giving of orders, where the medical professional was instructing other healthcare professionals, suggesting a power asymmetry:

> ***Orders*** *need to be clearly explained because it can be a little bit complex, it's important that you make sure that the person you are asking to do certain things understands what you want them to do. And that's sometimes where people maybe don't always quite get it* ***(003)****.*

The concept of a hierarchy was also evident in over two-thirds of interactions with allied professionals, though situations were not explicitly acknowledged as hierarchical – as they were with the medical professionals. Furthermore, allied professionals contextualised themselves within the transplant hierarchy, expressing little sentiment about the situation and apparently treating it as the *status quo*:

- *You make sure that even though he is throwing his instruments, whatever,* ***at the end of the day he will get his results (008)****.*
- *… if the doctor decides to actually inform the [names healthcare professional]. Because* ***we can't go above him*** *and say: "Let's call the [healthcare professional] anyway,"* ***(011)****.*
- *… our role, how the family perceives us…. You know how it goes, if the person is critical,* ***they will have more hope in what the doctor can do for the patient****. So we have to then look at other avenues to influence acceptance of our support* ***(019)****.*
- *But the doctors tend to be far less obliging when it comes to communication. We often get* ***one word answers, we often don't get replies to sms's or e-mails (021)****.*

Only two allied professionals questioned the hierarchy or expressed a sense of dissatisfaction with the perceived *status quo*:

> *The nursing staff I feel are there to literally carry out what's written down on a piece of paper and the impression I get is that it's almost like, I think* ***some of the other healthcare professionals feel they're (the nurses) not worthy of needing to understand what's going on****. And that's where there's a problem* ***(009)****.*
>
> *So it's just a matter of planning and being a little bit more like open-minded – not just narrow-minded like: "I'm going to be doing the transplant and that's what I'm going to be focussing on now. When I need the other professionals I'll deal with that when the situation arises"* ***(012)****.*

One member of a donor family also expressed a sense of hierarchy. Although the quote here suggests that the family saw doctors as a source of expertise and authority, hierarchy could be implied*:*

> *To the* ***doctors and medical researchers … to see them as heroes*** *because they are the ones that make life possible* ***(DFI2P1)****.*

This quote is relevant to excerpt 019, above. Allied staff are not mentioned by DFI2P1 at all, however medical professionals are seen as heroic.

Transplant coordinators who participated in my research did not appear to be affected by the hierarchical structure to the same extent as other healthcare professionals. This will be considered in Section 10.2, which demonstrates how coordinators take control of difficult situations. However, in the second focus group there was a notion of coordinators – like allied healthcare professionals - contextualising themselves within the hierarchy. The excerpt below illustrates the sentiments of two participants who discussed challenges when communicating with patients:

> ***TCFG2P4:*** *So in other words, if I have a problem and I can't reach this person (the patient) I know* ***if I [can] see that I can't, just to this person, I always call a White doctor****. So immediately it will be yes, no explanation.*
>
> ***TCFG2P1:*** *And* ***a man, and a man as well****. Ja….*

Furthermore, in communications amongst the transplant team, TCFG2 felt they were "allowed" to take an active role, suggesting that a hierarchical structure is in place and that, in this particular team, participants deliberately situate themselves within the hierarchy. The excerpt below also suggests that some coordinators from other teams may not be "allowed" to participate so fully:

> ***TCFG2P2****:* ***We are allowed to have opinions*** *in (our transplant team), ja, which is nice. And we can challenge whoever is here. We can challenge (the medical head of department) and he won't have a personal problem with it.*
>
> ***TCFG2P1****: Ja, you're* ***allowed*** *to say you don't agree.*

Although transplant coordinators appeared to contextualise themselves within the hierarchy as allied professionals have also done, one allied participant suggested that coordinators do not see themselves as being on the same level as allied staff, and rather consider themselves to be above:

> *(The transplant coordinators are)* ***HOLY NURSES. They're too too good to be nurses anymore****. That's what….* ***(009)****.*

This observation is perhaps borne out in results which suggest that transplant coordinators will stand up for themselves if this is required. It appeared that transplant coordinators experienced pressure from many different parties during the organ procurement phase:

> *… and **the doctor says: "You speak to the family now**, otherwise we're switching off the vent within the next hour" **(TCFG1P1).***
>
> *… (recipient coordinators) **want the process to go faster**. When [procurement coordinators] have got a certain amount of things to do before we can go through the whole process **(TCFG2P1).***
>
> *… (other transplant professionals who want swift consent) **get extremely irritated (TCFG2P3).***

In order to negotiate an ethical informed consent with a potential donor family – without undue time pressure and in an empathetic fashion - procurement coordinators said that it was essential to take control of the situation in the referring hospital:

> ***And also the ability to take authority of the situation and not to be pushed by others**. And as nurses who are coordinators, we're used to doctors telling us what to do. In this field, organ procurement, the coordinator is in charge of when to do things and needs to accept that responsibility. Because if you just do it on the demand of an outside person you are not going to get your consent **(TCFG1P1)**.*
>
> ***And sometimes you must take control**, you know, I often have arguments with people: "Listen, leave me alone, and I'll phone you when I am ready to phone you" and I think that's just what you need to keep going **(TCFG2P1)**.*

These results suggest that transplant coordinators are seen as fitting into the hierarchy, though they are situated between medical professionals and allied professionals. Coordinators consider themselves as relatively empowered, though still within the context of whether or not their actions are permissible. As I will argue at various points in this chapter, the healthcare hierarchy appears a barrier to transplant in Gauteng because it creates a context of power imbalance where

medical and allied professionals communicate in different styles (if at all) and with different consequences.

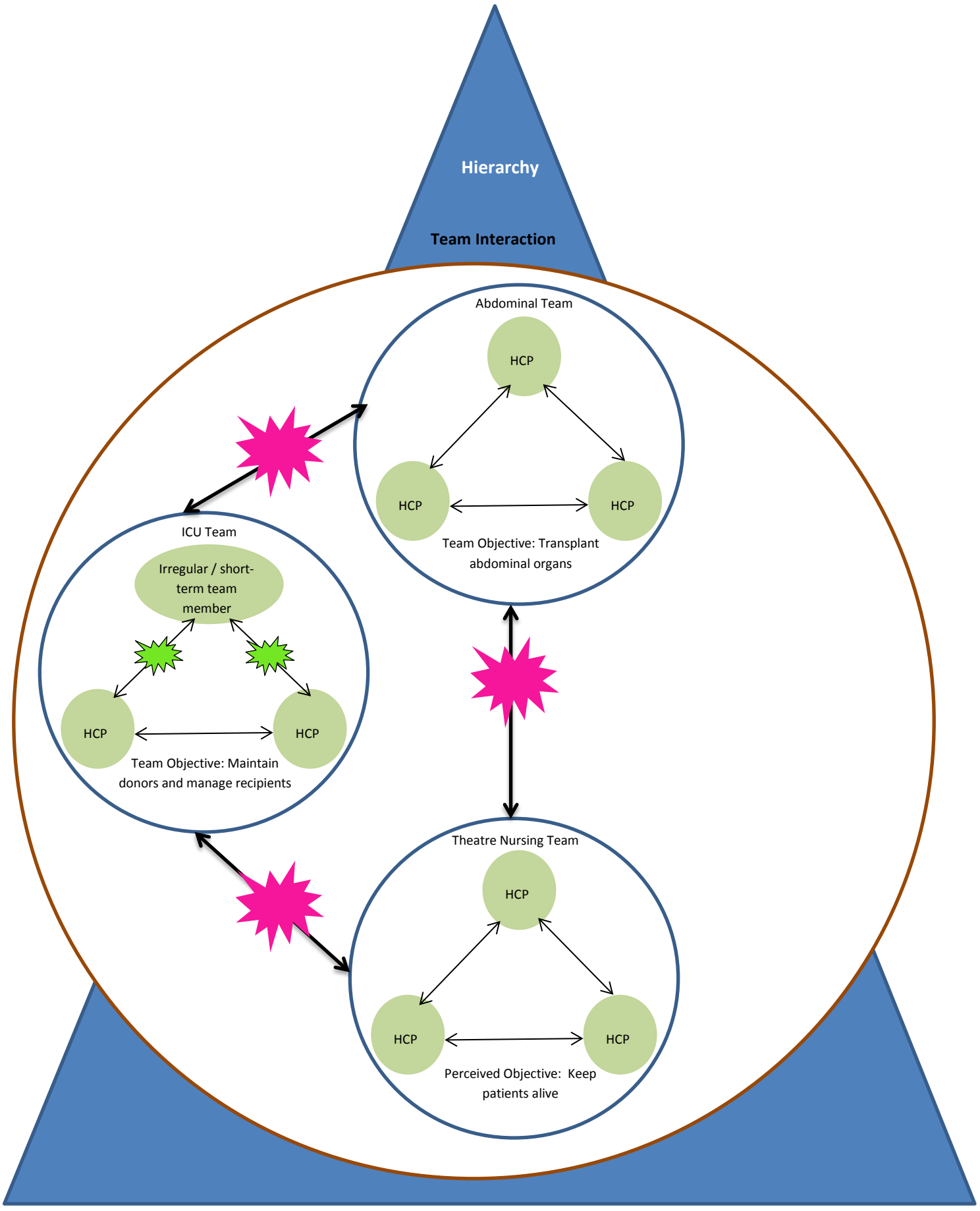
10.3. "TRANSPLANTATION IS A TEAM SPORT, THERE'S JUST NO TWO WAYS ABOUT IT" – PERCEPTIONS OF TEAMWORK AND TRANSPLANT IN GAUTENG.

My results thus far have explained the concept of the transplant hierarchy, and shown how this may shape the work and attitudes of transplant professionals. Within the hierarchy, transplant teams are expected to function optimally.

Chapter 4 was dominated by the word "team". The section aimed to give an overview of the large number of teams involved in transplant and the effort required to coordinate these teams within a limited timeframe. Although the number of teams involved in the process was emphasised, I did not specifically remark that each team is comprised of individuals - with different skills and personalities - all of whom are integral to the transplant process (Figure F10.3). For instance, a theatre team includes surgeons, anaesthetists and scrub sisters. Although each plays a different role, all are vital to the team successfully fulfilling its tasks.

Figure F10.3: Teamwork in transplant

The figure on the following page depicts the findings of my research regarding transplant teamwork in Gauteng and its situation within the transplant hierarchy. The figure depicts three transplant teams, though there are often many more involved. The communication patterns remain as depicted, regardless of the number of teams. A nursing team has deliberately been placed at the bottom of the hierarchy, to contextualise the position of teams within it and to indicate multi-level influences (Kozlowski & Bell, 2001). The objective of each team is stated (Lingard et al., 2012), and the uninterrupted arrows indicate where communication within individual teams is good in terms of fulfilling their objective. In one team, communication can be seen to break down when an irregular healthcare professional is required to contribute to the team, which detracted from a sense of cohesion (Kozlowski & Bell, 2001). Interrupted arrows show where communication between the teams on a multi-team level (Lichtenstein et al., 2004) breaks down.


Hierarchy
Team Interaction
Abdominal Team
HCP
HCP
HCP
Team Objective: Transplant abdominal organs
ICU Team
Irregular / short-term team member
HCP
HCP
Team Objective: Maintain donors and manage recipients
Theatre Nursing Team
HCP
HCP
HCP
Perceived Objective: Keep patients alive

Two thirds of the healthcare professionals who participated in my research emphasised the imperative of good teamwork as an integral aspect of transplant. This was necessary both within individual teams – for instance the surgical team, or the theatre team – and at a multi-disciplinary level where teams of different skill sets interacted with each other.

10.3.1. Core team efficacy and interaction

I found that members of core teams, provided they identified as a coherent unit, were considered highly effective. This perception appeared to be based on a familiarity with the other members of the team and their functions. Medical professionals who participated in my study perceived good team performance with good communication between team members:

> *I mean it's, and we have, I think evolved over the last few years and brought up a fairly constant team of people whose predominant interest is transplantation … So we become very familiar with them and we know that and that's the advantage of having a team all the way through* ***(005)****.*
>
> *Our particular team runs exceptionally well. We've got a lot of people involved who have a lot of mutual respect for each other…* ***(014).***
>
> ***And again when you work in teams for many years, as we have,*** *sometimes that's one of the benefits of being in a team, is that you can decrease the level of verbal communication and rely on each one there to do things without verbally checking them* ***because you've been together for so long (016)****.*

And allied professionals and TCFG2 concurred with medical professionals that individual teams performed effectively:

> *Ok,* ***within the team we communicate very well****, and we are constantly keeping each other updated with regards to our specialities* ***(021).***
>
> *Everything is ready, because* ***the team is not a casual team****. It's a team which does this job for a long time. Even the new ones, when they join, they find a culture of transplant, they get used to what is being done* ***(017)****.*

> *… we are lucky because the whole group is very supportive.* ***Because we're a close little group****, we're not a… It's getting bigger, but it's always been a nice close little group which is nice, ja* ***(TCFG2P2)****.*

Participants identified newly employed team members, or occasional team members who were not familiar with transplant, as a factor impeding team cohesion:

> ***The problem comes in when the team member is not a constant membe****r of the transplant unit and therefore is not aware of the sensitivities and the requirements of transplantation* ***(001).***
>
> *… and* ***particularly if you're with newer people*** *and there are people, for example, surgeons, that are not as experienced with the team, there's lots of stress involved* ***(015)****.*

The excerpts above suggest that participants consider core teams and the way in which they operate as effective.

10.3.2. Multi-team efficacy and interaction

Unlike perceptions of core teams, half of the transplant professionals and TCFG2 who participated in my research felt that teamwork was less effective when these cohesive individual teams were required to work alongside other teams in order for a transplant to take place. Interaction between individual teams was considered problematic, with fractious dynamics, power struggles and personality clashes:

> *The problem is not the team.* ***The problem is the interaction between the teams****. So there are various teams. And each team, I think, will, amongst itself, have its own view, and work very well by itself. It's the problem between the teams. So if you have a cardiac team and an abdominal team, that's the problem* ***(002)****.*
>
> *I honestly don't know what the dynamics are like between the [medical profession] and the [medical profession] at their own medical level, I don't know. There is a lot of tension, there is a lot of unhappiness a lot of the*

> *time.* ***But between the medical 'professionals' as such and the [allied] professionals there is very little communication, very very little (009)****.*
>
> *And* ***the reality is that each one thinks they are the most important****. The hearts think they are the most important, the livers think they're the most important. And I mean they're actually all as important as the next one. And I think that's… But, again, that's the type of personalities doing the job, and if they weren't the type of personalities they wouldn't survive in the job – other side of it* ***(TCFG2P1)****.*

As the previous section discussed, it appears that participants perceive individual teams to be effective. This section suggests that efficacy is compromised when multi-team interaction (Lichtenstein et al., 2004) is required.

10.4. AGGRESSION IN TRANSPLANT

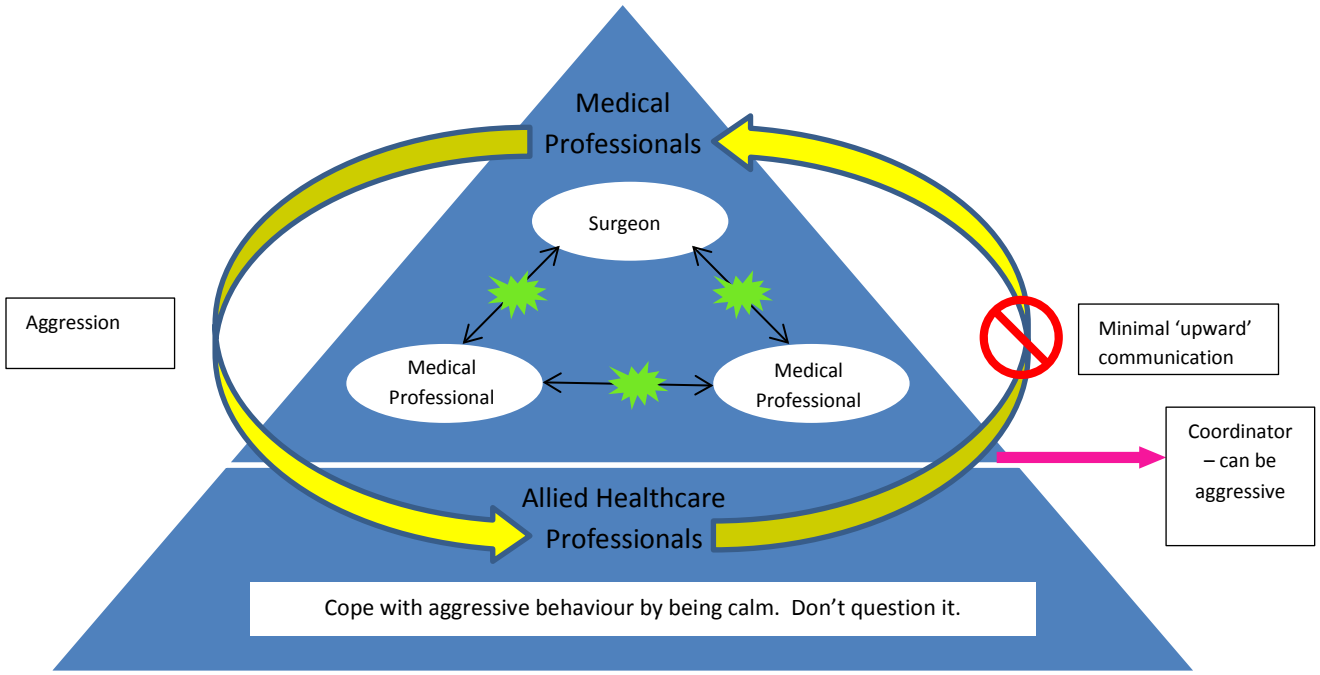
Chapter 9 considered results which suggested that patients – most specifically potential recipients and their families - sometimes displayed aggressive behaviour towards transplant professionals. In terms of interprofessional interaction, my analysis identified two facets of aggressive behaviour in the transplant setting. The first relates to general aggression as a possible by-product of the transplant hierarchy, which is prevalent throughout the process. The second relates to aggressive behaviour during the pressurised harvesting situation, where communication appears to break down. Each of these sub-themes will be dealt with in turn, and finally, mechanisms for coping with aggressive behaviour will be discussed.

10.4.1. Aggression and the transplant hierarchy

Figure F10.4 suggests factors which linked aggression to the transplant hierarchy. Although healthcare professionals in my study were not specifically asked about personality types, or about their own general behaviour and that of their colleagues, a large majority of participants mentioned that transplant is often characterised by aggressive behaviour. This behaviour seemed to come from medical professionals, such as surgeons, much of the time, but occasionally it was also seen in transplant coordinators.

Figure F10.4: Aggression and the transplant hierarchy

The figure below illustrates some facets of aggressive behaviour as found in my research. It shows that medical professionals display aggression towards each other, as well as to allied healthcare professionals. It demonstrates that there is little communication from allied healthcare professionals to their medical counterparts. It also shows that coordinators can be aggressive at times. Allied professionals are depicted as remaining calm under trying circumstances. The thin black arrows indicate medical professionals' relationships with each other, with the green flashes indicating aggressive behaviour.



10.4.1.1. Aggression amongst medical staff

Two thirds of medical professionals who participated in my study felt that other medical professionals displayed aggression, either towards each other in the transplant setting, or in their dealings with patients. This sentiment was echoed by one third of allied healthcare professionals. Both medical and allied professionals cited surgeons as that group which displayed the most aggressive behaviour towards other healthcare professionals:

> *… our surgical colleagues; they've sometimes* ***tended to be a bit aggressive*** *in their approach to their junior staff* ***(003)***.

> ***They'll shout, they will perform, you know, throw instruments around****, looking at the results…. **(008).***
>
> *But there's a very big attitude problem, if that's the right word, from the surgeons. You know, there's a few in particular that **walk in, grumble grumble, throw their toys**, and walk out **(009)**.*

However, medical professionals in general were thought of as headstrong and opinionated:

> *There's always something new that bites you and causes complications, **and there's often a lot of conflict because you know medical professionals are not known for their humility and people do speak their minds (020).***

and allied staff appeared fearful of the consequences if they made a mistake:

> *… you need to know what exactly is expected of you. Because if you don't understand that concept **then you won't do things right and you will be fighting with doctors** every day you are on the shift **(018)**.*

Healthcare professionals noted that a mis-timing of vital communication in a pressurised situation could result in aggressive behaviour:

> *…not communicated timeously, **it spirals a whole catastrophic chain of events** and that's been a bit of a weakness. **(001)**.*
>
> *… **if there's a communication gap … [the doctors] can get impatient, shouting and screaming, and that's not on (007).***
>
> *If the message is delivered in a short time it's really very stressful … **it causes some friction when the transplant is not well-organised**. Sometimes we have big problems **(017)**.*

10.4.1.2. Aggression amongst transplant coordinators

Notably, half of the medical professionals who participated in my study also felt that transplant coordinators displayed aggressive behaviour towards other healthcare staff, however, no allied staff expressed this sentiment:

> ***[Coordinators] cannot go to somebody else's home hospital, walk in and scream and shout at them****. They will not get another referral* ***(002)***.

Coordinators were also considered to be possessive of patients:

> *The clinicians often feel that they're [their] patients, and so* ***there's a bit of a friction between the clinical group and the coordinator group (016).***

whilst at the same time being criticised for perceived insensitivity towards donor families:

> *… you might have problems with the coordinators who some of the physicians feel are* ***too pushy and they're not sensitive enough to the families (005).***

and for behaving in an aggressive manner towards those medical professionals who were maintaining a consented donor till the time of harvest:

> *… if anything goes wrong* ***you've got this irate coordinator or something yelling at you*** *like you know: "You've ruined my donor! Now I can't use this at all!"* ***(003)***.

The quotes above suggest that aggression in transplant may be related to the healthcare hierarchy. It appears that medical professionals and transplant coordinators – both groups which are closer to the top of the hierarchy - display aggression. I note that while medical professionals may be aggressive towards both transplant coordinators and allied professionals, transplant coordinators were seen to show aggression mainly towards medical professionals.

10.4.2. Aggressive behaviour, time constraints and organ harvesting

The previous section considered aggressive behaviour in transplant in relation to the transplant hierarchy. This section looks at aggressive behaviour specifically in relation to time constraints in the surgical phases of organ transplant. Chapter 4 emphasised that organ transplantation – especially that from a cadaver donor – is a time-intensive process which requires meticulous liaison and communication. The consequences of mis-timing can be serious, and may result in a potentially life-saving organ becoming unsuitable for transplant (Figure F10.5). Hence, protocols

have been instituted at various stages of the transplant process in order to facilitate management from the pre-transplant phase through to post-transplant follow-up.

The effectiveness of protocols in regulating harvesting teams was questioned. These protocols were related to the time a surgical team took to harvest their organ (Appendix 2).

> *… we have also put in protocols, put in times, put in what's expected of people* ***but despite that we still get problems (002)****.*
>
> *… (the surgeon is) expected to start operating at that time, he has half an hour to get his organs out,* ***if he hasn't got his organs out he's going to get pushed out of the way (002).***
>
> *… particularly if things (the harvest process) are not getting done, you know, according to the time schedules,* ***people taking a bit longer or doing that, that creates a little bit of animosity (015)****.*

Participants were particularly critical of harvesting surgeons and their perceived inability to adhere to the harvesting protocol, noting that this could result in being disallowed from harvesting the organ which they were hoping to retrieve:

> *… (surgeons are)* ***always fighting amongst themselves about "this one's taking too long" and "this one's taking too long" (020).***
>
> *… they must* ***expect to lose the organs (002)****.*

However, it was also stated that the implementation of surgical protocols for harvesting was tempered with flexibility to prevent teams losing organs simply because of miscommunication:

> *… they are flexible because we don't want somebody to lose an organ purely because they didn't get back to us* ***(002)****.*

All allied staff responsible for follow-up of the recipient post-transplant noted that protocols were helpful:

> ***You don't make mistakes because you know you have to follow the protocol (025).***

> *…in the transplant and you know that* ***from this step, you are going to this step, from this step you are going to this step (013).***
>
> *… we make sure that we obey* ***the rules (025)****.*

Furthermore, TCFG2 viewed protocols as a tool which facilitated the transplant process:

> *I think you must just stick to,* ***there are certain protocols in place and steps to be taken. And the most important is if you follow those steps*** *then things will work as it should work* ***(TCFG2P1)****.*

The quotes above suggest that transplant protocols have varying effects, depending on the situation. Allied healthcare professionals and transplant coordinators suggested that protocols helped them to avoid mistakes and promoted positive outcomes.

In spite of measures, like protocols, to expedite organ transplant, one of the salient findings of my study is that during the highly pressurised harvesting process a breakdown in communication can lead to aggressive behaviour, primarily on the part of medical professionals. All but one of the medical professionals who participated in my study made observations related to this theme. All the allied professionals involved in surgical aspects of transplant reiterated this sentiment:

> *… (the time pressure of transplant) usually results in* ***aggressive, angry interchange between people, rather than in a collaborative, pushing forward for the best interests of the patient (001)****.*

The frenetic nature of the harvest and the interchange between several teams working under significant pressure was described by participants as an area of conflict:

> *In the actual operating theatre is* ***a bunch of prima donna surgeons each saying that their organ is the only one that is important and screw the other organs****. And depending on who the surgeons are it can be quite rough* ***(014)****.*

> *There's often friction between the various surgical teams because when [they] take multi-organ donors [they] have to fit in with [these] guys and [these] and [these] guys and there's* ***often huge conflict between them at the time of harvesting (020)****.*
>
> *…* ***at the time of the donation it is fire. Fighting fire. It is sssssserious****, arguing about who is and who does who think who is. Uh, the middle of the night, it's not uncommon to have a very very heated conversation about this* ***(002)****.*

The consequences of this behaviour at the time of harvesting were described as inducing a delay in the entire transplant process:

> *… let's say (the recipient physician) delays [them] by an hour, then he delays all the people on the other side.* ***He's delayed the anaesthetist, he's delayed the theatre sisters, he's held the theatre at ransom because they've got to stand open waiting for him****. And that's where [medical and allied professionals] start getting angry and start getting arguments amongst the people* ***(002)****.*

Delays related to ischaemic times also caused aggression in the harvesting context. For instance, a cardiac team is unable to remove the donor heart until an eligible recipient has been prepared for theatre at the receiving hospital. As the ischaemic time for a donor heart is only four hours the most effective manner of ensuring organ quality is to minimise the time between the harvest and the transplant. However, due to contextual factors like proximity to the transplant centre (Section 8.6.4) a potential recipient may arrive late or require additional tests. Should this occur, the recipient management team will request a delay in the harvesting (this is not only the case with potential heart recipients; it applies equally to the potential recipient of any organ):

> *And then [the harvesting team] stand there and [they] say: "Ok, now [we've] got to wait for an hour and a half" twiddling [our] thumbs, [we've] got to phone [our] guys telling them [we're] going to be an hour and a half late. And [they've] got to* ***shift all the anaesthetists, all the theatres, all the***

> ***things, everybody's got to sit around in the tea room waiting for the cardiac guy to wait his hour and a half because somebody else has delayed something somewhere along the line (002)****.*

Allied professionals described the consequences of this delay:

> ***The doctor will scream****, but you know, everything will be delayed* ***(018)***.

This delay also resulted in unhappiness amongst healthcare staff and the feeling that:

> *… it's a big problem because* ***not only are they not happy, they start saying: "I'm not doing this again" (002)****.*

The excerpts above suggest that communication which takes place under the time pressure of organ-harvesting is unpleasant, and that the main source of this friction is between the surgical teams. Disruptive and aggressive behaviour has been seen to have a direct impact on patient safety (Galandiuk, 2013; Porto & Lauve, 2006). Galandiuk (2013) noted that the essence of surgery is pursuing the best interests of the patient at hand, irrespective of time constraints and a medical professional in my study stated that:

> *If patient care plays any role, it plays a role in [the teams] tolerating that kind of stuff.* ***If it plays a role, it's probably the only thing that stops [the teams] from killing each other. You say: "Fine, there's a … patient on the other side of this"****, so you are very annoyed there has been a delay of two hours, but you tolerate it because there's a patient at the end of it* ***(002)****.*

10.4.3. Coping with aggressive behaviour – being "nice" and "calm"

None of the medical professionals who participated in my research discussed their mechanisms for coping with aggressive behaviour, however all those allied professionals who had experienced aggression at the hands of a medical professional or a coordinator, felt that being a *nice calm* person was helpful:

> *So* ***we won't be running around panicking*** *so the doctors, if they start panicking, obviously they will make your day very horrible* ***(008).***

> *… **if you know what you are doing then even if you are being pressurised**, but at least everything is done correctly, then you won't have any screaming and stuff **(018)**.*
>
> *And then, ja, and then obviously **I'm not going to make a big noise, shout and scream and carry on like that because there's better ways to handle the situation**, and then just try talking and keep on telling the people "Listen, this is how we should work, this is how we should work" **(007).***
>
> *… when we were students we were trained, we've done psychology, we've done... So those kinds of things. **You calm yourself down and you just don't entertain his outburst**. So if you know that you have done something right, so you calm yourself down **(008)**.*

The transplant coordinators echoed the sentiment expressed by allied healthcare professionals, stating that acting in a calm and polite manner served to dissipate aggressive situations. Both transplant coordinator focus groups felt that daily communication with staff and a positive attitude could help to change aggressive attitudes and behaviour:

> *And I'm doing this almost on a daily basis talking to the staff. And maybe they are starting to open up a little bit. Because I make it a point that I sit in that ward until I'm a…. **I don't mind being looked down upon, that's not a problem with me. Because I know one day you will smile (TCFG1P2)**.*
>
> *… the nicest person even nice to a stage where you end up laughing at even a fly passing by. **But just be nice to everybody. It helps wonderfully, especially when you are in such a situation**. You are able to reach each and every one without any hiccoughs **(TCFG2P4)**.*
>
> ***You actually get more right being nice than screaming and shouting**. Because I think it's already such a sensitive situation. You can go and do that outside, but you don't scream and shout at the person. Because you might get more out of being actually nice **(TCFG2P1)**.*

One possible reason why medical professionals did not feel it necessary to discuss their coping mechanisms may be that aggression in medical practice is often

accepted as the *status quo*, driven by the hierarchical framework which seems to simultaneously justify and facilitate it. For instance, a Canadian study examined the attitudes of junior doctors to aggressive behaviour from senior surgical colleagues. The participants felt that this was akin to a rite of passage, and that it actually improved their medical training (Musselman, MacRae, Reznick & Lingard, 2005). Findings such as these may serve to entrench the notion that aggressive behaviour is acceptable, and is a function of the healthcare hierarchy.

10.5. FEELINGS OF DISCOMFORT AND UNWILLINGNESS TO BE INVOLVED IN HARVESTING

The previous section of this chapter explored findings related to aggressive behaviour in the organ harvesting process. There was emphasis placed on protocol and time constraints which could cause aggressive interchanges and could lead to moral distress. However, this situation may be compounded by feelings of discomfort with the harvesting process amongst all the allied professionals who participated in my study and who had first-hand experience of harvesting cadaver donor organs:

> *… then **there are certain parts of the harvest that can be particularly difficult to watch**, like if they are going to take corneas, they take the whole eye out. And once they take the heart and the lungs that cavity is left open and vacant **(021)**.*
>
> *At some stage **I was just seeing everybody taking the organs, leaving the patient empty**, and I said: "No, I am stopping. I am stopping and I am not going to harvest anymore" **(017).***
>
> *… **it is not a nice experience**. That's why as far as I can, I ignore that side of things, I don't like that **(007)**.*

An analogy of the harvest and an animal kill or scavenging was regularly employed:

> *… (the harvest is like) **like a bunch of vultures (014).***

> *… a lot of people believe that **that person just gets treated like a chunk of meat** and we go in there like vultures and just yank the stuff out and we leave **(021)**.*
>
> *Ooooh, **here come these vultures (TCFG1P2)**.*

Many participants who expressed a negative sentiment about harvesting felt it went against the ethical imperatives of their chosen profession:

> *… **taking care of people and making them better, not taking pieces away from them (021).***
>
> *… **you want the patient out again alive**, you know, and now, this one takes eyes, this one takes bone, that one takes that. It's hectic **(007)**.*
>
> ***You know you are getting the organs for saving another life, but you also know there is life lost there**. When you do it continuously, that's my experience, you harvest every day, you are taking, you are removing, and you are leaving a patient just like that **(017)**.*

Although one participant acknowledged these difficulties, it was also felt that the donor was treated with dignity:

> *… we take a huge amount of respect, the body is washed and sewn back together, so they're never just left like an open vessel, but it's more a mental… Like the heart has now been taken from this body. Or when we take skin that is now taken from this **(021)**.*

Additionally, allied staff felt that the conditions under which harvesting took place perpetuated the negative experience because of the unpleasant atmosphere in theatre and working in unfamiliar surroundings:

> *… **the atmosphere in the theatre is also difficult**. Because we go to hospitals we don't know and we are not by ourselves. There are many teams who will be busy harvesting. … **it's very stressful as well when we go for harvesting**. Very unfamiliar surroundings, everything is strange for you, maybe you have been travelling… **(017)**.*

The quotes above illustrate how allied healthcare professionals' personal experiences of organ harvesting may impact on attitudes towards it and on willingness to be involved. This may be a barrier to transplant, as harvesting cannot take place without a sufficient number of willing staff members.

10.6. CONTINUITY OF CARE

In Chapter 4 communication during the transplant process was emphasised. This communication started at the time a potential donor was identified and continued through the recipient follow-up periods (sometimes a decade or more). Communication was found to be more, or less, intense, depending on the stage at which it took place. Transplant requires that a recipient make a lifelong commitment to maintaining the new organ. It also demands of a healthcare team the commitment to provide that recipient with lasting medical management (Steinberger, Douglas & Kirschbaum, 2009). This places the recipient at the locus of a communication and referral process that will continue for the rest of his or her life. The recipient is dependent on healthcare professionals to ensure that there are no gaps in the follow-up care which they provide. Given the consequences that miscommunication may have for a transplant recipient, continuity of care is essential in the transplant process. Section 9.8 considered recipient follow-up and communication between the recipient and the management team. In those cases where transplant professionals communicated with the recipients, continuity of care appeared to be good and to have positive consequences for relationship building and adherence. Chapter 9 has shown that continuity of care is also important for the donor family, however, in some of these instances, it appears to be lacking.

However, the Joint Commission (2014) notes that failure to relay vital information between healthcare providers, or between healthcare providers and patients, is the main cause of adverse events in the healthcare setting. Thus far, my research results have demonstrated that multi-team communication in Gauteng transplant is a challenge. Hence, it is not surprising that breakdowns in transplant communication were also identified in my study.

According to findings from healthcare professionals, continuity of care can be broken down into two broad sections:

- Interprofessional and trans-institutional continuity of care when communicating *about* patients (Figure F10.6)
- Perceptions of poor continuity of care and coordinator communication (Figure F10.7)

10.6.1. Interprofessional and trans-institutional continuity of care when communicating *about* patients

The majority of allied healthcare professionals who participated in my research expressed frustrations with medical professionals, citing communication gaps which negatively influenced continuity of care and also had a negative bearing on the quality of the patient care provided.

There were several instances where allied health professionals felt medical professionals had failed to transmit important information trans-professionally:

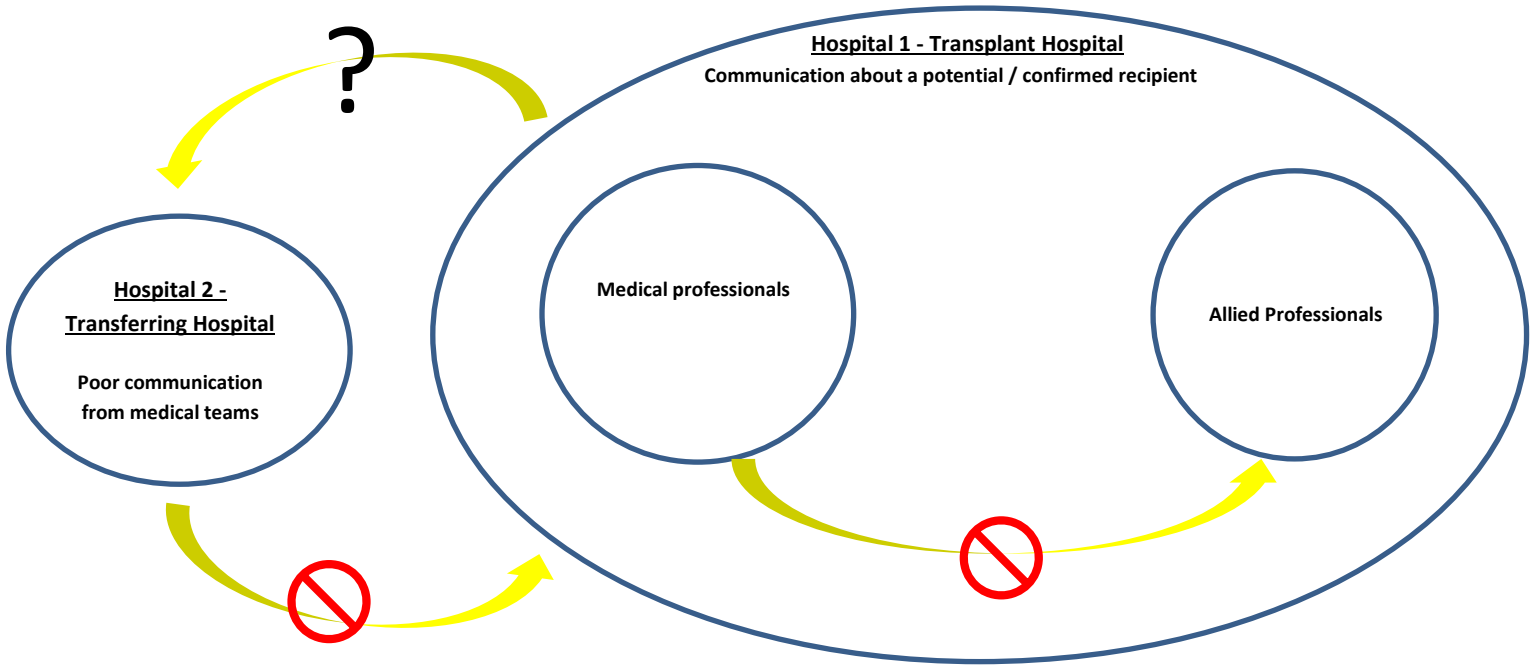
> *… the communication sometimes* ***you'll find that the doctor has just written a prescription but he didn't tell*** *[the nursing staff], [they] find out very late that the patient was supposed to get this [medication]* ***(006)****.*

Allied professionals expressed frustration when a medical professional asked them to consult on a potential transplant recipient - or post-transplant case – at the last minute, rather than being given sufficient time to attend to the patient:

> *… the patient has been bedridden say three months prior to the transplant* ***why are we not called in that three months to come and see the patient? (012).***

Figure F10.5: Interprofessional and trans-institutional continuity of care when communicating *about* patients

This figure depicts interprofessional continuity of care and communication processes as identified in my study. Yellow arrows indicate the flow of information. This flow of information is essential to the continuity of care. The figure shows that provision of information from transferring hospitals to transplant hospitals is poor. It also shows poor continuity of care between medical and allied healthcare professional teams within the transplant institution.



The result of this break in continuity of care is that staff were surprised when the transplant coordinator arrived to assess the donor:

> *… find the coordinator walking into the ward and [staff are] like: "What do you want?" and [the coordinator is] like: "I'm here for whoever whoever." [The staff] are aware that the patient is not well, but* ***[they] were not informed of [coordinator's] arrival (011)****.*

Although allied professionals identified medical professionals as a source of communication gaps, the medical professionals who participated in my research did not express a similar concern about their allied colleagues. Rather, medical professionals identified other medical professionals as a locus of breakdowns in communication, especially regarding sharing of essential management information amongst teams at different healthcare facilities. In the lengthy quote below, one medical professional explained how a lack of interprofessional communication potentially affected a patient's chances of being listed for a second transplant because the patient was perceived as being non-compliant:

> *So for example [they] had a patient who was labelled as being non-compliant, ok, so I said: "Well how do you know that the patient is non-compliant and [is] not a candidate for re-transplantation because [the patient] has been non-compliant?" So [they] go back to the chart and … [the patient] hasn't come at the three-monthly review … hasn't come to the six monthly review, but [the patient has] come to the annual review. But then [the patient] hasn't come to the next three-monthly review … not come to the next six-monthly, but [the patient] has come to the following annual review. So [they] then go back to the patient and [they] say: "So how have you been followed up?" And [the patient will] say, well [they were] seeing the doctor here and the doctor says: "It's not necessary for you to come here all the time, I want you to be followed up in whatever, [place name], for your three-monthly review and you six-monthly review and then we will see you on an annual basis."* ***So the patient has been perfectly compliant with the framework that the doctors gave them, but that information has***

> ***not been translated trans-professionally, and then that could have been significant because the patient was being denied a second transplant on the basis that [the patient] is non-compliant, but [the patient] was compliant (001)****.*

Medical professionals expressed frustration with colleagues from other institutions who referred patients for transplant without providing sufficient information:

> *… remember that also* ***we get referred people in from other centres that you've never seen before in your life****, you don't know who this person is* ***(003).***
>
> *I get a reasonable referral letter from [medical professional],* ***I get no information whatsoever from [other medical professional]. So there is no liaison, zilch (027)****.*

In some cases, poor trans-institutional communication between medical professionals affected continuity of care to the extent that a transplant would be delayed. For instance, a listed potential recipient may present with contraindications to transplant. If the medical professional managing the patient at another institution has not conveyed this information to the transplant team, that patient may be called to receive an organ which cannot then be given to him due to the contraindication:

> *…* ***it's particularly hell of an irritating when [the patient who has been called to present for transplant] is obviously sick, that recipient, and you do get a bit irritated with your colleagues when they've had someone on the list that they know had a problem****, or they hadn't seen that person frequently enough. And they've come and what they've basically done here is they've wasted time. So [there have been] occasions where patients will arrive, they are the so-called 'recipient' per the [waiting] list and they've got something wrong which precludes transplant. That is extremely annoying because it basically means that you have to reinitiate the process all over again but you are already four or five hours into ischemic time* ***(003)****.*

A lack of continuity of care was also seen as a confounding factor in referring a patient as a potential organ donor:

> *And the one, another thing about communication that is a problem and that hinders this harvesting of organs it's* ***this hospital transfer of patients. Then, I don't know how they practice it out there, but they don't tell the family that: "We have transferred your loved one to [hospital name]****, may you please go there, to this ward, and ask for them." Families can stay for a week, not knowing where their loved one is* ***(011)****.*

The Gauteng transplant context has shown that contacting donor families may be difficult due to geographical factors. In cases like the excerpts from 003 and 011 above, it may become particularly difficult as the management team is unaware even of basic patient details, let alone the contact details of his or her family. This important information had not been conveyed from the management team at one hospital to the management team at the other hospital.

10.6.2. Perceptions of poor continuity of care and coordinator communication

Over half of the healthcare professionals who participated in my research felt that transplant coordinators do not communicate effectively, however, this was not a question I specifically posed to participants, rather it came up in discussion without any prompting or leading (Figure F10.7). This lack of communication impacted upon two areas of transplant:

- Facilitating the transplant process in a timely fashion
- Potential recipient outcomes

10.6.2.1. Coordinator communication and facilitating the transplant process in a timely fashion

Chapter 4 explored the transplant process, and the imperative of organising a transplant within a limited timeframe in order to ensure best outcomes. This organisation is primarily the responsibility of the transplant coordinator:

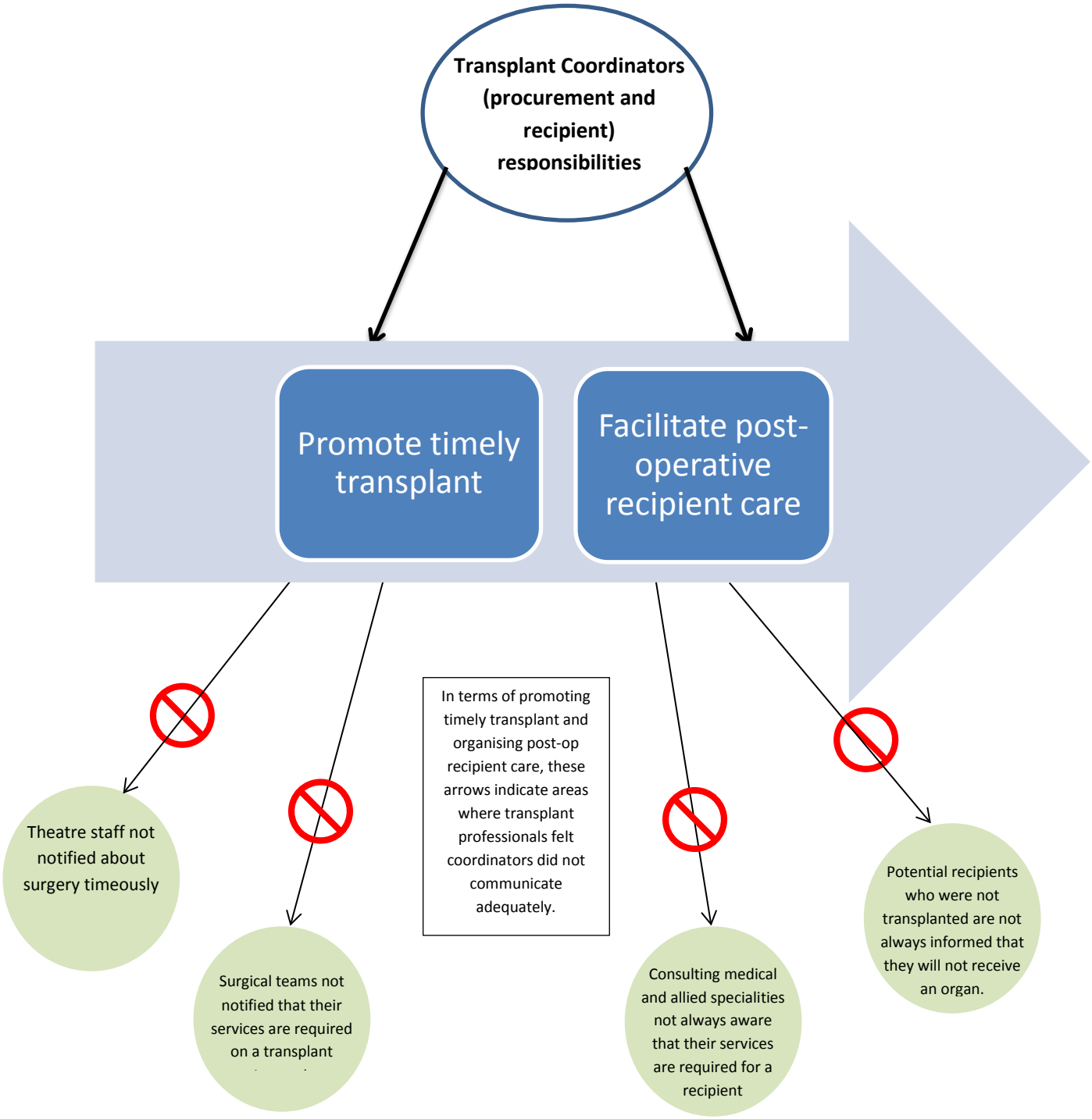
> *For the operation,* ***she's got to organise everything****. The doctors, the perfusionist, the anaesthetist. So she's got to speak to all of those people. And then she also has to speak to the specialist* ***(021)****.*

Both medical and allied healthcare participants were critical of transplant coordinators, stating that information essential to the transplant was not forthcoming in a timely manner. This criticism emanated from those who were integral to the surgical process and from participants involved in post-transplant care:

> ***Not getting notified in time is a common experience for me****. I see it commonly amongst my colleagues. It becomes frustrating when the first I hear about a transplant is when my mate … walks in and says: "I've come to see a patient pre-transplant." And that occurs with relative frequency. That's why I mention the coordinators in that scenario, that's their role, is to share that information. So that has been a source of frustration. But we get around it (****016)****.*
>
> *Sometimes [you] will have a problem from the coordinators to [the theatre staff], because the coordinators are the first people to know about the donor and then they have to communicate that down to [the theatre staff].* ***It happened before that they thought somebody in theatre knew about [the transplant] and they didn't communicate through to [the theatre staff****, who] walked … into theatre and nothing was prepared, it was chaos…* ***(007)****.*
>
> *… if it happens that maybe they communicate between the doctors and the coordinator.* ***At the last minute*** *they phone [theatre] and say: "there's a transplant", it doesn't make [theatre] happy to come and rush-rush, put things together. It's sometimes, it comes from the transplant coordinator if she doesn't communicate early* ***(017)****.*

Figure F10.6: Perceptions of poor continuity of care and coordinator communication

This figure depicts coordinator continuity of care as per the results of my research. It indicates the negative aspects of communication which were mentioned by healthcare professional participants. No positive aspects of coordinator communication are depicted. This is not to say that there are no positive aspects, rather that participants did not mention any, nor did I ask participants about any, because this was not part of the interview schedule.



Staff involved post-transplant also expressed frustration:

> … ***we did ask them to give us a little bit more time, sometimes the patient would be referred just the day before discharge****, but the patient was already here for two weeks. So there was a lot of time for us to see the patient in the wards but he was only referred at the end of the two weeks* ***(023)****.*

10.6.2.2. Failings in coordinator communication can influence potential recipient outcomes

The majority of allied participants expressed concern about the influence of the transplant coordinator and how this impacted on patient care and outcomes, sometimes resulting in situations which were not necessarily in the best interests of a vulnerable potential recipient who had been waiting a long time for a transplant. One allied professional emphasised this point at length in the research interview. It appeared that a confusion as to the exact role of the coordinator and who was responsible for contacting potential recipients resulted in miscommunication. Apparently, this confusion could cause a delay in calling a potential recipient to present for a transplant:

> *Now, because we've got coordinators, it's them who are running this whole thing. They know the donor. We just see the patient coming.* ***Sometimes they don't even tell us****, you see, and then there will be a patient they have chosen already. … So sometimes the communication gets poor. …* ***Sometimes the night staff they don't even know that there's a donor*** *because now the coordinators have taken the work load that they were doing before* ***(006)****.*
>
> *Sometimes it falls on you that you're supposed to call the patient, meanwhile we know that now* ***they are not giving us the patient names in time to call the patient****. … So can you see that it's the coordinators work? We take it as the coordinators work. But now the pressure is when it's you that's on duty: "They didn't tell me, I didn't know!" You see?* ***(006)****.*

> *So if they don't inform us, sometimes we'll find that the doctors they ask us, I mean, the patient was supposed to be called and we didn't call the patient because they didn't tell us. Or maybe they didn't tell the night staff. The night staff didn't tell us.* ***So we'll find that there is a delay (006)****.*
>
> *…* ***it affects even the patient that comes from far, and he comes here, and [the organ] has been given to somebody else because they didn't communicate****, maybe with those hospitals or what, I don't know* ***(006)****.*

A different scenario was described where coordinator miscommunication influenced the care provided to a potential recipient when two recipients had been asked to present for transplant, with the intention to give only the most appropriate one the organ:

> *There's been a couple of negative experiences where the patient, often two patients, will be called up, hoping to give it to patient A, but if something is not ok they'll give it to patient B.* ***And there have been occasions where patient A is still left sitting [in the ward] when patient B is already on the table in theatre. And I don't think it's the nursing staff's responsibility to communicate with that patient****: "I'm sorry, the organ is not suitable for you, for whatever reason, your bloods came back and we're concerned, we can't take you." And we've had to often, several hours later, had to phone the coordinator and say: "Listen, is someone coming up to speak to this patient?" So there have been a couple of negative incidents like that* ***(009)****.*

It appears that an ill-defined scope of work for coordinators may constitute a barrier to communication and hinder the facilitation of an effective transplant process, as well as having serious implications for patient management. One medical participant summed this up as follows:

> ***So we have lots of issues with coordinators because their role as yet has not been that clearly defined****… Or in my opinion not clearly enough defined. And so what tends to happen is there's gaps in the communication. I take it that their role is very difficult because they're trying to manage not only a*

group of patients but also a whole group of doctors, which, if you know doctors, is very difficult to do ***(016)****.*

10.7. INTERPROFESSIONAL COMMUNICATION AND MANAGEMENT DECISIONS IN TRANSPLANT

My research identified two means by which transplant professionals negotiated management options for their patients. The first was a multi-disciplinary forum of ward rounds, the second was one-on-one personal conversation – which may take place physically, over the telephone or in an instant messaging context. Given that transplant is a multi-disciplinary endeavour which relies on the skills of a number of individuals, this communication is vital to its success or failure. Furthermore, as inter-team communication can be problematic, some formal spaces for communication seem especially necessary.

10.7.1. Ward Rounds

Medical professionals expressed that ward rounds were an important forum for the discussion of the patients and could be used to facilitate patient care when all agreed that management decisions would only be made in the ward round forum and not at any other time:

> *… where the physicians, the surgeons, the physios, the social workers, the nurses are* ***all on the same ward round listening to the same story around the same patient*** *… Once a patient has been transplanted we go on a morning ward round and you follow-up the patients. And* ***we have avoided multiple clinicians making multiple decisions on the patient by insisting that all decisions will be made on the ward round****. So if you have a point of view that differs from the managing team, as part of the managing team you are entitled to express that opinion, however, it should be within the confines of that ward round and that avoids multiple people from the team coming in and making their own decisions* ***(001)****.*

However, allied staff appeared to disagree with this sentiment, stating that ward rounds were not as uniform or integrated as medical professionals suggested, and also that they took a long time:

> ***… they don't do their rounds all of them at the same time (006).***
>
> *… (the ward rounds) tend to be **very lengthy (012)**.*

There were also reservations from allied staff about professional respect during ward rounds which was seen to be lacking:

> *There's a transplant round … where about eight, nine people walk round and discuss the patients. From a nursing point of view, **the nursing staff are not involved. The nursing staff are almost, on occasions, physically moved out of the way. I think the nursing staff are physically moved out of the way often**, so that everybody who needs to hover over the chart and see on paper what's been happening with the patient **(009).***

The excerpts above suggest that participants held opposing views about the efficacy of ward rounds with medical professionals finding them helpful and allied professionals expressing reservations.

10.7.2. One-on-one communication

Other than ward rounds, interprofessional communication about transplant and patient care took place through personal one-on-one interaction, over the telephone or via instant messaging.

The majority of medical professionals felt that this means of communication was unproblematic:

> *… consultant to consultant communication … and **the matter is discussed until it comes to resolution (001)**.*
>
> *… we fight and whatever but it's usually about, you know we go toe to toe over patient care or something like that. But you know **I think that's a good thing. The freedom to be able to do that with your friends and colleagues** is important **(016)**.*

However many allied healthcare professionals felt that this type of one-on-one communication was problematic, especially when trying to communicate with medical staff who were seen as inaccessible:

> … ***the doctors tend to be far less obliging when it comes to communication. We often get one word answers, we often don't get replies to sms's or e-mails. So it gets very difficult to get them to engage****. So often we are catching them in the passages and literally running next to them and trying to have a conversation which is done probably at the speed of lightning. So probably not as good as it should be* ***(021)****.*

The modes used for one-on-one communication varied, with preferences for phonecalls or messages depending on the context within which the participant worked:

> … ***a detailed phonecall*** *to say: "I've got such and such a patient, these are the conditions, I've seen the patient, this is what's happening, could you see the patient urgently? These are my concerns"* ***(004)****.*
>
> ***It is easier to communicate with sms****... Because it gives us a gap, to finish your ward round, then communicate, then the other guy's got the thing, he can communicate back. You don't lose the message either* ***(002)****.*

Some participants noted that they make use of chat groups, either via Blackberry Messenger (bbm) or Whatsapp. However, this group was specific to a small team and was not accessible to more than four or five key individuals in the transplant process.

> *And* ***we also have a group chat on bbm*** *so we can constantly keep each other updated. So everybody is always in the loop* ***(021)****.*

One allied professional, when asked about the process of notification for a transplant, stated that a speed dial service notified all relevant individuals of a potential transplant:

> *They tell you: "There's a* ***possible*** *transplant" there's speed dial, it goes to everybody. Even the hospital manager* ***(017)****.*

However, this speed dial service did not appear to incorporate all settings, with one participant experiencing the opposite:

> *… they'll go and harvest and you'll find that sometimes* ***you left home without knowing there's a transplant****, the following day there's a transplant"* ***(006)****.*

Some healthcare professionals stated that there were problems when communicating electronically on a one-on-one basis, in spite of all the technology that is available:

> *If it's not communicated timeously, it spirals a whole catastrophic chain of events and that's been a bit of a weakness.* ***And you would think that with today's information systems in place, it wouldn't be very difficult to get the message out of what's going on (001)***.

The perceptions of one-on-one interaction expressed above, echo findings about communication in ward rounds, and we can see that both these forms of communication prove barriers to the transplant process in Gauteng.

10.8. SUMMARY AND CONCLUSION

This chapter has shown that a number of communication factors are influential throughout the transplant process, and these factors are shaped by larger frameworks such as the institutional health hierarchy. Teamwork has also been identified as an essential but sometimes challenging aspect of the transplant process, where the quality of interprofessional communication seems to depend on the nature of the relationship. When dissimilar objectives are factored in, the data suggests that communication breaks down. Continuity of care was also a factor, and the lack of effective communication across and within institutions, becomes a barrier to the transplant process because of the delays it can cause.

Interprofessional communication was shaped by a hierarchical institutional organisation which lacked continuity of care, and also by resource constraints, both factors which made it difficult for transplant professionals to provide care and resulted in moral distress. Participants reported feelings of discomfort, of aggressive treatment and unpleasantness in professional interactions. It appeared

that allied professionals at the bottom of the hierarchy did not stand up for themselves, preferring to be 'nice and calm' than to question the *status quo*. This constitutes an internal constraint which may be related to nurse socialisation within the hierarchy and could also be a factor in moral distress (Austin et al., 2005) as allied professionals were not comfortable demanding information which would be considered essential for ethical patient care.

Several elements of communication were identified as individual factors which influence the transplant process. However, it appears that transplant communication is framed by larger institutional forces. Many allied participants expressed dissatisfaction with the communication styles of their medical colleagues. When placed within the context of a transplant hierarchy, this observation takes on new meaning as I must ask whether the poor communication is driven by the hierarchy or whether it is a consequence of the context and multi-team nature of transplant interaction. Furthermore, it is possible that aggressive behaviour towards junior staff and allied professionals is also the result of an instilled hierarchy at the point where individuals are stretched to their limits, in this case in a pressurised transplant situation. My study identified teamwork as a cornerstone of transplant practice; however it showed that multi-team interaction is a challenge. Such an interactional challenge may account for poor continuity of care as professionals seem unable to recognise the value of other teams and hence do not always consider it necessary to communicate relevant information timeously. Time appears to be a crucial factor in interprofessional interactions. This is especially heightened in transplant due to factors such as ischaemic time (Section 4.3), which seem to serve as a stressor in the situation.

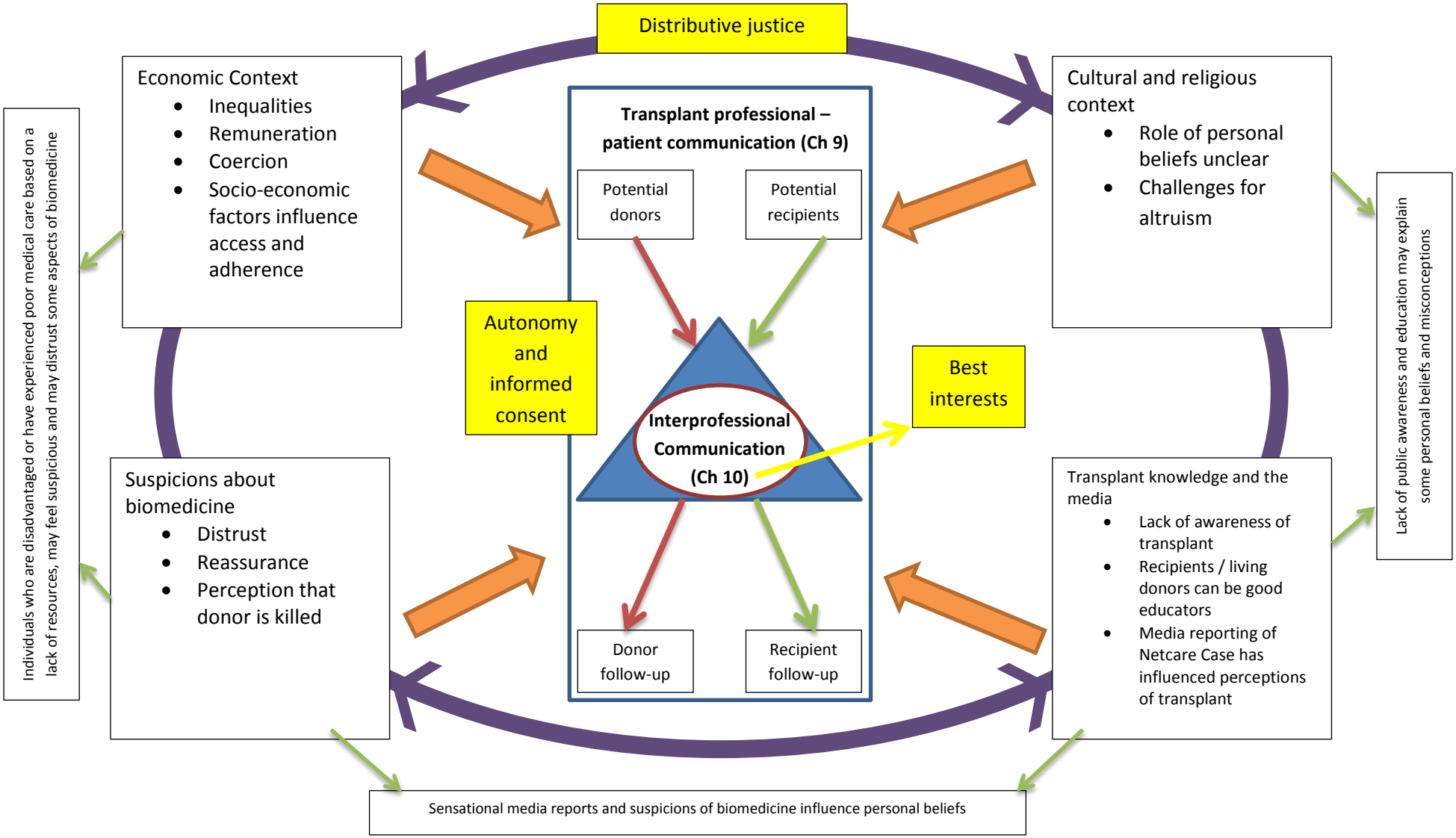
CHAPTER 11 – DISCUSSION

11.1. INTRODUCTION

In this chapter I will synthesise my research results. The discussion is based on a model of organ transplantation (Figure F 10.9) in Gauteng which I have derived through the synthesis and analysis of my data, and which also outlines my overall argument. By explaining each level of Figure F 10.9 in detail, this chapter intends to guide the reader through the main issues in communication and ethics which my research identified.

Figure F10.9 depicts a model of transplant communication in Gauteng based on the findings of my research. It is linked to Figure F8.1, which illustrated the Gauteng transplant context. In this model, the context is represented by the purple oval, which encompasses the processes depicted within it. The four main universal and resource-related aspects of context (culture and religion, suspicions of biomedicine, transplant knowledge and the media and resources and distributive justice) are depicted and the multi-directional arrows show that these four aspects of context can influence each other. The transplant journeys of recipients and donors are depicted as converging in the hierarchical healthcare setting where interprofessional communication, also influenced by context, takes place. The yellow boxes show the primary ethical challenges identified at each level.

Figure F11.1 – Multilevel factors influencing communication and level of ethical practice in Gauteng transplant



11.2. SUMMARY OF MAIN FINDINGS

As the model suggests, the results of my study show that the context in which organ transplant takes place in Gauteng is complex and multifaceted, and that the transplant system in Gauteng is not as straightforward or structured as it is in many other countries. The convergence of these complex systems explains the differences between my research findings and those reported in similar international studies. Depending on this context, communication between transplant professionals and patients varies, and is largely random. This type of communication depends on the particular phase of the transplant process and whether the communication is with donors or recipients. My study found that interprofessional communication is also influenced by context and is both complicated and hierarchical. Indeed, the healthcare hierarchy seems so engrained as to significantly hamper communication, especially that between multi-disciplinary teams of transplant professionals. However, some aspects where good communication was perceived to take place were identified.

Three main, overriding ethical issues present themselves in my data. At the contextual level, ethical issues centre on the concept of distributive justice, where the allocation of resources necessary for transplant and the allocation of donor organs pose particular ethical challenges. At the level of transplant professional – patient communication, factors of autonomy were pervasive, and questions related to informed consent and decision-making, which are constructed around notions of autonomy, arose. Ethically, many practices at this stage are questionable, and there are challenges for patient-centered care. Looking at the issue of interprofessional communication, I would argue that this may be so badly fractured that the best interests of the patient are ethically compromised. Through synthesising my main findings on communication and ethics within the framework of Tronto's ethics of care, I argue that transplant in Gauteng cannot be considered as a caring process or institution.

The complexity of my overall argument surprises me, because when I embarked on this research project, I had a sense of idealism, and I hoped my research would be

able to produce some concrete results which could simplify and improve practice. However, my data set told a different story and did not lend itself to simplistic interpretation or straightforward recommendations. A number of research findings relate to highly complex issues. These included some unpleasant factors - amongst them organ trafficking, strained interprofessional relationships, aggression, inequality and perverse incentives within an environment of contradictions and dichotomies. The findings suggested significant moral distress in a field where medical science often intermingles with personal beliefs and emotion in a way which was seen to affect interaction and communication. I was surprised by the finding that, far from a sense of consolation, one particular donor family felt they had been "cheated" in the transplant process and had not received adequate follow-up.

It became clear that the study was not what I had anticipated and a paradigm shift was required to consider some of the complexities identified. This involved re-evaluating and broadening some research objectives as well as considering the impact of the South African context in detail in order to understand my results. One of the strengths of the qualitative methodology I chose was that it allowed for the emergence of unexpected data (Kitzinger, 2005; Holloway & Wheeler, 2010). My research is unique in that such a large transplant study has not been conducted within such a complex context before.

My results are different from – and seem more complicated than – those reported in a number of other studies which have been referenced throughout this thesis and will be considered in this chapter. At this stage, it is prudent to reflect on why such differences may have occurred. Firstly, it could be due to my use of qualitative methods. These have been shown to produce more complex research findings and to identify contradictions or paradoxes which are often outside the scope of quantitative enquiries. This is because qualitative research lends itself to probing questions and gives an opportunity for a researcher to seek clarification. However, it seems that it is unlikely that my choice of method alone has led to such complex findings as many other qualitative transplant studies have produced more

straightforward results (Kometsi & Louw, 1999; Mbeje; 2013; Rekneke, 2014) than mine did.

Secondly, the complexity of my results could be due to the multipart research context. This may well be a more plausible explanation. My literature review highlighted the diversity of South Africa, and included issues such as distributive justice, population diversity and historical disadvantage, which influence the healthcare sector. My research has shown such factors also influence and shape the context of transplant in Gauteng.

The third factor may be the nature of transplant itself, which is a highly complex health intervention. I argue that combined this complexity, exacerbated by both the convoluted South African health-care and transplant context, and the use of a qualitative methodology best accounts for the nature of my results. It is possible that such complexity would not have been highlighted had I used quantitative methods.

Transplant is unique among health interventions for a number of reasons. Firstly, it involves many individuals all of whom go through the process with different experiences. This may be true for all health interventions. However, my study has demonstrated that it is the polarisation of experiences that makes transplant communication so complicated. For the donor family, it is an experience of grief. For a recipient and family, it is an experience of relief and hope. This polarisation of experiences gives rise to polarised communicative expectations: empathy versus entitlement, time for consideration versus urgency in action. There is also an apparent polarisation of professionals' roles in transplant. Medical professionals seem to be powerful decision-makers, who, under stressful circumstances, argue with each other. Allied professionals seem to be marginalised, to the extent that they are on the receiving end of aggressive behaviour from medical professionals. Secondly, transplant challenges the very nature of healthcare, with the notion of sanctioned harm. Whilst sanctioned harm is the mandate of all surgical procedures, cadaveric transplant is the only one where the end point is necessarily the death of the donor. Even if this sanctioned harm takes place in order to save a

life, it is contrary to the perception of health professions as caring and life-preserving.

11.3. THE TRANSPLANT CONTEXT

The context in which organ transplant in Gauteng takes place seems remarkably complex, as evidenced by my findings related to South Africa's history, the structure of the healthcare system, socio-economic considerations and media reporting of transplant-related material. It is also influenced by personal beliefs about transplant.

11.3.1. Suspicions about biomedicine, sensational media reporting and personal beliefs about transplant in Gauteng

In terms of South African history, suspicions of biomedicine amongst the general public appeared to influence perceptions of organ transplant. Though these suspicions may be historically rooted, my data suggests that they are also affected by a perception that the donor may be killed for his or her organs and by the sensational media reporting of transplant transgressions. It appears that these factors converge as part of the complex transplant context in Gauteng, and filter through to affect quotidian decision-making.

Both the general public and healthcare professionals themselves may feel suspicious of biomedicine. Published studies acknowledge that aspects, such as the personal beliefs of healthcare professionals, do affect transplant because they can impact on decision-making interactions and patient management (Gross et al., 2000; Naude et al., 2002; Pike et al., 1993; Weiland et al., 2013). My data clearly corroborates this, as it reflects a perceived unwillingness to refer potential donors in the hospital setting. My study found that this unwillingness to refer a potential donor may be related to a perception that organ transplant involves killing the donor, a factor which was identified as a barrier to transplant. Such a feeling in the healthcare community could also be exacerbated by the possibility – which also emerged in my research - that the general public may also perceive organ donation as a situation where the donor is to be killed 'for his parts'.

Another factor which adds to suspicions about biomedicine, and further lends complexity to the transplant context, is media reporting of transplant activities. My research suggests that the media may be a double-edged sword in transplant, with the power to positively or negatively shape public opinion about organ donation. My evidence suggests that transplant professionals, while endorsing the media for promoting awareness, may also condone the circulation of damaging transplant information, such as sensational reports on organ trafficking, as in the Netcare St. Augustine's Hospital Case.

In terms of the Netcare Case, transplant professionals were critical of those who had taken part, and felt that their actions had damaged the public image of organ donation, especially when the case was reported in the media. This finding is aligned with research from the UK and Germany (Chouhan & Draper, 2003; Pondrom, 2013) and I argue that it is not surprising, because the unpleasant realities of organ trafficking appeal to worldwide sensitivities about fairness in organ allocation (Neuberger, Adams, MacMaster, Maidment & Speed, 1998) which may come into question when organ trafficking or transplant tourism takes place (Lundin, 2015; Scheper-Hughes, 2014).

By considering the convergence of suspicions of biomedicine and perceptions that transplant may involve killing the donor against a backdrop of socio-historical inequality, and in light of the influence of media reporting of transplant, the complexity of the Gauteng transplant context seems undeniable. All of these contextual factors may need to be accounted for at a procedural level in transplant institutions in order to tailor transplant practice and patient care.

11.3.2. Context, knowledge of transplant and personal beliefs

My study identified a perception amongst participants that there is a lack of knowledge about organ transplant in Gauteng, and I argue that the manner in which transplant information is conveyed to the general public may influence personal beliefs about transplant. This is a vital aspect of the transplant context and the complexity is once again evident here in the role of the media – which influences personal beliefs both through sensational reporting (as discussed in the

previous section) and also through the manner in which information about organ donation is disseminated. My results suggest that two means to disseminate transplant information should be considered. The first is through the mass media, such as magazines and television, and the second is through involving individuals who have been through the transplant process in some way - as educators and advocates.

A lack of knowledge about transplant has been previously identified in South African literature (Bhengu & Uys, 2004; Pike et al., 1993) and the finding that the majority of participants in my study also felt knowledge was lacking suggests that this is a significant barrier to the transplant process. However, two previous South African studies reported that the majority of the sample studied were aware of organ transplant (Buthelezi & Ross, 2011; Etheredge et al., 2013). The reason for differences in awareness reported in my study may be due to differences in study populations. In Etheredge et al. (2013) the urban population may have been better educated, given that there is a higher concentration of education facilities in urban areas. In Buthelezi and Ross (2011) participants were university students amongst whom I attribute a certain level of education.

In South Africa, there is little readily available information about organ donation, and I have previously argued that that which is available in the media, is potentially too artistically complex to provide much useful information (Etheredge et al., 2013). I feel that this is important, because the results of my study suggest that by effectively structuring educational campaigns there may be an opportunity to enhance public awareness which, in turn, could influence personal beliefs about transplant and help to allay suspicions of biomedicine. My findings from this study agree with some international literature suggesting that media interventions should be utilised for information dissemination (Blok, 2006; Chouhan & Draper, 2003; Muller, 2013). However these may also be ineffective if the interventions do not account for the language and literacy levels of many South Africans (Etheredge et al., 2013). Internationally, community-level educational interventions which have little media involvement (Davis & Randhawa, 2004) and have substantial

financial backing, have reported excellent outcomes (Callender & Miles, 2010) and this may be a better solution for South Africa than relying wholly on the media.

My study also found that many transplant professionals felt recipients and living donors are potentially better advocates of organ donation than the media. Although previous studies (Callender & Miles, 2010; Davis & Randhawa, 2004; Etheredge et al., 2013) have argued that the media may have limitations as a means to inform the public about organ donation, my data goes further, and suggests that individuals who have been through the transplant process have an advocacy role to play. It may be possible to account for this difference by noting that South Africa is a complex country with a population from a number of different linguistic, cultural and socio-economic backgrounds (Mesthrie, 2002; STATSSA, 2004; STATSSA, 2012a) and that, in a context where individuals could be suspicious about biomedicine (Boozary et al., 2014; Vaughn, 1991), messages advocating transplant may be better coming from members of a person's own community, with whom they can better identify. Notably, this argument is corroborated by Bhengu and Uys (2004) in their study amongst the isiZulu community of South Africa, which found that the promotion of organ donation through the mass media was considered alienating, and that respected community members might be a more effective mouthpiece. Community members could also include recipient advocates.

My research suggests that considerations of religion, culture and other personal beliefs about organ transplant may influence personal attitudes towards it, and a sustained education campaign, which addresses suspicions and misconceptions, is required to tackle this situation. Although in South African literature cultural preference has often been couched in terms of a facilitator of or barrier to organ donation (Buthelezi & Ross, 2011; Etheredge et al., 2013; Pike et al., 1993) my research data differs in that it found that, whilst overarching personal beliefs about transplant are formed by these factors, some transplant professionals seem sceptical about the role culture plays, likening it to a smokescreen, where cultural beliefs seemed to be invoked as an excuse to avoid more complex aspects of the issue. This finding also hinges on the media and transplant knowledge, with

participants feeling that cultural or religious practices are sometimes used as an excuse to justify the failure to adequately educate the general public. Here again, we see how media, personal beliefs and suspicions about biomedicine are inextricably linked within the complex transplant context.

The reason for my more nuanced finding regarding personal beliefs may be in the use of qualitative methods which allowed me to explore transplant in greater detail than the quantitative studies (Etheredge et al., 2013; Pike et al., 1993; Van den Berg, 2005) were able to do. Furthermore, my research examined these aspects from the perspective of transplant professionals. This had not been done before in South Africa and it has allowed for the ambiguity which transplant professionals feel about religion and culture – based on their experience - to be foregrounded. This finding suggests that we can no longer refer to overarching factors like religion and culture when exploring barriers to and facilitators of transplant in South Africa - sometimes they are and sometimes they are not. In reality, whether something is a barrier to or facilitator of the transplant process seems more a matter of individual preference and of one's role in the process. Potential recipients and their relatives seem more likely to agree with transplant (because they need an organ to survive) than are those who are uninvolved.

11.3.3. Access to, and availability of, transplant services and suspicions about biomedicine

The results of my research suggest that transplant takes place within a healthcare system permeated by inequalities. This further complicates the transplant context because it may lend to an overall suspicion of the biomedical system within which transplant happens. My results suggest a perception that transplant services are primarily available to the wealthy and employed, raising questions about justice, fairness and equality and suggesting that the best interests of those who occupy a position of vulnerability (the unemployed, homeless or those living in rural areas) have not been considered (Calnan & Rowe, 2004). It has been extensively argued that socio-economic organisational structures in healthcare can create a suspicion of biomedicine because of perceptions that medical decisions may be based on

cost, rather than patient best interests (Jacobs, 2005) and because of the fundamental ways in which systems are run and financed (Calnan & Rowe, 2004).

Like previous South African research, my study confirmed discrepancies between the state and private sectors (Coovadia et al., 2009; Hassim at al., 2007; Dhai, 2012) and it showed that state-based transplant services were perceived to be slow and inefficient. The geographical context of transplant in Gauteng, with centres located primarily in urban areas (Davids et al., 2012; Hassim et al., 2007) was found to influence individual chances of receiving a transplant. Furthermore, employment status, and its accompanying access to medical aid, was considered an important factor, as this facilitated access to the private sector where, as my data has suggested, transplant care is superior. However, availability of transplant services in the private sector was also constrained, sometimes by a lack of staff or theatre capacity for transplants. The findings from McIntyre et al. (2009), that over-servicing – with a money-making motive - took place in the private sector, were confirmed in my research. My evidence suggested that a financial motive – such as maintaining potential donors on ventilators in ICU for a daily fee - may prevent both the referral of potential recipients and potential cadaver donors. The types of perverse incentive which impact upon referral decisions – like medical aid reimbursement according to the number of patients under one's care or the number of patients ventilated - is problematic in health institutions as it can compromise patient care - the primary function of medicine (Puttagunta, Caulfield & Griener, 2002) and lead to suspicions about biomedicine.

11.3.4. Context conclusion

My study has shown that the transplant context is shaped by barriers to and occasionally facilitators of transplant which have a bearing on the process and influence decision-making and actions taken at an institutional level. I argue that complexity is created by the interaction of the various aspects of context detailed in Figure F11.1 and discussed in this section, which interact with each other. This complexity seems unique to South African transplant, and I posit that the substantial differences between my findings and similar research from other

settings can be most realistically accounted for by considering current South African conditions. South Africa's recent history is peppered with reports of corruption and scandal, which create distrust and suspicion. There is also growing inequality in the South African population and questions about resource distribution are more frequently asked, often utilising the media as a mouthpiece.

11.4 COMMUNICATION

Transplant communication takes place within both a complex context and a complex system, as the Gauteng transplant system itself is multileveled and non-static. The results of my research have shown that transplant communication occurs across regions and institutions, and that coordination and collaboration between different institutions and teams is essential for good outcomes. Transplant also involves a very large number of people, all of who have differing expectations and roles, and this further adds to the complexity of the system. Within the transplant system, I identified two main categories of transplant communication – the one, communication involving transplant professionals and their patients and the other, interprofessional communication - with each sort facing unique challenges and being influenced by the transplant context. This section will discuss the two types of communication which my research identified.

11.4.1 Transplant professional – patient communication

Within the transplant system, transplant professional – patient communication was found to be largely uncertain, and depended on the stage of transplant within which communication took place and also whether the communication was between transplant professionals and donors (and/or their families) or recipients (and/or their families), as illustrated in the model in Figure F11.1. Pre-consent communication with cadaver donor families, when there was an interest in procuring organs, appeared to be characterised by empathy and good uncertainty management. It took cognisance of the emotional trauma which the family had suffered, and donor families apparently appreciated this. However, post-consent and post-transplant communication with cadaver donor families was more

variable, did not account for uncertainty as effectively and sometimes left families highly dissatisfied. On the other hand, communication with recipients seems to follow the opposite pattern to that with donors. Pre-transplant communication with recipients was seen as challenging because of the intense uncertainty and desperation experienced on the transplant waiting list. However, post-transplant, when there was an acute interest in attaining a successful transplant outcome and ensuring graft survival as far as possible, communication seemed adequate, and effective to the extent that a beneficial relationship of trust developed between recipient and transplant team.

The variations in transplant professional – patient communication across the phases of transplant and depending on the role-players can be explained in a number of ways. It could be argued that at the critical points - without which transplant could not occur, such as procuring cadaver organs and recipient follow-up - transplant professionals are more experienced in communication and better aware of the challenges and uncertainties inherent thereto. At other phases, especially post-transplant for cadaver donor families, professionals may not be as well-versed – unless of course they themselves have made a donation decision at some stage. Another, though more cynical explanation, could be that communication is effective at those points where the patient and/or family is a means to an end in the transplant process, which cannot take place without donors and cannot be considered a success without rigorous recipient follow-up. My research results could be read in such a way as to suggest that when a role-player is not instrumental to the *success of transplant*, for instance whilst waiting for an organ or when consent to donate the organs of a deceased loved-one has already been given, communication may be neglected and uncertainty management can be inadequate.

Communication with potential recipients in the pre-transplant phase appeared to pose particular challenges. Transplant professionals – especially coordinators who participated in my research – felt that the stress and desperation of waiting for an organ shaped communicative interactions with potential recipients. The evidence presented to this end suggests that these interactions were sometimes unpleasant,

and could involve accusations of failure to do one's job and threats to report grievances to the press.

This finding seems to differ in detail to the sparse literature published on the topic. In a study based in the USA, Hashmi and Moss (2008) note that dialysis patients can be difficult or disruptive; but the dialysis patients in their study sample were not waiting for an organ. In fact, the study recommends referring the patient for renal transplant as a possible means of addressing disruptive behaviour. Similarly, an Australian study (Burns & Smyth, 2011) found that dialysis patients can be aggressive, but did not analyse their findings to establish whether this behaviour was related to potential recipient status. A reason why aggressive behaviour amongst potential transplant recipients has been identified in my research, and not in other studies, could be differences in the study settings. Neither the USA nor Australia experience organ shortages on the same acute level South Africa does. Thus, the chances of receiving an organ in either of these countries are better, and the sense of desperation, uncertainty and frustrated entitlement may not be as intense as it is in South Africa.

These findings link back to the transplant context. Suspicions of biomedicine and the sometimes sensational reporting of transplant activities in the media, may exacerbate the notion that transplant professionals are not acting in the best interests of their patients – as in the case of organ trafficking – and that failure to procure organs is symptomatic of a health system where professionals are not doing their jobs properly. There are also links to the economic context, as organ themselves are scarce resources which need to be shared equally and fairly. The sense of entitlement and desperation exhibited by potential recipients is at odds with the context of finite resources within which transplant takes place and, as my results show, is relevant to both the state and private sectors.

11.4.2. Uncertainty management and communication

In those instances where communication required particular attention, such as when speaking to a grieving potential donor family or maintaining communications with recipients post-transplant, my evidence suggests that interactions were

effective and uncertainty was well-managed. The finding that donor families appreciated displays of empathy, which have also been identified in the transplant literature (Birkeland et al., 1997; Reyneke, 2014), backs this up. Similarly, my finding that through ongoing communication a relationship of trust between the transplant team and the recipient develops post-transplant, has also been identified (Gremigni et al., 2007; Lurie et al., 2000). The influence of long-term contact between the management team and the recipient has been found to affect the recipient outcome and apparently the morale of healthcare professionals (Johnson et al.,1999; Raiz et al., 1999). Furthermore Gremigni et al. (2007) and Lurie et al. (2000) confirm a positive association between a trust relationship and adherence. This relationship may also have implications for chronic uncertainty post-transplant, where a recipient is unsure about graft survival and relationships with his support network (Martin et al., 2010). Constant communication and attention within a framework of long-term supportive management may assist in managing this uncertainty effectively.

However, my evidence suggests that transplant professional–patient communication was not effective across the entire transplant process. My study identified the main stages of deficient communication as post-consent and post-transplant for cadaver donor families. The latter case (post-transplant for donor families) seems particularly important because, by contrasting the stories of the two families, I have shown how communication, or lack thereof, affects the overall transplant experience. This finding takes on further import when considered in the light of the fact that communication with donor families post-transplant was not even mentioned by any of the transplant professionals or transplant coordinators in my study.

My thesis made use of uncertainty management theory (UMT) in order to evaluate communications between transplant professionals, potential recipients and their families, as well as with donor families, across the transplant process. Many of my findings regarding UMT were similar to those found in Martin et al., (2010). Transplant professionals and coordinators expressed an understanding of the medical uncertainty a potential recipient may experience while waiting for an

organ, identified by Martin et al. (2010), emphasising their desperation and frustration. These medical uncertainties were also evident in the pre-surgical phase where fear about the procedure escalated and careful uncertainty management was required.

However, the inclusion of donor families has enabled me to extend the findings of Martin et al. (2010) by considering uncertainties for donor families throughout the transplant process. The results have shown that if donor families do not receive adequate information about organ recipients and which organs were harvested, and if they do not receive a gesture of thanks, uncertainty can become chronic and families may feel they have not obtained closure. An implication of this finding is the sense of uncertainty expressed by a participant in Martin et al. (2010) who was unsure about writing to the donor family and thanking them. However, this uncertainty was relieved when the family welcomed communication. In my research, donor families said that they would welcome communication from recipients. Because addressing the post-transplant phase for families seems to be a necessary ingredient of a caring transplant institution it follows that recipients themselves should make more effort in thanking their donor families.

11.5. INTERPROFESSIONAL COMMUNICATION

My results suggest that interprofessional communication in Gauteng transplant is complicated and hierarchical, and I argue that this hierarchy appears so deeply ingrained that it hinders their communication. However, I did identify some instances where communication appeared to be effective.

11.5.1. The healthcare hierarchy

This hierarchy affected the nature of communication significantly: medical professionals, at the top of the hierarchy, were considered to communicate inadequately, whilst allied professionals, at the bottom of the hierarchy, were not included in communication and did not appear to be actively communicating with those at the top to any substantive extent. Allied professionals often saw their role as one of following orders or following protocols, which suggests little room for professional autonomy (Varjus, Leino-Kilpi, Suominen, 2011) and initiative. My

study found evidence of aggressive behaviour directed towards transplant professionals lower down the hierarchy and confirmed Longman's (2013) findings that hierarchy may shape health communication.

Lupton's (2003) writings about the concept of hierarchy in health align strongly with my results. Lupton (2003) argues that the healthcare hierarchy is constructed according to position in society. Medical professionals were seen as 'heroes' and trust of medical professionals in my study seems evident in patient requests for a medical professional, rather than an allied professional, to speak to. At the same time, it is apparent that allied professionals felt their care was not always accepted or valued by patients, a finding similar to Van Waltsleven's (2014). This finding may not be surprising if it is the case that allied professionals do not possess all relevant information about the patient's management plan, something which my results suggest happens regularly. Further evidence of a greater trust of medical professionals in the hierarchy can be inferred when transplant coordinators, who were found to be relatively empowered compared to their allied counterparts, may request assistance from a White male doctor in a difficult case. This aligns with trends in South African society, where White males seem to be perceived as being more powerful (Baldwin-Ragavan et al., 1999). Thus, it appears that healthcare professionals themselves contribute to the construction of the hierarchy in which they work, by identifying a societally powerful person and transposing them into a position of power in the transplant context. However, it is also the case that hierarchy is inherent in healthcare settings.

Jewkes et al. (1998) found that an established health hierarchy in the Western Cape Province of South Africa, which remained unacknowledged, resulted in nurses abusing patients. The hierarchy identified in my research took a similar form, though it was primarily related to relationships between transplant professionals. The reason why a hierarchy between patients and professionals has not been identified in my research may be because a large patient sample was not utilised. However, in the few cases where accounts of patient behaviour have been forthcoming – for instance regarding the demanding potential recipient – my study

suggests a hierarchy where the patient is situated above the allied health professional.

This is evidenced by patients openly reprimanding allied professionals for failure to do their jobs and threatening to report them to their superiors or to the press. The fact that patients in my research appear much more empowered than those in Jewkes et al. (1998) may be because transplant is an expensive, tertiary intervention and, unlike the antenatal clinic, it is only accessible to a very few people. Because these people are typically in the private sector, and enjoy the privileges of wealth and employment, it is likely that potential transplant recipients are more comfortable asserting themselves than the patients surveyed in Jewkes et al. (1998).

11.5.1.1. Transplant coordinators in the hierarchy

Whilst my research suggested that transplant patients are empowered in the hierarchy, it also identified a feature of the hierarchy which may be unique to Gauteng transplant. This was the finding that transplant coordinators are actually in the middle of the hierarchy, with coordinators being above the level of allied health professionals. This makes sense, because coordinators are in a managerial role. This is especially evident in the way which coordinators may take control of difficult situations and do appear to challenge medical professionals and other coordinators if they see this as necessary. Lupton (2003) argued that the healthcare hierarchy is a convergence of asymmetries in status, gender and the types of tasks performed. It may be that the particular skills of a transplant coordinator (in Gauteng, all coordinators are female) and the types of complex tasks they perform, make their role seem elevated above other allied transplant professionals. However, the results of my research suggest that this role is not always well-defined, and that miscommunications can occur.

Naude et al. (2002) reported that misunderstandings in transplant may be related to poorly-defined roles and scopes of practice. This finding, viewed in tandem with my research results, suggests that it is possible that a defined scope of practice for coordinators could mitigate the sense of “holy nurses” who are superior to other

allied professionals. It may also help to improve continuity of care by reducing the frequency of misunderstandings which happen when roles are not clearly defined, for instance, deciding who is responsible for contacting potential recipients to present for transplant.

My study confirms a number of results in Naude et al. (2002), but because of methodological differences, I was able to examine the role of transplant professionals throughout the transplant process in more detail than Naude et al. (2002) were able to; and by doing so, I identified other aspects of transplant communication which had not previously been articulated in South African transplant literature. These included the finding that multi-disciplinary team interaction was a challenge in transplant and that inter-service challenges (Lingard et al., 2012) are prevalent. My research also identified an aversion to organ harvesting amongst allied professionals.

11.5.1.2. Professional autonomy within the hierarchy

My results show that in the healthcare hierarchy medical professionals are seen as giving orders and allied professionals following through on these, apparently without questioning their subordinate position or requesting more information. This suggests a lack of professional autonomy for allied transplant professionals within the Gauteng healthcare hierarchy. These findings differ from Russell and van Gelder's (2008) international study which examined job satisfaction specifically amongst transplant nurses, half of whom were coordinators. The 2008 study reported that transplant nurses were overall highly satisfied with their jobs and expressed an agreeable level of autonomy and empowerment in the workplace (2008). Transplant nursing was seen as an exciting opportunity for teamwork and collaboration which was also well remunerated. My findings also differ from Rabøl et al. (2012, p. 133) who found a "flat hierarchy" between medical and allied professionals.

The context of transplant practice in Gauteng may explain why Gauteng-based allied transplant professionals did not express a similar level of autonomy to their international counterparts. The participants in Rabøl et al.'s (2012) study were

Danish health professionals. Participants for Russell and van Gelder's (2008) study were recruited from the International Transplant Nurses Society (2013) database which runs chapters primarily for transplant nurses in developed nations like the USA, Canada, Italy, the UK, Australia, Sweden and the Netherlands. The only member country which could be considered as 'developing' (and thus comparable to South Africa), is Turkey. The context of transplant in the majority of these countries differs substantially from that found in South Africa as a result of the latter's unique socio-political characteristics. These other countries appear to have a greater level of gender, racial and socio-economic equality than South Africa (though this is by no means always the case) which may provide a framework in which to understand differences in job satisfaction and professional autonomy.

Another indicator of hierarchy and limited allied professional autonomy which emerges from my results is that allied professionals felt protocols were helpful, whereas medical professionals did not appear to find them effective for. This finding suggests that participants at the bottom of the hierarchy, who are perceived to have less professional autonomy (Felblinger, 2008) and are thought of as more flexible and willing to compromise (Paris et al., 1995) felt satisfied working within the confines of a protocol. Once again, this may indicate contextualisation at the bottom of the hierarchy, where one follows instructions and obeys orders. However, transplant protocols did not appear as effective when directed towards medical professionals, most notably harvesting surgeons. This may be due to a hierarchical challenge as noted by Katz (2006), where surgeons who are used to being in control of complex medical situations are required to relinquish control to others, with equal, but different expertise. This argument is perhaps backed up by reports of physical interactions, such as pushing other medical professionals out of the way during a harvest.

11.5.2. Teamwork and interprofessional interaction

My analysis suggested that individual Gauteng transplant teams are cohesive, and display good collective mood and collective efficacy. However, I identified substantial challenges to transplant communication when it came to multi-

disciplinary team interaction, which is pivotal for successful transplant to take place. Here results agree with many reported in Lingard et al. (2012).

11.5.2.1. Core team interaction

In light of Kozlowski and Bell's (2001) framework for evaluating individual teams, my data suggests strong cohesion, good collective mood and a perception of collective efficacy. This is framed by a context of mutual support, understanding and shared objectives. It may also be helpful that these teams work within institutional boundaries and in close physical proximity (Lingard et al., 2012). Temporal dynamics (Kozlowski & Bell, 2001) are also significant. Participants noted that their teams had been working together over a long period of time and had become familiar with each other, which may prove to facilitate transplant practices in a timely manner. Amongst these individual teams, there is a suggestion of trust and familiarity, which was identified as an important element of teamwork in Treadwell et al. (2014).

The main factor limiting efficacy of core teams appeared to be the temporal dynamic, where new or irregular team members had not been assimilated into the team culture, which could give rise to an element of distrust or uncertainty (Porto & Lauve, 2006; Treadwell et al., 2014). My data suggests that, without prior knowledge of a newcomer's competence, participants were unwilling to put themselves in a position of vulnerability, an essential feature of a trusting relationship (Frowe, 2005), because there was no previous experience of the individual upon which to make an appraisal (White, Cohrs & Göritz, 2011). Given the context of human resource constraints, Gauteng health institutions are often obliged to employ short-term staff which may have negative implications for cohesion in these individual teams. In their 2006 study, Porto and Lauve noted that short-term staffing solutions undermine the cohesiveness of a team and can result in frustrations.

11.5.2.2. Multi-team interaction

In my research, interservice challenges relating to timetables and physical proximity (Lingard et al., 2012) were seen primarily when professionals were too

busy to communicate, were late for procedures or where there was a lack of continuity of care, especially across institutions. This could illustrate the impact that physical distance has on teamwork. More notably, however, my research identified Lingard et al.'s (2012) second interservice challenge, namely that teams were not working toward the same goal - especially during the harvesting process. This was seen to create friction and conflict in the surgical phases.

In transplant it is essential that teams interact effectively in order to prevent delays which could compromise organ quality. This requires the participation of a number of different teams with differing skill sets. Multi-level influences (Kozlowski & Bell, 2001) seem evident in my data, conforming to institutional and healthcare hierarchies. My findings are similar to those in Lingard et al. (2012) where inter-service challenges proved complicated. Because transplant is often unpredictable, "knotworking" (Lingard et al., 2012, p. 872), rapid negotiating and trouble-shooting to solve problems in real-time, may be helpful in these situations to improve communication.

Similarities between Lingard et al. (2012) and my findings are evident, with both studies making use of a similar population and exploring the views of medical and allied professionals as well as transplant coordinators. However, Lingard's (2012) study only took place across one transplant hospital whereas mine took place across several transplant settings in order to give an overview of the transplant process in Gauteng. These multiple settings may add to the complexity of interservice challenges in Gauteng, thus allowing me to explore multi-team interactions in more depth than the study by Lingard et al. (2012) did.

11.6. ETHICS

11.6.1. Distributive justice

11.6.1.1. Healthcare and transplant resources

The Gauteng transplant context, as one permeated by inequalities in access to both health and transplant services, does not appear to have met the challenge of distributive justice. This is compounded by discrepancies between access to care in

the state and private sectors which exacerbate the problem. The concept of distributive justice speaks to a fair and equal distribution of resources in a setting where individuals are treated as equals (Lamont & Favour, 2013). In South Africa there has been some movement towards promoting distributive justice in health care. As discussed in Section 1.4.2, resource allocation seems to be directed by policies which favour channelling funds into primary, preventative healthcare interventions with perceived extensive community benefits (Kautzkyi & Tollman, 2008; Peterson, 2000) .

At face value, such an intervention may be in the realm of distributive justice because it claims to treat individuals as equals. However when it comes to transplant, my results suggests that distributive justice is not realised through such policies. Firstly, the preventative healthcare policy appears to be a barrier to transplant for state patients, as the services required are diverted from curative interventions. Secondly, my data suggests that access to transplant seems much easier for wealthy or employed patients with private medical insurance. The private sector functions relatively independently of the government and has circumvented resource constraints to some extent. This may change in South Africa with the initiation of the NHI. Although NHI policy documents do not mention transplant services, the notion of tertiary care is considered. Transplant would fall into this category.

It appears that for disadvantaged individuals, the very contextual factors that render them disadvantaged, such as unemployment and geographical location, are also those which prevent their access to transplant. For the wealthy, contextual factors facilitate access to transplant. I cannot easily escape the irony of this finding, especially given the drive in South African for an equal society where distributive justice is paramount.

11.6.1.2. Donor organs

My study found that people who may be unwilling to donate organs nevertheless seem willing to receive them, and in this way my thesis takes the notion of distributive justice a step further, in that it does not only deal with scarce

healthcare resources, but scarce donor organs as well. My data has shown that once they are listed for transplant, potential recipients may make specific demands for their transplant, even expressing a sense of entitlement to it. At this point, where recipients are desperate for a donor organ, another factor of distributive justice and fairness is highlighted: who should receive organs, and how do we decide?

The title of my thesis is relevant here because it speaks to the sense of expectation and an entitlement to be treated in a just and fair manner when donor organs are allocated. Thus, the 'sister' could be a family or community member who is expected to donate. The potential recipient invokes a relationship of close kin and sisterhood in order to ground the expectation. The 'sister' could also be the transplant coordinator who is expected to fulfil the mandate of securing a donor. No matter who the 'sister' is, it seems that she may be in an uncomfortable position, pressurised by an expectant potential recipient to act in a manner which secures an organ in a system where organs are notoriously scarce, and in which the demand of distributive justice to procure an organ for every individual who requires one is not possible.

In their qualitative study with isiZulu-speaking South Africans, Bhengu and Uys (2004) similarly observed a willingness to receive an organ and an unwillingness to consider donation. In a quantitative, South African population-based study of which I was an author, 77% of respondents stated that they would willingly accept a transplant. Only 67% were willing to consider donating the organs of an eligible loved one (Etheredge et al., 2013). Although these papers are consistent with my findings, it is important to acknowledge that these sentiments were expressed by healthy individuals. Many had not had first-hand experience of organ donation and none at the time required a transplant.

At an international level, Sanner (2001) reported similar findings in a Swedish study. Willingness to receive an organ, but not to consider donation, was identified as a major theme in the analysis. It was noted that at the point where one needs a transplant, desperation to survive overtakes all other considerations. However, the

survival instinct is also related to an anxiety about death, which rendered Swedish participants unwilling to consider donation. The Swedish participants acknowledged that there was an element of hypocrisy in their preferences.

At the level of transplant professional–patient communication, the main ethical issues I identified were related to decision-making. This has to take into account family structure and family autonomy, which was sometimes relegated when families were not given sufficient information to make a donation decision. In the transplant literature a number of strategies have been advanced to mitigate some of these factors, and they are explored in this section as they are important for understanding the ethical implications of transplant professional–patient communication and making realistic recommendations for South Africa.

11.6.2.1. Autonomy and informed consent

My study found that potential cadaver donor families were not always aware of the seriousness of the condition of a loved one, were not always well-informed about the potential for organ donation and were not always given the choice to donate, particularly if the personal beliefs of staff in referring units were unfavourable. This has implications for autonomy, as it removes the bioethical imperative to be familiarised with all the necessary information and then make a reasoned decision in line with one's overall lifeworld (Beauchamp and Childress, 2001; Gillon, 2003). A lack of decisional autonomy for potential cadaver donor families does not seem unique to Gauteng, as Ballieu (1999) similarly argued that families are not receiving sufficient information to make a decision about organ donation, and that they are not always given the choice to donate. In order to mitigate some of these ethical complexities, published studies and reports indicate that in several countries there is a requirement for mandatory end-of-life decision-making (Centre for Clinical Practice at the National Institute for Health and Care Excellence (NICE) (UK), 2011; Organ Donation Task Force, 2008). Such measures could be seen as promoting autonomy if they include a conversation where a family's expectations are realistically managed and organ donation is offered as an option.

Because my results suggest that potential cadaver donor families in the Gauteng setting are not always given sufficient information to make an organ donation decision, it is important to also consider the implications for informed consent.

In South Africa, at the point where a family is approached to consider donation, the loved one has generally been certified as brain-dead (or else is just about to be) , and is being maintained on mechanical life support. The family is faced with a medical decision: When to turn off life support? The legal requirements of informed consent stipulate that a decision-maker should be familiarised with all the medical management alternatives available in the situation and then decide between them (National Health Act No. 61 of 2003, Chapter 2). My results suggest that the option of organ donation is not often part of the perceived management package, and thus families are not made aware of it. This has implications for informed consent. In these cases an argument could be made for organ donation to be included as a possibility amongst the decisions facing the family. Once brain-dead, no management decision can change the mortality outcome. Rather, organ donation could be presented either as an opportunity for 'doing good' or as a way of creating some meaning from the experience of losing a loved one.

Given that donation is a viable alternative in the case of brain-death, practitioners should offer it to families as part of their medical management. Omission of this option may constitute a failure to fulfil the requirements of informed consent – where a decision-maker ought to be familiarised with all the options available and not just those which a healthcare professional has deemed appropriate to share, based on his or her own personal beliefs or stereotyped perceptions.

11.6.2.2. Family decision-making

The results of my research have implications for decision-making in transplant, as they highlight the importance of shared family decision-making This finding complicates the ethical issues of autonomy and informed consent discussed in the previous section as they add another layer of complexity which needs to be considered when making recommendations to improve transplant.

My research suggests that a patriarchal family structure may be important in transplant decision-making and that a possible barrier to organ donation in Gauteng is being unable to contact a family's male elder. This finding aligned with other transplant literature which showed that patriarchal family structure was an important consideration (Green, 2000; Bhengu & Uys, 2004). However, in her interviews with families, Reyneke (2014) found that most families had a 'key decision maker' who would ultimately make a decision about organ donation, and who was not necessarily a patriarchal male head of the family. It is not easy to account for the difference in findings here, however it is important to note that Reyneke's (2014) study sampled families themselves, whereas in my study it was transplant professionals who commented on family structure. This may suggest that transplant coordinators themselves do not appreciate the subtle nuances of family structure, and may assume that the emergence of a key decision maker is automatically a patriarchal process. My research, along with Reyneke (2014) and Kometsi and Louw (1999) highlighted the importance of the family in a donation decision, while Labuschagne (2013) does not appear to have identified it. This may be due to a difference in methods, with the first three studies making use of empirical methods and considering actual practices, as opposed to Labuschagne's (2013) desktop analysis, based on legal and ethical principles, which do not necessarily account for practices as they actually happen in referring hospitals.

11.6.3. Best interests of the patient

Communication failures, poor continuity of care, confusion about roles and responsibilities and a dislike of organ harvesting converge in such a manner as to question whether Gauteng transplant satisfactorily accounts for the best interests of patients through the transplant process.

11.6.3.1. Best interests, continuity of care and moral distress

Continuity of care across the transplant process was found to be variable, with substantial gaps in communication and numerous instances where transplant professionals were not apprised of all the necessary information. In order to act in the best interests of a patient, it is important that health professionals have all the

necessary information communicated to them (Reach, 2014), but in Gauteng transplant this information was not always forthcoming. This resulted in an inability to act in the best interests of the patient (a moral imperative) and hence may have led to the feelings of moral distress which my study identified. The healthcare hierarchy appeared to manifest itself strongly in one-on-one or small group interprofessional communication, where my data suggested that allied staff were often shut out of the communication process, further creating an atmosphere of distrust and moral distress, where sufficient information to act in a patient's best interests had not been provided.

The finding of a lack of continuity of care in Gauteng which prevents transplant professionals from acting in the best interests of patients and leads to moral distress is an important one, as literature suggests that such communication failures are one of the most significant risks to patients in the healthcare setting (Sutcliffe, Lewton & Rosenthal, 2004). The main reasons identified for communication failure in the literature are the inherent complexity of healthcare interventions, as well as human limitations, such as the need to sleep and the limits of memory (Caldwell, 2005; Leonard, Graham & Bonacum, 2004).

In their 2009 study, Steinberger et al. aimed to identify those points in the transplant process where continuity of care was most likely to break down. Their study was based in the USA and hence many of the aspects of communication breakdown related to the UNOS transplant system, which is very different to the organ transplant systems in Gauteng. However, some of the points where continuity of care broke down are similar across contexts. These include communication between the donor hospital and the transplant centre and aspects of coordinator communication where essential information about the donor is not passed on timeously. Leonard et al. (2004) recommend that standardised computer protocols which facilitate complex clinical processes are effective tools in minimising communication errors.

A Canadian study explored healthcare professional communication in general medical wards through ethnography, participant shadowing and interview interactions (Zwarenstein, 2013). The study described different communication

styles amongst the role-players, which reflect the findings reported in my thesis, and may account for some of the gaps which my research identified. Medical professionals generally communicated in the context of structured ward rounds. The nature of this communication was abrupt and primarily consisted of requests for information and the issuing of orders for patient care. In those cases where an allied professional did make an observation, this was often overlooked. Furthermore, allied professionals were seldom asked about their experiences of managing particular patients, and medical professionals rarely communicated with anyone on a one-on-one basis.

11.6.3.2. Best interests and dislike of organ harvesting

Allied professionals appeared averse to being involved in an integral aspect of organ transplant, namely harvesting. They cited issues with the process – such as a feeling that the donor "is being killed" – as a barrier to transplant. Ethically, acting in the best interests of the patient, including the cadaver organ donor - who is still a patient - sometimes requires that healthcare professionals participate in activities which make them feel uncomfortable. In the case of transplant, an unwillingness to participate in harvesting may compromise both the best interests of the donor (who although deceased must still be treated respectfully), and those of awaiting recipients if such actions cause a delay. However, this must also be tempered with the ethical mandate of conscientious objection (Wicclair, 2014) which is the right of all health professionals to refuse to participate in activities which conflict with the dictates of their consciences, within reason. Because a dislike of harvesting may affect the best interests of the patient, it is important to unpack the possible reasons for the objection.

In terms of the organ harvest, participants seemed to be functioning within the conflicting paradigms of reducing morbidity and mortality and participating in transplant, which requires an opposite outcome - the death of the donor. This is a factor likely to lead to moral distress (Austin, 2012). It appeared that allied healthcare professionals felt the morally correct action was to preserve life; however an obligation to assist in harvesting prevented them from acting in a

manner which they deemed to be in the best interests of the patient. This may be particularly challenging in light of perceptions of animal killing and the notion of vultures, which are not unfamiliar in transplant, as Wang and Lin's (2009) study suggests. Furthermore, aspects such as the stress of travelling to unfamiliar locations, collaborating with numerous harvesting teams and managing the expectations of colleagues, created a complex situation where transplant professionals sometimes experienced personal and professional conflict. This has been found to influence attitudes towards organ harvesting (Lloyd-Jones, 1996; Regehr et al., 2004). Naude et al. (2002) identified a conflict between the goals of healthcare and those of transplant in their South African study. This finding is corroborated by my data. However, my data relate specifically to the harvesting process whereas Naude et al. (2002) were concerned with the donor maintenance phase. The experiences of allied healthcare professionals who participate in harvesting have not been explored in detail in South Africa, though they seem to be similar to those found internationally.

It is possible that dislike of organ harvesting could be informed by the contextual finding that a donor was felt to have been killed during organ transplant, because the images involved are similar – for instance killing, leaving empty and the notion of vultures and murderers. All of these images have unpleasant connotations, and can arouse a sense of suspicion and distrust which is also perceived to manifest itself in the general public. The dislike of involvement in organ harvesting may also have links to distrust and suspicions about biomedicine. For instance, the complicated relationship between organ donation and criminality appears in South African studies by Reyneke (2014) and Kometsi and Louw (1999), both of which found that if a potential donor had died as the result of a criminal act then families were less willing to consent to donation. The findings of my study differ because they identify situations where allied professionals link the concept of removing organs to an act of criminality itself. However the fact that criminality is common across the three studies suggests it has an important influence on the transplant context.

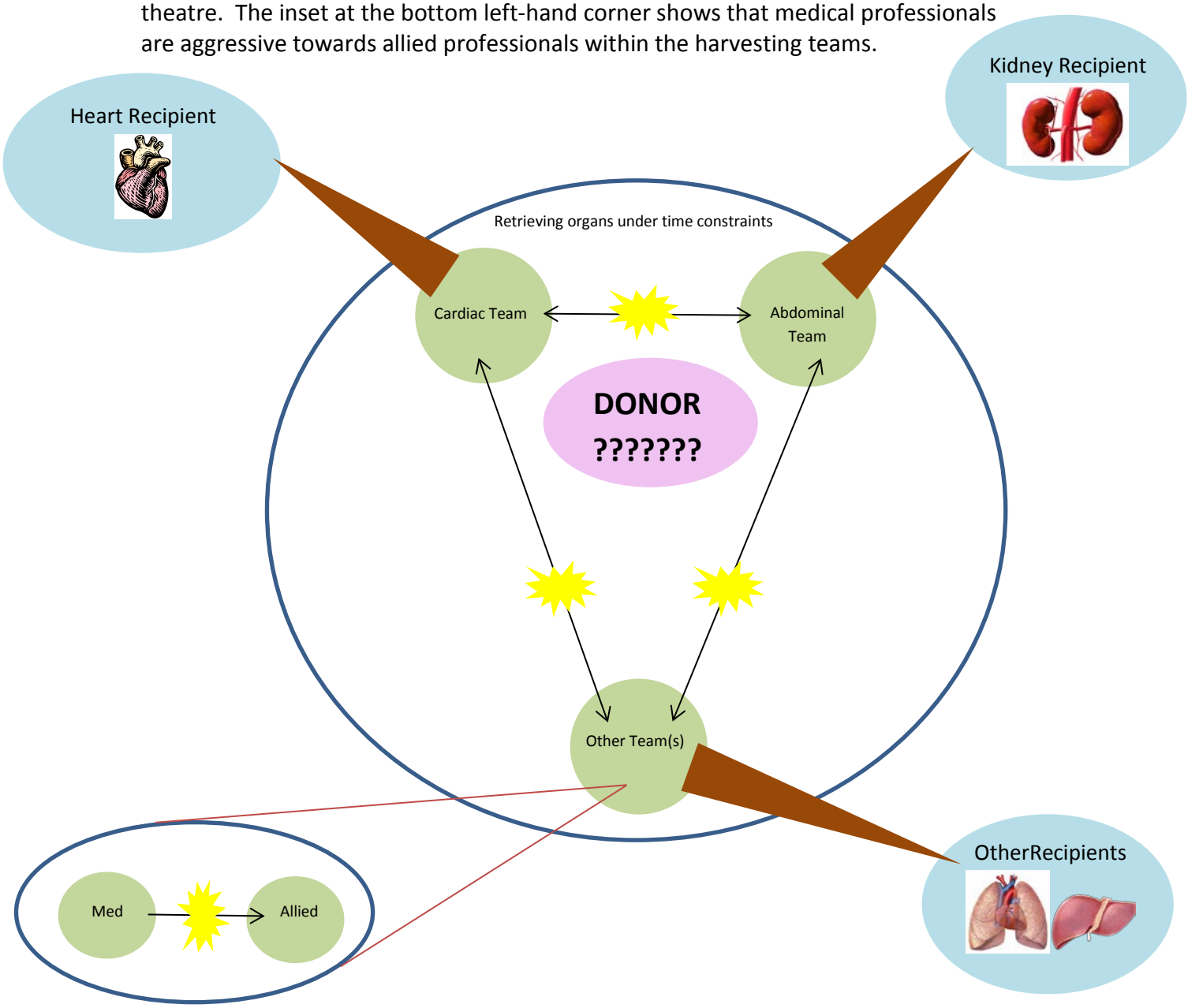
My findings differed from some other research studies. Gross et al. (2000) reported that Swiss transplant professionals felt that the experience of an organ extraction would not influence their beliefs or feelings about transplant. There are a number of reasons why attitudes may be different in the Swiss context. Firstly, transplant in Switzerland is better regulated than in South Africa, with Swisstransplant as a central authority (Swisstransplant, 2014a). Furthermore, Switzerland has a donor rate of 12.3 per million population per year (Spaight, Weiss, Keel & Immer, 2013) whilst this figure is much lower in South Africa. This may reflect a more positive attitude towards transplant in Switzerland and in turn may suggest that healthcare professionals in Switzerland are more accustomed to harvesting than their South African counterparts. Finally, Switzerland makes use of an "extended consent solution" (Swisstransplant, 2014b) which allows that an individual's donation preferences as stated before death, are final, and will be adhered to; this removes the factor of next-of-kin decision-making which has been seen to influence transplant in South Africa.

11.6.3.3. Best interests and organ harvesting in theatre

Synthesis of my results regarding dislike of harvesting, aggressive behaviour and strained relationships in theatre suggests that the best interests of the donor at the time of harvest may not be a foremost consideration. My data suggests that conflict and aggression in the harvesting theatre were related to the speed necessary when procuring organs for potential recipients. There were arguments about which organ was the most *important* and the ways in which the performance of one team may have implications for *the organ* which was to be harvested by another team for a different *recipient*. The donor was not referred to in these interactions and it is unclear who is considering the best interests of the donor at these times. This is illustrated by Figure 11.2, below.

Figure F11.2: Aggressive behaviour, time constraints and organ harvesting

The figure below demonstrates the nature of transplant communication during harvesting. For the sake of simplicity, two teams are diagrammed. One is concerned with harvesting the heart, the other with harvesting kidneys. However, there may be many more teams involved than those depicted here and communication would follow the same pattern. The recipients depicted at the top of the diagram are those whom the organs are intended for. The objective of each team is to procure the organs for the recipient as quickly as possible. The figure illustrates conflicting objectives which have been identified as hindering or shaping communication during the harvesting process. Each surgical team can be seen to have its own recipient in mind, and it is unclear whether anyone is considering the donor (hence the question-marks). Considering the donor is important in light of findings about a perception that the donor is being killed. This type of concern seems to suggest that the utmost care must be taken to consider the dignity of the donor and prevent any perception of killing or scavenging. The thin black arrows with yellow flashes indicate aggression between different harvesting teams in theatre. The inset at the bottom left-hand corner shows that medical professionals are aggressive towards allied professionals within the harvesting teams.



As Figure 11.2 shows, each harvesting team seems to have their own purpose - harvesting organs *for their particular recipient*. These teams clash, because all have a different purpose of care (recipient) in mind. The fact that the teams do not come together and agree on the purpose of care seems to compromise care because it causes aggression and hence produces an environment conducive to conflict, where the patient on the table (the donor) seems to become a resource for organs rather than being in need of 'care'.

11.7. BARRIERS TO AND FACILITATORS OF TRANSPLANT IN GAUTENG

Throughout this thesis I have highlighted and explained barriers to and facilitators of transplant in Gauteng. As discussed in Section 1.7, a phenomenon is considered a facilitator of transplant if it appears to positively affect the transplant process. Barriers to transplant are identified as those aspects which appear to hinder the transplant process, and are considered the opposite of facilitators in their consequences. Table T10.8 summarises the barriers to and facilitators of transplant in Gauteng which I have identified.

Table T11.3: Facilitators of and barriers to transplant in Gauteng

This table summarises facilitators of and barriers to transplant which have been discussed throughout this thesis. This table should be seen as a summary, as reiterating findings in detail here seems repetitive. However, the section in which a facilitator of or barrier to transplant was discussed is indicated.

Facilitator of transplant	Section #	Barrier to transplant	Section #
Awareness of donation preferences of a loved one can assist a potential donor family in decision-making.	9.5	Lack of transplant awareness in the general public	8.5
Empathetic approach by coordinators to potential donor families	9.6	Reluctance to divulge poor diagnoses of a loved one to their family	9.5.2.1
Organisational routine for recipient families.	9.3.3	Potential donor families not always given donation decisions	9.5.1.3
Communication with recipient and recipient families post-transplant.	9.8	Health staff uncomfortable discussing end-of-life / organ donation with donor family.	9.5.2.1
		Logistical difficulty contacting elder decision-makers for cadaver donation.	9.6.2
		Communication with donor family post-consent not always appropriate.	9.6.3
		Donor family follow-up not always appropriate.	9.10
Effective core teams in transplant[34]	10.3.1	New / unfamiliar team members can affect core team efficacy.	10.3.1
		Interprofessional communication breakdowns under time pressure.	10.4.2
		Interservice challenges.	10.3.2. &10.4.2
		Aggressive behaviour and lack of professional respect.	10.4
		Health hierarchy can negatively affect communication.	10.2
		Discomfort about organ harvesting	10.5
		Ill-defined scope of practice for coordinators.	
		Lack of continuity of care	10.6
		One-on-one and ward round communication	10.7

[34] I have put this facilitator of transplant lower down the table so it sits with a corresponding barrier to transplant.

11.8. IMPLICATIONS FOR THEORY - THE ETHICS OF CARE

11.8.1. Caring institutions – power, particularity and purpose

My study showed that a number of factors converge to create a particular context in which transplant care takes place in Gauteng. This context –formed in part by universal factors such as cultural and religious beliefs – is essential for understanding caring, because it influences institutional organisation, resource availability, transplant availability and access to transplant facilities. Findings about the larger context which shapes Gauteng transplant mirror factors which create the South African context as a whole.

Joan Tronto (2012) argued that a caring institution must acknowledge particularity, power and purpose in caring relations. Without explicit attention to these three details, Tronto (2012) argued, care as a moral basis in institutions would not be realised because it would remain the private realm of those who are subordinate in society (Tronto, 1987). By forcing an acknowledgement of care through emphasising particularity, power and purpose, Tronto (2012) hopes that caring roles will be brought to the fore and the ethics of care recognised as an alternative form of morality.

11.8.1.1. Power in Gauteng transplant

My finding of better resources for transplant in the private sector suggests that transplant care is more accessible to the powerful and wealthy who can afford management in this sector. Hence, transplant care becomes a commodity, and this is a sign of an institution that is not caring well (Tronto, 2010). Similarly, the finding of a lack of resources available to provide transplant care in the state sector suggests that the mandate of good caring in this setting is not being met (Tronto, 1993).

Power (Tronto, 2010) was identified at a contextual level where employment status facilitated access to the better-resourced private sector. Those who were unemployed had no choice but to seek help in the under-resourced state sector, which was seen as being particularly slow, even at times contributing to the death

of patients. Power was also found in terms of educational level, with my participants feeling that those who were better educated had more knowledge about transplant and therefore could understand it better than their less educated counterparts. Power is also seen where closer geographical proximity to a transplant centre may improve one's chances of receiving an organ. Typically the wealthy, who are educated and employed, live in these areas. Hence, it is apparent that those with better prospects and who would be considered more powerful in society – the educated, the employed and the wealthy – had better chances of gaining access to transplant.

This shows that injustices, which have been identified across the South African health system, are transposed onto Gauteng transplant. Those who are historically (Baldwin-Ragavan et al., 1999; Cameron, 2014) or socioeconomically (Handmaker & Berkhout, 2010; McIntyre et al., 2006; Price, 1998) disadvantaged in accessing the healthcare system generally experience the same disadvantages in accessing transplant services.

In order to create caring institutions, an acknowledgement of the power relations within them is required at an institutional level. Tronto (2010) argues that this helps to stimulate debate and to identify points where policies are required to keep power in check. In terms of context and inequalities in access, my research suggests that this acknowledgement is not forthcoming from those political leaders who have been mandated to address contextual factors. This results in a fractured system where uniform policies are not in place, and where uncertainty is a major factor. Furthermore, access to transplant care is restricted for the most vulnerable (the illiterate, the unemployed, the poor). The NHI (Department of Health, 2011; Matsoso & Fryatt, 2013) may contribute towards initiating an explicit political acknowledgement of asymmetrical power relations in the Gauteng transplant institution, because the package of care which the NHI aims to provide is likely to be a source of much debate – and this could give transplant professionals and academics the opportunity to advocate for the types of transplant services necessary (Ataguba & Akazili, 2010). This may be a way in which powerful individuals can have an impact on transplant care, by advocating for (health

professionals and academics) or providing (the Department of Health) better resources which are necessary for providing good care.

I also identified asymmetrical power relations at a number of points or phases in the transplant process. The most obvious of these was the healthcare hierarchy. The healthcare hierarchy was seen to permeate interprofessional interactions. Allied professionals at the bottom of the hierarchy were sometimes found to experience aggressive behaviour such as yelling, or the throwing of instruments, from medical professionals. Similarly, they were sometimes treated as subordinates when communicating with medical professionals above them in the hierarchy.

I also identified instances where relevant information, such as aspects of patient management, or the fact that a transplant was going to take place, was not shared with allied professionals. This could result in delays. Furthermore, the views of allied professionals were not readily elicited by their superiors. Overall, my research suggests a somewhat voiceless allied professional cohort in transplant. These allied professionals were physically moved out of the way during ward rounds, saw their role as being to carry out orders with little questioning, and appeared unable to stand up for themselves when faced with aggressive behaviour, maintaining an outward appearance of calmness and acquiescence.

In terms of asymmetrical power relations in the transplant process, it does appear that hierarchy is acknowledged, particularly by medical professionals, who explicitly mentioned it in my study. An explicit acknowledgement of hierarchy did not seem forthcoming from allied professionals. This finding indicates that the hierarchical *status quo* in transplant may remain unchallenged, particularly by allied professionals (Austin et al., 2005). This situation was found to create moral distress (Austin, 2012; Lutzen & Kvist, 2012; Varcoe et al., 2012).

11.8.1.2. Particularity in Gauteng Transplant

It appears that when transplant professionals recognise particularity and communicate accordingly, the resulting processes exhibit the hallmarks of ethical behaviour. However, a failure to recognise particularity results in a communicative need remaining unmet and hence ethical care, which considers autonomy and advocates against doing harm, is not necessarily forthcoming.

Tronto (2010) argues that a requirement of caring institutions is the recognition of universal and particular aspects which indicate what kind of care will be acceptable and to whom. Receiving care is the fourth level of care giving, and it is through appraising the responses of those receiving care that we can see if the original need identified in caring about someone or something was met (Tronto, 1993). As Tronto (1993, 2010) and Held (2006) have both argued, care is about relationships. The requirement of particularity seems to entrench this notion of relationship, and suggests that caregivers and care receivers alike must communicate about their particular needs. My thesis suggests that through communication, or lack of communication, particular needs are either considered and addressed or they are not.

An expectation of care is seen throughout the transplant process. There is an expectation that someone in the community, perhaps a 'sister' – as in my thesis title - will care for a desperate potential recipient by donating an organ. A similar expectation is that a transplant coordinator will care for a desperate potential recipient by procuring this organ. There is an expectation that transplant professionals will care for donor families after they have provided consent. There is an expectation that transplant professionals will care for recipients, committing to support them in the post-transplant journey. These all comprise particular needs for care.

Particularity seemed to be realised to a greater or lesser extent at different phases in the transplant process. The recognition of particular needs was found to facilitate the provision of care for donor families, when asking for consent, and for recipients in the pre-surgical and post-transplant phases. When it came to asking

family consent, recognition of grief resulted in displays of empathy which my study suggests made families feel cared for. For recipients and their families, transplant professionals seemed to recognise particular factors, such as fear and hope pre-surgically, and to accept the possibility of psychological and support needs post-transplant. This lead to gestures of care in the pre-surgical phase where participants prayed with potential recipients and their families and to the establishment of a relationship of trust post-transplant. In the case of recipients, one sees the notion of caring as a process which takes place over time. Tronto (2010) argues that it is through this process that a moral base of care becomes enshrined in institutions.

Although particularity is recognised at some points in the transplant process, my thesis seems to show that particularity in identifying and meeting the care needs of transplant patients and families is not uniformly acknowledged. Pre-transplant my results suggest that health professionals assume families will be unwilling to donate, based on an appraisal of apparent personal belief systems, because health professionals themselves may not believe in organ donation, or because healthcare professionals feel uncomfortable speaking with the potential donor family. As a result families were not always given the opportunity to make a decision about organ donation. This suggests that the needs of potential donor families as care receivers were considered identical. Tronto (2010) argued that seeing the needs of all who require care as identical was a sign of an institution caring badly. Post-consent and post-transplant, donor families expressed the feeling that their needs for care in terms of receiving relevant and adequate information had not always been met. This has consequences, especially for DFI1 who felt “cheated” through the transplant process. Because there were only two donor families in the sample, it cannot be concluded that particularity is always absent from the post-transplant phase for donor families, even though no transplant professionals mentioned it. However, my evidence does highlight the unfortunate consequences of not recognising particularity and the impact it has on care.

When it comes to the four levels of care (Tronto, 1993), it appears that in relation to recipients, transplant professionals do communicate across all four of these

levels. Care giving is clearly part of the process and this is manifested in the relationship of trust which develops post-transplant and the consideration of particularity in offering support and education. Considerations of the recipient as the receiver of care are also evident as transplant professionals attempt to understand their emotional and social background and tailor care to fit within this framework. This contrasts with donor families because, in the post-transplant process, it does not appear that transplant professionals consider these families to be care receivers. DFI1 responded very strongly when care was not given. Tronto (1993) argues that if care receivers perceive inadequate care this can help to identify whether the first level of care – caring about – has been met or not.

11.8.1.3. Purpose in Gauteng transplant

Tronto's (2010) third requirement for establishing caring institutions is an acknowledgement of the purpose of care provided. This is an institutional objective of caring which all role-players should understand and upon which all should agree. Overall, an agreement about the purpose of care does not seem evident in my data, and perhaps the fact that medical professionals did not always communicate with allied professionals, suggests that the purpose of providing multi-disciplinary care, which is essential for transplant, is not always recognised.

My study identified a number of facets of the transplant institution where it appeared that there was little agreement on the purpose of care provided. The most pointed of these is my finding of a dislike of organ harvesting amongst allied professionals who experienced aggressive behaviour which seemed to stem from surgical teams who had not agreed on the purpose of the care they were providing. Some allied professionals disliked harvesting because of a sense that it was contrary to the purpose of their professional role – which was to preserve life. Being involved in harvesting created a sense of moral distress for these participants because they were required to participate in achieving an institutional objective with which they did not agree. The reason for this disagreement may be related to universal factors such as personal beliefs or a feeling that the donor was being killed.

Another aspect where it appeared there was little agreement on the purpose of care was seen amongst surgical teams when performing the harvest. My research shows that the purpose of each team was to harvest an organ for their particular recipient. This was evidenced by reactions of anger and aggression when medical professionals felt the actions of others were hindering them from the removal of the organs they needed. It was also not clear whether there was a shared purpose in promoting the dignity of the cadaver donor, and this possibility takes on greater meaning when considered according to the reasons given for dislike of harvesting, where there was a sense of "taking" and "leaving empty".

Purpose of care was also challenged in the situation where a transplant coordinator is trying to obtain consent with the aim of getting a donor, and she may experience pressures from other professionals with the purpose of transplanting a recipient as quickly as possible.

11.8.2. The ethics of care and considerations of resources

Donor organs are scarce resources in transplant, and Tronto (1993) argues that sufficient resources must be available in order to promote good caring. This shortage of organs prevents transplant professionals from taking direct action to meet recipient needs for care and thus the third level of care giving is not fulfilled (Tronto, 1993). My research has shown that a number of universal factors can be barriers to organ donation, thereby influencing the availability of donor organs. These factors may include personal beliefs held by the general public which preclude organ donation , personal beliefs of the healthcare staff which are unfavourable to organ donation and thus prevent the referral of potential donors, and a lack of knowledge generally about organ donation.

The need for donor organs if one is to provide good quality transplant care is interesting, because unlike a financial or human resource, an organ cannot be manufactured or trained and it necessarily requires an act of giving body parts from one person to another. Hence, to state that more organs are needed to facilitate an ethics of care in Gauteng transplant requires a sensitive approach which encompasses plurality and purpose to consider individuals and their donation

preferences. It is not simply a question of distributive justice and requesting more funds.

11.8.3. Is Gauteng transplant a caring institution?

In order to consider whether Gauteng transplant is a caring institution in the light of my data, it is necessary to consider firstly Tronto's aspects of good care (1993) and secondly, the seven indications that institutions are not caring well (Tronto, 2010) and determine which are relevant in the Gauteng context.

Good caring requires repeated, decisive thought and action as well as a complex negotiation of what kind of care is acceptable to different care receivers. We see the effects of good practice in caring at some points of the transplant process in Gauteng – in caring for donor families making a decision and caring for the recipient preoperatively and post-transplant. Here, care seems tailored to individual experiences and good caring requires an acknowledgement of these particular needs. Particular needs are sometimes recognised (at the same points where the practice of care and determining acceptable care has been identified). However, there are also aspects where particularity is not realised, such as in donor family follow-up.

My evidence suggests that there are major resource constraints in Gauteng which hinder good care. Human resource shortages mean that care is often rushed, or it is not provided in a timely fashion. A shortage of organs hinders the provision of care for potential recipients who desperately need them to stay alive. Inequalities in access to transplant services across sectors also hinder care in transplant, and the standard of care in the state sector may suggest that the caring actions which take place within it are at times inappropriate.

In institutions that are not caring well, the needs of those who receive care are considered identical. My study shows that this may be the case when the donation preferences of families are assumed - based on a perception of their cultural background. This lead to a type of blanket decision-making where health professionals observed certain traits of a potential donor family. Based on a combination of this observation and the expected personal beliefs the potential

donor family may hold about transplant, health professionals sometimes assume that families would be unwilling to donate. Hence, some families would not be offered a donation decision at all.

In institutions that are not caring well, care is considered a commodity. My research suggests that care is commodified. In the private sector it can be bought and sold, for example by a person being on dialysis as long as he or she can pay for it. This is also reflected in the living donor work-up, where medical expenses must be met by the potential donor or recipient, and will only be refunded if the transplant takes place. Care seems similarly commoditised in the reservations which transplant professionals expressed about reimbursement for services.

Another sign of institutions that do not care well is an emphasis on care giving rather than seeing care as a process. This is evident in my study - which considered transplant as a process - and found that care is not forthcoming to an equal extent to all role-players throughout the process.

A final indication that institutions are not caring well is that caregiving roles are considered as the sole province of women, ethnic[35] minorities and previously disadvantaged groups. Considering the demographics of transplant professionals in my research the majority of allied professionals sampled were female (sixteen out of seventeen) and of these sixteen, ten described their race as Black African[36]. Here, we see that women and previously disadvantaged groups in my research have assumed caring roles associated with allied professions such as nursing (Lupton, 2003) and it could be argued that this structure in transplant may negatively impact on institutional care. Evidence of the health hierarchy in my study suggests that care in Gauteng transplant is gendered and raced. In addition, those who fulfil caring roles are considered subordinate to those who fill more decision-orientated roles, such as medical professionals.

My findings, compounded by the notion of moral distress and aggressive behaviour in transplant, lead me to conclude that the Gauteng transplant institution is not

[35] This term is used by Tronto herself; it is not my term.

[36] I have made reference to the racial characteristics of my participants here, because it is an important consideration in the ethics of care, and as such my analysis and argument is incomplete without it.

caring well, and that an ethics of care cannot be realised until these factors, as well as resource constraints, moral distress and aggression are directly addressed. The best way to do this would be through policies that aimed to increase the supply of organs, regulated health interactions and advised practitioners on acting ethically.

Tronto's ethics of care has been useful for examining the findings of my research because the ethics of care allowed me to explore caring as a process over a period of time. Given the emphasis on relationships, of which there are many in transplant, the ethics of care has also allowed for the identification of relationships in the transplant process where care is especially neglected.

11.8.4. Extending Tronto's concept of caring institutions to account for transplant in Gauteng

I argue that transplant in Gauteng is sometimes a caring institution and at other times it falls short. Tronto (2010) argued that a sign of poor caring in institutions was caring not being seen as a process. By considering care across the entire process of transplant, I have been able to identify aspects where caring seems evident and aspects where it does not. These seem related to particularity and purpose.

In the pre-transplant phase the purpose of the transplant institution is to acquire donor organs for potential recipients. My research showed that at this stage special attention was paid to the particular needs of the donor family. However, once organ donation has been authorised, the purpose of the transplant institution changes. Pre-surgically, the purpose is to ensure a successful procedure. The study showed that at this stage special attention was paid to the particular needs of potential recipients and their families. Post-operatively, the purpose of transplant is to ensure long-term graft survival. My research showed that at this stage special attention was paid to the particular psychological, emotional and support needs of recipients and their families.

It was at this stage, where the purpose of transplant shifted from obtaining organs from donor families to that of implanting recipients, that donor families expressed dissatisfaction about the care they received, both post-consent and post-

transplant. This is backed up by the finding that no transplant professionals mentioned communicating with the donor family post-transplant in their interviews or focus groups.

Transplant is unlike any other health intervention in that it brings into stark contrast the tragic experiences of one individual or family through which the experience of another individual and family is changed from one of desperation to one of hope and optimism. Tronto's (2010) argument that a caring institution should recognise power, particularity and purpose may be helpful in health interventions where there is just one recipient of care (for instance cancer treatment or hip replacement surgery) or when there is more than one recipient of care, but where the purpose of providing care is uniform, and the particularity requirement of all recipients of care is the same (for instance, childbirth). However, in transplant, the particularity requirements of the parties involved are very different, and my results suggest a failure to recognise the particular needs of all role-players throughout the transplant process. The purpose of care, here, is too narrow; and the result is that maximum care is directed to some role-players and less than adequate care to others, depending on the stage of the process.

In order for Gauteng transplant to become a caring institution, it is not enough that the acknowledged purpose of care is simply to provide a transplant. This has to be extended into a more experiential requirement where the purpose of care is to provide a well-managed *transplant process* for all those involved. This would then allow for a consideration of particularity for all role-players across the process, not just for those whose needs are incidental to the purpose of the care being provided at the time.

The recommendation of a more experiential sense of the purpose of transplant is still in line with the ethics of care, it simply takes the notion of relationship further, suggesting that a caring relationship should still normatively happen, even when the care provided at that point has no obvious implications for the purpose of the health intervention.

11.9. SUMMARY AND CONCLUSION

In this chapter I have presented my argument that the context in which organ transplant takes place in Gauteng is complex and multifaceted, and that depending on this context, transplant communication between professionals and patients varies, and is largely uncertain. My study found that interprofessional communication is also influenced by context, is complicated and hierarchical. However, some aspects where good communication was perceived to take place were identified. Three main, overriding ethical issues – distributive justice, autonomy and best interests – were explored as the primary ethical considerations in the data set. A synthesis of all these ethical issues in terms of Tronto's ethics of care showed that transplant in Gauteng cannot be considered as a caring entity or institution. Thus, in the current environment, where there is little legal direction or political buy-in, it is unlikely that transplant in Gauteng will be able to reach its full potential because an ethics of care is not fully realised. Recommendations pertinent to these discussions will be made in my final chapter.

Chapter 12: Conclusions and recommendations

12.1. INTRODUCTION

The final chapter of my thesis makes recommendations for practice, policy and future research. It then makes an appraisal of my research methodology. To end the thesis, I offer some final reflections.

12.2. RECOMMENDATIONS FOR PRACTICE

12.2.1. Addressing aggressive behaviour and moral distress during the surgical phases

My research found that the organ harvest was one of the aspects in the transplant process most conducive to aggressive behaviour, inter-service challenges and moral distress. Addressing this may require a paradigm shift where harvesting teams see themselves as a unified entity rather than as separate units with differing objectives. One way in which this might be facilitated is to provide all harvesting teams with some information about all the potential recipients, rather than just that recipient for whom they are harvesting an organ. This could be done through a pre-surgical briefing or even during the harvest itself.

Aggressive behaviour was found to be an unpleasant aspect of interprofessional transplant communication, and it often occurred during times of intense pressure such as harvesting. Given the challenge of ischaemic times, and the objective of maintaining organ quality, it would perhaps be unreasonable to recommend that healthcare professionals are given more time to facilitate a transplant, especially in the surgical stages. However, as time pressure seems to lead to aggressive behaviour, it may be helpful for transplant professionals to consider the role which apology may play. Lin (2014) argued that apology could help restore trust between healthcare professionals and patients, especially in terms of aggressive behaviour. Ideally, aggressive behaviour would be minimised and a sense of accountability for behaving in such a manner would be instilled. Use of apology in interprofessional

transplant communication may also facilitate trust, a sense of worth and a sense of belonging.

12.2.2. Addressing continuity of care factors

Given that transplant professionals felt information was not always shared timeously it is recommended that a computerised algorithm be considered. This could contain the contact details of all healthcare professionals involved in Gauteng transplant. When there is a potential transplant a nominated coordinator could send an alert to all staff. Staff could decide how to respond to this alert based on their call status and could then take steps to elicit more information about the transplant, should there be a likelihood of them being involved.

I have considered this recommendation carefully and acknowledge that it has limitations. A possible objection may be that healthcare professionals would not appreciate superfluous messages about transplant - especially when not on duty. However, it appears that all individuals receive unwanted communication in this mobile age and that these are a minor irritant which can be either disregarded or acted upon. Conversely, an advance warning system may have benefits in helping to improve continuity of care and cohesion in Gauteng transplant. It may also promote healthcare professional autonomy by allowing time to rearrange personal and professional schedules if necessary.

Furthermore, this system is relatively simple. Whilst there is scope to recommend a more sophisticated telecommunication transplant algorithm, such an intervention may be very expensive. I feel that as telecommunication is not uniformly utilised in Gauteng transplant it may be wise to begin with simpler interventions and ascertain whether they would be supported, before implementing a more sophisticated system.

Another factor which may assist in improving continuity of care is better defined roles for transplant professionals, especially for transplant coordinators. As it appears there is substantial confusion in this area, I recommend that defining and agreeing on professional roles may be a relatively inexpensive strategy. This may

give transplant professionals a clearer idea of what is expected of them, and remove assumptions about who has - or has not - done what.

12.2.3. Addressing demanding and difficult potential recipients

My thesis showed that out of desperation to receive an organ, potential recipients were sometimes seen as difficult and demanding in their communication with transplant professionals. A participant in TCFG1 suggested that when this happened she would print out the waiting list and take it to the potential recipient, in order to give him or her a sense of the length of the list. This may be a good strategy for transplant coordinators to adopt. Not only could it give potential recipients a sense of perspective, but knowing their listing position may also help to reassure them that the process is going to be fair. In order to implement this type of method ethically, it would be necessary to anonymise names on the waiting list in order to protect the confidentiality of listed potential recipients.

12.2.4. Addressing organ donation terminology

Many of my participants used the term organ harvesting. However, given that 'organ harvesting' was a procedure imbued with moral distress, and one which evokes images of animal killing, scavenging or unpleasant removal of body parts, it is likely that the concept in Gauteng has negative connotations. For this reason, I would recommend a re-think of donation terminology in the Gauteng setting, as it may assist in allaying some of the doubts which my participants expressed. For instance, the term 'organ harvest' could be replaced with a more neutral phrase like 'organ recovery' as per Finger Lakes Donor Recovery Network's (2015) recommendations for appropriate terminology on organ donation. 'Organ retrieval' could be another appropriate phrase. The word retrieval does not have the same negative connotations as does harvesting, which in itself suggests the killing or removal of living things.

12.2.5. Addressing communications with donor families post-transplant

My research has shown that when a donor family did not receive a gesture of thanks from the transplant centre or representative institution like the ODF, donor families experience a sense of frustration and disappointment. To this end, I recommend that all transplant centres carefully implement and enforce policies which ensure that a member of the transplant team drafts, signs and posts a thank you letter to the donor family.

Because organs are scarce, and cadaver donor families make decisions to donate organs as 'gifts' it does not seem unreasonable to request that recipients 'give back' in recognition of the decisions the donor family made. A recipient could give back to the donor family by committing to keep them updated on his or her recovery and progress. Ethically, it is considered inappropriate for donor families and recipients to meet, so a third party, such as the transplant centre or the transplant coordinator, would be required to relay communications. Recipients present at the transplant centre regularly for follow-up, and would be able to bring communications with them. Such communications need not be lengthy or even regular; however my thesis has shown that receiving even some news may mitigate a number of the negative consequences which donor families discussed.

There are several reasons why the notion of a recipient's obligations and responsibilities to a donor family may seem controversial (Austin et al., 2005) and I acknowledge that adding a set of recipient responsibilities into transplant may seem a contentious recommendation. It is however based on my findings, in particular the contrast which they revealed between highly emotional donor family interviews, where follow-up was found to be very important, and transplant professional and coordinator interviews, where donor follow-up was not mentioned at all, even though recipient follow-up was discussed extensively. Furthermore, international studies, which examined notions of communication between organ donor families and recipients, reported sentiments that some

contact would be favoured by both parties (Lewino, Stocks & Cole, 1996; Ono et al., 2008; Azuri & Tabac, 2012).

I submit that objections to the idea that there should be a degree of reciprocity from recipients can be mitigated through careful consideration of systems and communication. For instance, a thank you letter need not be written by the recipient him or herself; it could be written by a family member or friend. This would remove those psychological factors which may result if a recipient were compelled to communicate with a donor family directly (Austin et al., 2005). Furthermore, it is possible that a donor family may not wish for information and contact; this would need to be established at some point so as to prevent unwanted communication.

12.2.6. Addressing public awareness

My thesis identified a perception that knowledge about, and awareness of, transplant was lacking in the Gauteng context. It argued that both the media and transplant recipients could be good advocates for organ donation. I argued that the notion of recipients as advocates was noteworthy because the recipient constituted a community link (Section 8.5). I recommend that recipients are encouraged to participate in donor advocacy programmes. It would probably be unrealistic to expect a recipient to take part in a lengthy campaign. However, a short visit to a hospital and/or community centre once the recipient has sufficiently recovered, where the recipient can explain how receiving an organ has affected his or her life, does not seem unreasonable. This could be framed as a way of 'giving back' for the donor organ which he or she received. By going into a hospital setting, a transplant recipient may also assist in addressing issues of health professionals' perceptions of organ donation and transplant, which is important because my research has shown that health professional attitudes can affect the transplant process.

12.3. RECOMMENDATIONS FOR POLICY

12.3.1. Ministerial Advisory Committee (MAC) commitment to review cases in a certain time frame

My thesis argued that the MAC, which is responsible for approving non-related living donation, was perceived to be slow, and that this could have both emotional and financial consequences. In order to mitigate these consequences and their inherent uncertainties, I recommend that the MAC formally commits itself to reviewing cases within a certain time-frame. I acknowledge that the MAC is understaffed, however it seems that this may be an aspect where employing an extra staff member could have significant benefits, as it would decrease the workload of current MAC members. Non-related living donation is also an area which should be carefully considered in the National Health Insurance plan, which has committed to providing tertiary services and may be able to allocate resources which would assist the MAC in its task.

12.3.2. Weak express consent required response for potential cadaver donors

When considering the referral process, results of my research suggested that potential donor families were not always given the option of donating organs. This seemed to be due to cultural typecasting on the part of transplant professionals, and manifested itself in stereotypes about preferences, based on the population group of the potential donor. The effect of this can be seen in those instances where transplant professionals are unwilling to offer a potential donor family the option of organ donation because of their own personal beliefs about transplant. It is recommended that cadaver organ donation in Gauteng be reframed as an ethical undertaking of 'giving potential donor families a choice'. This would entail every patient who is declared brain-dead being referred to the transplant coordinator, who could then initiate the donation discussion with a family. The exact manner in which this should be done is explored in substantial detail below, and is based on other South African literature and the discussion of ethical issues in Section 6.2 in order to identify the most appropriate structure for such a policy.

I agree with Labuschagne (2013) that a required response may be the most effective means of increasing the availability of donor organs. A required response is ethically and legally sound, and it also formalises the donation process.

Furthermore, Labuschagne's (2013) recommendation that such a system be implemented only after an extensive public awareness campaign has been undertaken would also have the effect of addressing the lack of knowledge and awareness about organ donation which have been identified in my research.

A possible limitation of Labuschagne's (2013) recommendation may be the requirement for strong express consent (Rens, 2008) where donor families do not play a role. My findings suggest that transplant professionals in Gauteng see the role of the family as important, if sometimes frustrating, and Csillag (1998) has shown that in Brazil, a setting comparable to South Africa, where legislation deemed family consent was unnecessary, transplant professionals continued to seek it. My research also shows that a consideration of cultural practices is important. Family deference and structure could be considered an aspect of cultural practice.

In light of my findings, it is possible that South African transplant professionals would feel uncomfortable excluding a donor family in the decision-making process as Labuschagne (2013) seems to suggest is necessary. Hence, a better recommendation would be to suggest a 'weak express consent required response' where the person making it must indicate whether their family is aware of his/her preferences. Here Labuschagne's (2013, p. 142) donor questionnaire could possibly be improved by the addition of the question: "Have you discussed organ donation preferences with your family?" This could simplify the consent process because more families may be aware of the donation preferences of their loved one. Previous research has argued that families are unlikely to agree to donation if they are unaware of a loved one's preferences (Barcellos et al., 2005). Also, such a method would uphold respect for the family structure and practices because they would still be included in donation decisions.

There appear to be two advantages of required response with weak consent. The first is that it removes the paternalistic practice of non-referral based on other considerations, and the second is that, as an endorsed policy, it may help to alleviate moral distress for healthcare professionals by removing some factors which would otherwise influence the decision whether or not to refer a potential

donor. Furthermore, if all families are offered a donation decision it might be possible to create a pool of statistics which would indicate the extent to which stereotyping and blanket decision-making accurately reflects the attitudes of those to whom it is attributed.

12.4. RECOMMENDATIONS FOR FUTURE RESEARCH

My thesis differed from research which has already been published in two unique ways. Firstly, it considered the transplant process as a whole. This approach yielded findings about communication with donor families in the post-consent and post-transplant process. An essential implication for future research is to consider these aspects in more detail and undertake more research which explores the experiences of donor families post-transplant. Secondly, my research considered a number of voices and experiences across the transplant process. By integrating the views of transplant professionals, transplant coordinators, living donors and cadaver donor families it has produced results which had not been highlighted before. These in turn lent themselves to appraisals of the ethics of care in transplant, the function and location of moral distress and the role of uncertainty.

Future research in this area could advisedly focus on implementing and evaluating practical strategies for addressing some of the problems in transplant which my research has identified. I hope to undertake some of this work myself. For instance, a pilot programme to evaluate changes in donation terminology would be useful; and an intervention where transplant recipients are encouraged to make some, even limited, contact with donor families could provide valuable results. It would be important to undertake these programmes as research studies, in order that empirical evidence as to the efficacy of the intervention may be reported. Likewise, a valuable research project could pilot and evaluate a version of the early warning system, which was recommended in Section 12.2.2, and evaluate whether it may be useful on a larger scale in the transplant arena.

Practical recommendations aside, communication research which explores actual interactions between individuals through the transplant process could now be considered. My thesis has highlighted those aspects where interaction is most

problematic and phases where interactions appear effective. I would argue that based on my findings, other researchers would be better able to design such projects and to tailor them to account for the specific nature of interactions taking place. Whilst I maintain that recording some interactions are ethically problematic – for instance the interactions where a donor family is asked for consent – a recording and detailed conversational analysis of the interactions between transplant coordinators and demanding potential recipients has the potential to produce fruitful results and data. Similarly, interactions between transplant professionals in theatre may produce interesting results and assist in further focussing recommendations to enhance clinical practice and respect amongst professionals, as contemplated in Section 12.2.1.

12.5. RESEARCH DESIGN AND METHODOLOGY

The main aim of this study was to explore transplant communication in Gauteng. The study was designed utilising several qualitative methods in order to produce a data set which was both sufficiently broad and detailed whilst also accounting for differences in participant characteristics and ethical considerations. For the most part, it appears that this choice of methodology was appropriate and that the objectives of my research have, in the main, been achieved. However, I would recommend reconsidering some methodological aspects in future research.

In light of discussions at a feedback session I feel that a focus group with allied transplant professionals may have been helpful in starting a dialogue about communication in transplant. This seems important in light of the findings that allied professionals did not always feel empowered to express their views (Section 10.2). By promoting discussion in a non-judgemental group forum allied transplant professionals may have had an opportunity for open dialogue and mutual support. However, one-on-one interviews did produce rich data.

Secondly, I would have liked to undertake more interaction with families, especially those who were unwilling to consider donation. Although the reasons why this was not possible are described in Section 7.7, future research may benefit from including the views of non-consenting families in some other way. However,

recruiting donor families to participate in my research was a challenge (Section 7.8) and it appears that any research which proposes to make use of these methods ought to do so with circumspection.

Thirdly, it is possible that my research could have benefitted from a transplant recipient focus group or, because each individual journey seem so different, from research interviews. However, upon appraising the data it became apparent that it was dominated by considerations of the transplant recipient journey. This was especially evident in interviews with transplant professionals where the recipients often commanded the majority of conversation and donor families were not mentioned. I submit that augmenting the data set with additional recipient data may have only served to unbalance my research results.

Some methodological choices seem to have worked particularly well. The forum of a focus group for transplant coordinators produced complex results and facilitated open conversation. In the living donor focus group it appears that my participants built relationships with each other and exchanged contact details. This suggests that they may have found the discussion therapeutic.

12.5.1. Study limitations

In terms of my methodology, a number of limitations have been identified. Firstly, the small sample of donor families in my research may be seen as a significant limitation. Secondly, the fact that I was only able to undertake one focus group with living organ donors is also a limitation, as including a larger number of recipients may have led to more convincing theoretical saturation in this group. Thirdly, I did not include transplant recipients in my research, and this could be seen as a limitation in terms of achieving a balanced data set. However, I submit that these limitations have not significantly influenced my work, that my data set is still representative and that this research has provided many new and original insights, despite these limitations.

The lack of ethnography (Longman, 2013) in my study could also be seen as a limitation and the choice of Gauteng as the study province also limits my research. State facilities in Gauteng do not provide the most comprehensive range of organ

transplants available to state patients in South Africa. This served to limit my research in terms of observations and interviews regarding state-run facilities, and may have the effect of biasing the research towards the private healthcare sector. Secondly, Gauteng does not offer the most extensive paediatric transplant programme in this country, somewhat limiting the application of my research to paediatric settings. This limitation has possibly resulted in a bias towards adult transplantation.

12.6. FINAL REFLECTIONS

This thesis is the start of what I hope will be a process of exploring communication in transplant. I undertook my study based on perceived transplant trends, such as the lack of referral, and in order to try and address a gap in the South African transplant literature. As this is the first study of its kind in the complex South African context, my results should be considered as a starting point. My study was an exploration and as such it has not provided many definitive answers to problems in transplant. I have sought to make recommendations which are practical and helpful, and I have identified a number of new questions which now require answers.

Unfortunately, my data and results do not always portray organ transplant in Gauteng in a positive light. It seems possible that many participants know about a number of issues facing transplant in Gauteng but the extent to which anyone is aware of the larger picture is unclear. My research perhaps helps to present the larger picture and it also provides evidence for some of the issues which transplant professionals face on a daily basis. I hope that with this evidence transplant professionals will be able to motivate for programmes of change and development within their institutions.

My thesis identified some issues which do not lend themselves to easy answers. Problems of inequality because of resource scarcity and barriers to access seem embedded in the historical and economic South African context. Shifting these paradigms requires collective will and commitment, which does not always seem in evidence.

I hope that, with the establishment of guidelines across centres and institutions in Gauteng, transplant could become more unified, and that this may improve conditions such as moral distress and uncertainty which appear to permeate the transplant process. Of course these would require teamwork and commitment, which could pose a major challenge for the Gauteng transplant fraternity because of the communication barriers which my research has identified.

However there are reasons for hope and optimism when some of my results are considered. Clearly, certain aspects of transplant communication in Gauteng exemplify a sense of caring and mindfulness, such as communication when asking a potential donor family for consent. Similarly, the development of a trusting relationship between the management team and recipients is heartening. It shows how caring practice arises spontaneously when time, context and complex interactions are not a constraining factor.

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Appendices

APPENDIX 1: RATIONALE FOR TABLE T2.1 – ORGAN TRANSPLANTS FROM DECEASED DONORS BY COUNTRY

South African transplant numbers were not available from IRiODT – the source of other transplant per million population figures. I calculated the number for South Africa using the following equation and variables:

$$\mathrm{R} = \frac{N}{\frac{P}{1{,}000{,}000}}$$

Where: R = Transplantation Rate (pmp per annum)

N = Number of transplants in a period of years

P = Population of country

Variables

2011	2013
N – 214 (ODF, 2015)	N – 209 (ODF, 2015)
P – 51.58 million (World Bank, 2015)	P – 53.15 million (World Bank, 2015)

From ODF (2015) statistics, both living donor transplants and cornea transplants have been excluded as the table depicts cadaver donor transplant rates.

APPENDIX 2: GAUTENG PROTOCOL FOR CADAVER DONOR PROCUREMENT PROCESS

This protocol was obtained from a medical professional involved in transplant. In order to protect participant confidentiality, I cannot divulge the name of the individual.

PROTOCOLS FOR DECEASED DONOR ORGAN PROCUREMENT

1. Stable donors. OT startup operating (Cutting) time 4.30am
    a. To be managed and run by the procurement coordinator from the time of Brain Stem death declaration, according to the protocols agreed to
    b. Steroids may be part of standard management
    c. Any use of, or changes to, inotropes and the dosages needs to be communicated to Cardiac team
    d. Stable donor's routine operation timing should be planned as follows:
        i. 4.30am: booked startup time for abdominal surgeons
        ii. 5.00am: arrival time for lung team to begin bronchoscopy. Abdominal surgeons will continue operating
        iii. 5.30am: arrival time for cardiac team (No Lung harvest)
        iv. 6.00am: Abdominal team should be ready and finished the warm faze, they will stand back for the cardiac team for 20 min while the cardiac teamworks alone to remove their organs (Lung and Heart). After 20 min the abdominal team will return and begin removing abdominal organs irrespective of cardiac team progress
        v. The abdominal team may arrange their startup time earlier than 4.30am if they anticipate they will need additional time to be finished the warm faze by 6.00am. All other times remain unchanged
        vi. Cardiac team will wait a maximum of 60 minutes post Cross Clamp for abdominal team, after which they will leave. The abdominal team will have to find their own way home if not able to leave within that time
        vii. Closing, corneas, bone harvesting is not a concern of the cardiac team
2. Reasons not to start at 4.30am
    a. Family Request. A counselor or doctor may consult with the coordinator to assess if this might be negotiable at all
    b. OT availability in the donor hospital

   c. The Donor becomes unstable:
      i. Contact the abdominal and Cardiac teams and inform them. They will need to know: BP, Heart Rate, CVP, Urine Output, Current Inotropes and changes made to Inotropes, ABG, Saturation and changes
      ii. The Cardiac team has an anesthetist available to help manage unstable cases. The cardiac team will arrange for the Doctor / Anesthetist to go out to the donor and take charge of the donor management and optimize donor stability.
      iii. If the Cardiac team is unable to send a Doctor out to the donor, and measures suggested telephonically have no stabilizing effect, then the judgment of the coordinator managing the case is to be taken as the final word as regards instability, the timing and urgency of the donor procedure.
3. Coordinator professional respect:
   a. Is expected at all times. Inter team and region protocols for referral and communication can be established amongst the coordinators themselves
   b. Includes not shouting at or abusing the coordinator. Coordinators have been instructed to record on their cell phones any abusive communication for later evaluation and review either by the local teams, SATS meetings or if necessary, HPCSA, where they will be played back
   c. Includes accepting coordinator assessment as provided from their perspective at the donor site
4. All donor hospitals and staff should be approached in a ‘Be Nice’ manner irrespective of any difficulties they present

APPENDIX 3: INTERVIEW GUIDELINES FOR TRANSPLANT PROFESSIONALS

Questions
Tell me about communication with other healthcare professionals about organ donation? Prompts: • Tell me about the process of referring potential donors? • Tell me about working with the rest of the team under pressure? • How is understanding amongst the team?
Tell me about culture, religion and organ transplantation? Prompts: • Tell me about working with patients from different cultures? • What kind of influence do you think culture and religion have on organ donation?

APPENDIX 4 – QUESTION GUIDE FOR TRANSPLANT COORDINATOR FOCUS GROUPS

Questions
What is it like to be a transplant coordinator in Johannesburg / Pretoria? Prompts: • Do you feel under time pressure when trying to get patient/family consent for an organ donation? How do you deal with this pressure? • Do you feel that you have enough support from people around you to do your job? • What do you think about training and education for transplant coordinators?
Tell me about all the different languages that your patients speak? Prompts: • What do you do when there is a language barrier? • What do you do when you feel a patient/family member can't understand you? • Do you use an interpreter or other ways of communicating? Like diagrams, gestures, other people? Can you recall a situation where this happened?
Tell me about all the different cultures and religions of your patients? Prompts: • Do you try to tailor your interaction with a patient/family member according to their culture? • Do you ever consult a religious leader during the process of organ procurement?

APPENDIX 5: INTERVIEW GUIDE WITH CADAVER DONOR FAMILIES

This questionnaire contains many prompts, which were suggested in the pilot study. However, in the interviews I seldom used prompts, as my participants spoke at length about their experiences.

Question
Tell me about when you had to make the decision to donate the organs of your loved one? Prompts: • Explain the process to me? • Can you talk a bit about who approached you to donate your loved ones organ? • How did you feel when you were asked to consider organ donation? • Do you know how your loved one felt about organ donation? • Did you know what you wanted to do straight away? • Were your family or friends involved in the decision-making? Did you feel well- supported?
Tell me what people in your community/culture think about organ donation? Prompts: • Is organ donation allowed in your culture? What does your culture generally believe about organ donation? • Is organ donation allowed in your religion? If not allowed did you feel judged about your decision? • Do you think the medical personnel understood your culture and religion? Was this mentioned when you were approached? Did you mention it to your health care professional? Do you wish this was discussed more? • Was a spiritual leader available to you while you were making the decision? Who did you turn to for guidance with your decision?
Tell me what it was like to talk about organ donation with your family and the medical staff? Prompts: • Did you understand everything that was said to you about organ donation? • Is there anything about the communication that stands out for you? • Did you have any positive or negative experiences? • Looking back, how do you think your experience could have been made better? • Do you advocate for individuals to register as an organ donor?

APPENDIX 6: QUESTION GUIDE FOR LIVING DONOR FOCUS GROUPS

Question
Tell me about when you found out about organ donation Prompts: • Explain the process to me when you were asked to donate a kidney. • How did you feel when you were asked to consider organ donation? • How did you feel about all the medical personnel who were involved in your decision? • Why did you decide to donate a kidney?
Tell me what people in your community/culture think about organ donation Prompts: • Is organ donation allowed in your culture? • Is organ donation allowed in your religion? • Do you think the medical personnel understood your culture and religion?
How was talking about organ donation with the medical staff? Prompts: • Did you understand everything that was said to you about organ donation? • Did you understand the words and language that was used? • Is there anything about the communication that stands out for you?

APPENDIX 7 – TRANSPLANT PROFESSIONAL STUDY INFORMATION SHEET

Dear transplant professional,

My name is Harriet Etheredge and I am a PhD student at Wits University. For my research, I am exploring the cultural and linguistic factors which influence organ transplantation in South Africa. As a professional involved in transplantation, I would be interested to find out what this aspect of your work is like and what you think about culture and communication in the transplant field.

I would like to invite you to participate in an interview discussion so that we can talk about your experiences of culture and communication in the organ transplant process. I have permission from your hospital to invite you to participate in this research.

Before you decide whether or not to participate, let me give you a little more information about the interview:

We will meet at a time and place of your choosing (to be arranged at a later stage). The interview will also be tape recorded with your permission. The discussion will be scheduled for an hour, but it can go on for longer if you feel that there is more you would like to say.

Your identity will be kept confidential and all of the data which I collect will be kept under lock and key. Only myself and my supervisors will have access to it. The results of the research will be written up as a thesis and published in academic journals. For the purposes of these publications, neither your name nor your institution will be mentioned, so nobody will be able to identify you.

Your participation in this research is completely voluntary, and you may withdraw from the research at any stage and without explanation. Please also feel free to ask me questions about the research, my phone number is 082 735 1704 and e-mail is harreth@hotmail.com. Furthermore, if you are dissatisfied with the research, please contact the Human Research Ethics Committee of Wits University on 011 717 1234.

Thank you very much for considering participation in this research, you time is appreciated.

Harriet Etheredge

APPENDIX 8: TRANSPLANT COORDINATOR FOCUS GROUP INFORMATION SHEET

Dear transplant coordinator (name will be inserted here),

My name is Harriet Etheredge and I am a PhD student at Wits University. For my research, I am exploring the cultural and linguistic factors which influence organ transplantation in South Africa. As a transplant coordinator, you play a vital role in the transplant process, and there is not much published research about the experiences of transplant coordinators in this country.

I would like to invite you to participate in a Focus Group discussion with some other transplant coordinators so that we can talk about your experiences of culture and communication in the organ procurement process. I have permission from your hospital to invite you to participate in this research.

Before you decide whether or not to participate, let me give you a little more information about the focus group:

We will meet in Johannesburg at a time which suits you and the other transplant coordinators (to be arranged at a later stage). You will need to come to the venue, and you will be reimbursed for your travel expenses. The focus group will also be tape recorded with your permission. The discussion will be scheduled for an hour, but it may go on longer if you feel there is more to say.

You need to be aware that confidentiality of your identity cannot be guaranteed in a focus group discussion, but that all participants will be asked to try and avoid discussing the group with outside parties. All of the data which I collect will be kept under lock and key and only myself and my supervisors will have access to it. The results of the research will be written up as a thesis and published in academic journals. For the purposes of these publications, neither your name nor your institution will be mentioned, so nobody will be able to identify you.

Your participation in this research is completely voluntary, and you may withdraw from the research at any stage and without explanation. Please also feel free to ask me questions about the research, my phone number is 082 735 1704 and e-mail is harreth@hotmail.com. Furthermore, if you are dissatisfied with the research, please contact the Human Research Ethics Committee of Wits University on 011 717 1234.

Thank you very much for considering participation in this research, you time is appreciated.

Harriet Etheredge

APPENDIX 9: CADAVER DONOR FAMILY STUDY INFORMATION SHEET

Dear (insert family name here)

My name is Harriet Etheredge and I am a PhD student at Wits University. For my research, I am exploring the cultural and linguistic factors which influence organ transplantation in South Africa. As a family who has had to make a decision about donating the organs of a loved one, I would be interested to find out what this was like for you.

I would like to invite you to participate in an interview discussion so that we can talk about your experiences of culture and communication in organ transplantation.

Before you decide whether or not to participate, let me give you a little more information about the discussion:

We will meet at (the transplant centre) at a time of your choosing for the interview. I will refund your travel costs, however I cannot pay you for taking part in the discussion. The interview will be tape recorded with your permission. The discussion will be scheduled for an hour, but it can go on for longer if you feel that there is more you would like to say.

Your identity will not be told to anyone and all of the data which I collect will be kept under lock and key. Only myself and my supervisors will have access to it. The results of the research will be written up as a thesis and published in academic journals.

You may find that some of this discussion makes you feel upset, please tell me if this happens. If you feel upset I can refer you to a professional psychologist who can help you. We can stop the discussion at any time, and if there are any points you are not comfortable discussing we can skip these. Please know that your participation is completely voluntary and you can withdraw from the research at any time without explaining why.

Please feel free to ask me questions about the research, my phone number is (xxx xxx xxxx) and e-mail is harreth@hotmail.com. Furthermore, if you would like to speak to me after the research or if you would like a referral to the study psychologist, please call me anytime. If you are dissatisfied with the research, please contact the Human Research Ethics Committee of Wits University on 011 717 1234.

Thank you very much for considering participation in this research, you time is appreciated.

Harriet Etheredge

APPENDIX 10: INTERVIEW CONSENT FORM FOR DONOR FAMILIES

I, _____ (name here),

Have been informed about Harriet Etheredge's project which explores Cultural and linguistic Factors influencing organ donation in South Africa.

I am aware that:

- My participation in the research is voluntary and I may leave at any time
- My identity will be kept confidential
- I may ask questions about the research and contact the researcher at any time

I am willing to participate in this research.

Signature: _____

Name: _____

Date: _____

APPENDIX 11: CONSENT FORM FOR AUDIO RECORDING (ALL PARTICIPANTS)

I, _____ (name here),

Give my permission for the discussion in which I have agreed to participate to be tape recorded.

Signature: _____

Name: _____

Date: _____

APPENDIX 12 – CONTACT SHEET FOR DONOR FAMILIES AND LIVING DONORS

Name: _____

Telephone number: _____

E-mail address (optional): _____

APPENDIX 13: LIVING DONOR STUDY INFORMATION SHEET

Dear (insert name here)

My name is Harriet Etheredge and I am a PhD student at Wits University. For my research, I am exploring the cultural and linguistic factors which influence organ transplantation in South Africa. As a kidney donor, I would be interested to find out what this was like for you.

I would like to invite you to participate in a focus group discussion so that we can talk about your experiences of culture and communication in organ transplantation.

Before you decide whether or not to participate, let me give you a little more information about the discussion:

We will meet in Johannesburg at a time which suits you. I will refund your travel costs, however I cannot pay you for taking part in the discussion. The focus group will be tape recorded with your permission. The discussion will be scheduled for an hour, but it can go on for longer if you feel that there is more that the group would like to say.

You need to be aware that confidentiality of your identity cannot be guaranteed in a focus group discussion, but that all participants will be asked to try and avoid discussing the group with outside parties. All of the data which I collect will be kept under lock and key and only myself and my supervisors will have access to it. The results of the research will be written up as a thesis and published in academic journals.

You may find that some of this discussion makes you feel upset, please tell me if this happens. If you feel upset I can refer you to a professional psychologist who can help you. We can stop the discussion at any time, and if there are any points you are not comfortable discussing we can skip these. Please know that your participation is completely voluntary and you can withdraw from the research at any time without explaining why.

Please feel free to ask me questions about the research, my phone number is (xxx xxx xxxx) and e-mail is harreth@hotmail.com. Furthermore, if you would like to speak to me after the research or if you would like a referral to the study psychologist, please call me anytime. If you are dissatisfied with the research, please contact the Human Research Ethics Committee of Wits University on 011 717 1234.

Thank you very much for considering participation in this research, you time is appreciated.

Harriet Etheredge

APPENDIX 14: FOCUS GROUP CONSENT FORM FOR LIVING DONORS

I, _____ (name here),

Have been informed about Harriet Etheredge's project which explores Cultural and linguistic Factors influencing organ donation in South Africa.

I am aware that:

- My participation in the research is voluntary and I may leave at any time
- The confidently of my identity cannot be insured
- I may ask questions about the research and contact the researcher at any time

I am willing to participate in this research.

Signature: _____

Name: _____

Date: _____

APPENDIX 15 – WITS HREC(MEDICAL) CLEARANCE FOR PHASE 1 – TRANSPLANT PROFESSIONALS INTERVIEWS AND COORDINATOR FOCUS GROUPS

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Harriet Etheredge

CLEARANCE CERTIFICATE	**M120751**
PROJECT	Cultural and Linguistic Factors Influencing Organ Donation in South Africa
INVESTIGATORS	Ms Harriet Etheredge.
DEPARTMENT	Health Communication Project/SHCD
DATE CONSIDERED	27/07/2012
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 27/07/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Prof Claire Penn

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

APPENDIX 16 – WITS HREC(MEDICAL) CLEARANCE FOR PHASE 2 – CADAVER DONOR FAMILY INTERVIEWS AND LIVING DONOR FOCUS GROUPS

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M131041

NAME: (Principal Investigator)	Ms Harriet Etheredge
DEPARTMENT:	Health Communication Research Unit Umthombo Building/Main Campus
PROJECT TITLE:	Cultural and Linguistic Factors Influencing Organ Transplantation in South Africa-Pahse 2
DATE CONSIDERED:	25/10/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Claire Penn
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 02/12/2013

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature M131041Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX 17: INFORMED CONSENT FORM FOR TRANSPLANT PROFESSIONAL INTERVIEWS

I, _____ (transplant professional name here),

Have been informed about Harriet Etheredge's project which explores Cultural and linguistic Factors influencing organ donation in South Africa.

I am aware that:

- My participation in the research is voluntary and I may leave at any time
- My identity will be kept confidential
- I may ask questions about the research and contact the researcher at any time

I am willing to participate in this research.

Signature: _____

Name: _____

Date: _____

APPENDIX 18 – INFORMED CONSENT FORM FOR TRANSPLANT COORDINATOR FOCUS GROUPS

I, _____ (transplant coordinator name here),

Have been informed about Harriet Etheredge's project which explores Cultural and linguistic Factors influencing organ donation in South Africa.

I am aware that:

- My participation in the focus group is voluntary and I may leave at any time
- The confidentiality of my identity cannot be guaranteed
- I may ask questions about the research and contact the researcher at any time

I am willing to participate in this research.

Signature: _____

Name: _____

Date: _____