SUBJECTIVE FRAMEWORKS OF MEANING OF KIDNEY TRANSPLANTATION AMONG AFRICAN RECIPIENTS

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ABSTRACT

This study investigates the experiences of African patients who have undergone a kidney transplant within the past ten years, either from a live donor or from a cadaver. The study further examines how these patients made (and still make) sense of the transplant experience, and hence attribute a particular subjective meaning to the factors and variables which have been at play during the course of the transplant.

Little is known about kidney transplantation among African patients, in particular about psychological and social responses to the process. Hospital staff often find it difficult to break through communication barriers that exist as a result of language differences. Several studies have found that the medical discourse (as opposed to the lay person's discourse) has contributed to the lack of understanding on the side of the patient.

Semi-structured interviews were conducted with fourteen African patients (8 females and 6 males), from the Renal Unit of Groote Schuur Hospital, Cape Town. The interviewees were selected from the records of the Unit. As mentioned above, the transplant had taken place no more than 10 years ago and no less than 6 months ago. The data was analysed thematically based on the emerging trends in interviews.

It was found that several themes accounted for the frameworks of meaning that patients attribute(d) to the transplant process. These are: religion and indigenous belief systems; the role of the extended family; patients' respective routes to the hospital; feelings about the transplant; and experience in the hospital. These themes are discussed in order of importance in the lives of patients, as they unfolded in interviews, in conjunction with available literature on the subject.

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CHAPTER 1: INTRODUCTION AND BACKGROUND

INTRODUCTION

Much is known about psychological aspects of organ transplantation. Some of these aspects are people's general attitudes towards organ donation, educational attempts to change some of these attitudes, and organ recipients' feelings and thoughts about either a live-related and /or a cadaver donor. Another well known area of study is recipients' subsequent psychosocial adjustments following an organ transplant. While most research in this area has been conducted among dominant cultures in the world, in recent years more effort has been made to look into the still under-researched area of transplant experiences of minority groups. For example: studies on Hispanics, Latin Americans as well as African Americans have shown that several factors beyond the individual patient, come into play when patients are to undergo a transplant procedure. Two of these are: the patient's home language versus that of the hospital setting; and the importance of elders' role in the family when it comes to important decision making processes. Although there has been a shift towards looking more closely at population groups that (till recently) have not been studied sufficiently, still not much is known about South African Africans' experiences of transplantation.

In the light of such little research in this area, it seems necessary that the types of research methods employed provide a forum wherein researchers can throw their nets wide, beyond the confines of structured and quantitative methods. It is for this reason that the present study has chosen semi-structured interviews as a mode of data collection.

STRUCTURE OF DISSERTATION

The present study starts off by exploring available literature on the subject of kidney transplantation, with particular reference to experiences of recipients of organ transplants. Factors that influence patients' frameworks of meaning about and around the transplant process are also discussed. Chapter 2 focuses on methods and procedures of how the data was collected and

analysed. The next chapter (three) unpacks the findings through a thematic analysis of the semi-structured interviews.

LITERATURE REVIEW

As has been mentioned in the introduction, research has identified several significant factors that impact upon transplant patients who come from varied sociocultural backgrounds. These are: the extended family; patients' respective home languages; education level; modern versus traditional perspectives of illness and healing; traditional medicine; and religion. These factors are discussed in some detail below.

1. The Extended Family

The word 'family' as used in the west is said to be used slightly differently in the African context (Mbiti, 1969). In Africa it traditionally includes children, parents, grandparents, uncles, aunts, brothers and sisters (who may have their own children), and other immediate relatives. Thus the number of family members may range from ten people to even a hundred. The family also includes the departed relatives, who are now referred to as the ancestral spirits. These are said to be alive in the memories of their surviving families, and are thought to be still interested in the affairs of the family to which they once belonged in their physical life (ibid).

In the light of the family relations being so closely knit, Mbiti (1969) and Raum (1972) observed that individuals cannot therefore exist in isolation. Individuals are said to owe their existence to other people, including past generations (now ancestors), and contemporaries. The community therefore makes, creates and produces the individual. Only in terms of other people does the individual become conscious of his/her being, his/her duties, privileges, responsibilities towards him/herself and towards others.

With specific reference to organ transplantation, studies in non-western societies have identified

the role of the extended family as the most important factor. In Puerto Rico, Fernandez, Zayas, Gonzalez, Morales Otero and Santiago-Delpin (1991) found that decisions were frequently made at family reunions and discussions. Thus even within the presence of the next of kin in the hospital (who in the western culture may be regarded as one who has a say in what happens to the patient), the family preferred to wait for other relatives, either senior or prominent living members of the family . Consideration was also given to elders of the family, irrespective of whether they were conversant with issues around donation and transplantation.

This reliance on family (social) structure was also found among Black South Africans. Gold, Mokone and Mongangane (1977) wrote that the extended family assumes major significance in decision-making processes which concerned the patient in terms of the kind of treatment to be embarked upon. The medical team's efforts, thus may be seen as interference with family decisions and may be resented. The family may react to what Gold et al. (1977) refer to as intrusion, and may influence the patient to abandon hospital treatment (dialysis or transplant) and seek help elsewhere.

2. Language

One of the difficulties faced both by patients coming to the hospital setting and the hospital staff receiving them, is that of language differences. The patient's language often does not have equivalent terminology to explain the relevant concepts. Gold et al. (1977) and Bisceglie and Mzamane (1983) point out the difficulty often experienced in explaining the natural history of chronic renal failure, to a patient who is not familiar with the medical discourse. In many instances hospital staff have resorted to using interpreters, as a means to breaking communication barriers. But even in this mode of communication there seems to be enormous loss of information between physician and patient, since with translation comes subtle changes in meaning (Shangase, Randeree & Schlebusch, 1993). An illustration by Ngubane (1979) makes the point clearer.

Ngubane (1979) maintained that the word 'medicine' in English means substances that are used to restore health. On the other hand, the Nguni word *umuthi*, (used by Xhosa and Zulu among

other Nguni groups), often used as a synonym for 'medicine', has a wider connotation. *Umuthi* (plural *imithi*) literally means 'tree' or 'shrub'. When used for 'medicine', it applies to noxious as well as curative substances. Another example that Ngubane (1977) gave was that of the word 'disease'. This refers to a serious derangement of health. The Nguni equivalent, *isifo*, applies not only to somatic symptoms but also to various forms of misfortune as well as to a state of vulnerability to misfortune and disease.

Given the foregoing illustrations, Hallem and Sodipo (1986) conclude that it is almost impossible to ascertain whether the meaning assigned to a word carrying a certain connotation in one language, is equivalent to that of a word in another language. Given the language barriers in the hospital setting, Washington (1993) highlighted that the use of language is one of the places where the real essence of cultural diversity is embedded. Furthermore, people's language reflect who they are and what their history has been. Thus Washington (1993) seems to be suggesting that the language is symbolic of a whole cultural context and is perhaps the tip of the iceberg in communication barriers. Some of these barriers will be discussed in some detail under the heading "Modern Versus Traditional perspectives".

3. Education

Coupled with language barriers in communication between staff and patients, Gold et al. (1977) further mentioned that patients' education levels impact on how patients understand and make sense of that which the hospital staff is trying to communicate. The lower the education level, the less chance patients are said to have of being able to engage meaningfully with hospital staff. This is because they are said to lack a conceptual framework that could allow meaningful engagement with medical jargon. Furthermore, many are said to be unclear about their illness, much less understand the purpose of treatment (Bisceglie et al., 1983). It is perhaps for this reason that several authors have written at length about possible education strategies that would give patients and potential donors insight into the concept of transplantation and hence help increase donor capacity as well as general awareness. Some of these authors are: Taylor and Hart (1989); Randall (1991); Davidson and Devney (1991); Dominguez, Gonzalez, Morales Otero, Torres and

Santiago-Delpin (1991); Toledo-Pereyra (1992); and Hong, Kappel, Whitlock Parks-Thomas and Freedman (1994). The 'campaign' for transplantation awareness seems to be focused towards minority groups, who have been seen to be resistant to transplantation due to sociocultural reasons (Callendar, 1987; Seedat, 1990; Kobryn & Kowiczyk, 1993; and Pike, Odell & Kahn, 1993).

4. Modern Versus Traditional Perspectives

Schlebusch (1985) argued that in South Africa the modern and the traditional are sometimes at loggerheads. Many black patients, particularly from rural areas, find the transition from a rural agrarian society to a western technological one a difficult process to cope with. Because of traditional belief systems that they bring into the modern setting, black patients do not easily consent to being dialysed (or transplanted). Patients may be hesitant to accept cadaver transplants because of the traditional value of human parts of the body (Schlebusch, 1985).

In tracing the context of this transitional difficulty, Ngubane (1979) argued that there is a general belief that non-Africans do not understand those notions of health, diseases and causation of disease that are based on African cosmology. Disease in this category are referred to as *ụkufa kwabantu*, meaning disease of the African people (Ngubane, 1979). The name is said to be used mainly because the philosophy of causality is based on African cultures. This does not necessarily mean that the disease or the symptoms themselves are associated with African people only, but rather that their interpretation is bound up with African ways of viewing health and disease.

Gumede (1990) concurred with the above notion by arguing that western medicine is based on what he called "The Germ Theory". The modern healer is said to be on a mission to find the offending organism, and eradicate it using pharmaceutical high technology now available to modern medicine. On the other hand, the traditional healer is said to make a diagnosis, decide whether the patient has been bewitched, and if so by whom. All this comes prior to the decision to heal. Thus the traditional healer, has been said to be holistic in his/her approach to treatment. It is perhaps the holistic approach in the latter treatment that explains health-seeking behaviour

among some societies in Taiwan. Kleinman (1979) demonstrated that while Taiwanese patients go to western doctors for the control of potentially life-threatening diseases, they go to traditional healers for personally and culturally meaningful treatment of illness.

Yet another bone of contention between modern and traditional perspectives is the significance of colour symbolism in traditional healing. Ngubane (1979) demonstrated that important symbolic colours among the Zulus are black (*mnyama*), red (*bomvu*) and white (*mhlophe*). They are said to be used in that order. The sequence is rigid and is never reversed. Black and red are said to be equivocal in that they stand for both goodness and badness, while white represents only good. While there may be significance attached to symbolic colours among some African cultures, western medicine does not appear to give much cognisance to this (Ngubane, 1979).

Given the clashes between modern and traditional perspectives, black patients are said to come to hospital to seek a second opinion and help, after consulting an indigenous healer (Schlebusch, 1985). At times patients find difficulty in reconciling the opinion of the indigenous healer with the present diagnosis. At the back of the patient's mind (s)he may still be clinging to the explanation of aetiology given by the healer. Therefore the history of kidney failure given by the physician may not be understood. The patient may be unwilling to express doubt, for possible fear of provoking a reaction in the physician (who in most cases is white). The patient may even be reticent in conveying his/her thoughts and feelings to black staff members who often act as interpreters (ibid).

Thus a major factor with regard to the clash between the modern and the traditional is the role of traditional healing (discussed below).

5. Traditional Healing

There ha been no definite pattern of health seeking behaviouramong African patients. Behaviour

is said to depend on the seriousness of the disease, material resources and the person who makes decisions in the household (Raum, 1972; Ngubane, 1979). In order to understand adequately the process of healing, it may be important to consider some of the causes of illness.

Causes of illness

Addles: The equivalent English word seems to be 'poison'. One has been given (to consume) something that will cause one to fall ill and eventually die if one does not get treatment readily.

Umeqo: (the verb is *ukweqa*) One contracts a disease by stepping over or walking through dangerous tracks. The environment (the track) may be also made dangerous by sorcerers, who place noxious substances on a particular person's pathway.

Ukuhabula: Undesirable elements in the atmosphere are picked up through inhalation or through contact either by touching or 'stepping over' (*ukweqa*).

There are several types of traditional healers that are consulted for the above mentioned conditions. To these we now turn.

Traditional healers

Isangoma: The English equivalent for isangoma is a diviner, usually female. She is said to be chosen into this profession by her ancestors, who in turn endow her with supernatural powers. She may divine by 'listening' to her ancestors, or she may throw bones and from the shape and position of such bones, she can tell the unknown.

Umthandazi: The English equivalent for *umthandazi* seems to be a prophet. (S)he stands as a medium between people and their ancestors to foretell diseases and major events, sometimes through the interpretation of patients' dreams. (S)he receives his/her revelations from God or the

spirits.

Inyanga: This is a traditional doctor who is usually male. He gets himself apprenticed to an already practising Inyanga for a period of no less than a year.

In addition to generally practising *izinyanga* (plural for *inyanga*), there are *izinyanga* whose skills concern the preparation of medicines for particular types of illnesses.

Gumede (1990) and Washington (1993) have argued that the process of (traditional) healing cannot be separated from (African) religion discussed in the next section.

6. The Role of Religion

Five components that constitute African traditional religions have been identified. These are belief in God, belief in the divinities, belief in the spirits, belief in ancestors, and the practice of magic and medicine (Mbiti, 1969; Idowu, 1973). Within these components, Idowu (1973) mentioned that a process of modification and adaptation has taken place. African religions, like all others, have taken into themselves elements from other religio-cultures, through immigrant religions, thus changing the complexion of local practices.

Raum (1972) reiterated this notion by mentioning that western and European cultures, in their multiplicity and diversity, are passed on to non-western societies through a great variety of channels and by agents with a multiplicity of purpose and motive. This then has resulted in most African customs being remodelled to fit new situations.

On a more radical note, Round (1982) and Gumede (1990) see western forms of religion as having come to Africans as an unknown entity, which served to alienate those who converted from those who held on to indigenous forms of worship. This state of affairs has necessitated a transition and adjustment of indigenous practices. Through these changes, God has remained central.

With God as the centre of African religious beliefs and practices, several authors have described how this God is perceived in Africa: God is seen to be Almighty, eternal and embracing all of creation (as a Creator of all). He is also seen as all good, merciful and protector, provider and sustainer (Mbiti, 1969; Idowu, 1973; Rounds, 1982; and Gumede, 1990). Be that as it may, God is also attributed with the potential to inflict pain and tragedy upon the world. This is partly for humankind to learn and be reminded of God's Almighty power. It is also the belief of many that though God is Almighty, he does not necessarily cause affliction, but rather allows it to come to pass, and may use this for His ultimate plans and purposes (Mbiti, 1969; Idowu, 1973).

God is said to have 'associates'. Mbiti (1969) referred to these as divinities. The word divinities generally cover personifications of God's activities and manifestations, of natural phenomena and objects. Included in these personifications are what literature loosely speaks of as 'gods', 'demigods', 'nature spirits', and 'ancestral spirits' (ibid).

Divinities are on the whole thought to have been created by God, in the ontological category of the spirits. They are associated with Him, and often stand for His activities or manifestations, either as personifications or as the spiritual beings in charge of these major objects or phenomena of nature (Idowu, 1973).

In terms of religion's direct relationship to organ transplantation (and donation), there has been much contention among researchers. Some (e.g. Fernandez et al., 1991) did not find it to be as significant as other factors, such as the family structure. Other researchers have found it to be a crucial factor, e.g. Townsend (1990), Hall, Calleder, Yeager, Barber, Duston and Pinn-Wiggins (1991), Sass (1992), Toledo-Pereyra (1992), and McCarthy (1993).

Researchers such as Sass (1992) have found that there are several reasons for the importance of religion. Some patients see the human being's body as one with the soul. This is a monistic perspective in which the wholeness and essential integratedness of body and mind are stressed (Sass, 1992). Thus to transplant an organ from one human being into another is to transplant the personhood of one into another. Dr Ellen Stein, chair of The Organ Foundation of South Africa, stated in a radio interview (13 August 1996), that fewer religions now than in the past, would

object to the concept of a transplant.

On the other hand however, there are religions which advocate that the soul -the seat of personhood- is separate from the body. The Christian religion, for example, sees the soul as existing within and dependent on, but separate from, the physical body. Hence when one dies, one's soul departs from the body (Sass, 1992). Therefore transplanting an organ from a dead body to a living person is not seen to have any implications on the soul and personhood of either party. Father Gabriel, of the Roman Catholic Church, said in the same interview as Dr Stein, mentioned above, that the church has no religious objection to transplantation as this is regarded as a religious attitude and practice of unselfish giving.

In the midst of disagreements among religions and transplantation, Gumede (1990) noted that as the new Africa emerges, with different hues of religions and urban complexes, large numbers of people are confused and unsettled. Thus both the rural and urban Africans, still turn to traditional healers to help with problems. Thus the traditional healer and the diviner are seen to still be part of the community (Idowu, 1973; Gumede, 1990).

The foregoing literature review has discussed several factors that have been found to impact on recipients of kidney transplants. These are; the extended family, language, education, modern versus traditional perspectives, traditional healing and the role of religion. It is these factors that form the theoretical basis for the present study. A discussion on the methods employed in this study follows.

CHAPTER 2: METHODS

CONTEXT

The study was conducted in the Renal Unit of Groote Schuur Hospital, Cape Town, one of the leading centres of kidney transplants in South Africa. This is a 20 bed unit. In 1996 the unit had 81 patients on haemodialysis (Table 1) and in 1995 had conducted 83 transplants (Table 2).

Table 1

Number of patients on haemodialysis and pentoneod dialysis at the Renal Unit in 1996

	MALE			FEMALE			
DIALYSIS	B	W	C	B	W	C#	TOTAL
Haemodialysis 10	6	27	9	2	27	81	
Pentoneod	-	5	13	2	6	24	50
TOTAL	10	11	40	11	8	51	131

#B = Black

W = White

C = Coloured

Table 2

Number of transplants done at the Renal Unit between 1992 and 1995

	MALE			FEMALE			
TRANSPLANTS	B	W	C	B	W	C#	TOTAL
1995	15	13	34	11	5	15	83
1994	18	12	25	13	7	24	99
1993	17	13	23	10	6	20	89
1992	13	10	23	7	6	16	75
TOTAL	63	48	105	41	24	75	356

As one of the leading centres in kidney transplantation, the Unit performs transplants on patients from all over the country. However, the majority of the patients are said to be from the Western Cape. The number and proportion of transplants seem to reflect the demographic pattern of the Western Cape, as illustrated in Table 2. In both male and females, so-called Coloured patients had the most transplants. Over the years, the total number of transplants seems to fluctuate. Between 1992 and 1995, the average number of transplants was about 86.

THE SAMPLE

Fourteen African patients (8 females and 6 males), who had undergone a kidney transplant, were selected from the unit's transplanted patients. All the patients in the study have had (a) transplant(s) more than six months ago and no earlier than 1982. Seven patients out of the 14 have had at least one unsuccessful transplant, and 2 have had to go back on dialysis, hence rejoining the queue for yet another transplant. The sample is made up mainly of patients whose families are based in the Eastern Cape (n = 10). All had come to the Western Cape in search of better job opportunities. Thus while they are rooted in the rural areas of the Eastern Cape, they are temporarily based in the Black townships of Cape Town. Most come from socioeconomically disadvantaged backgrounds. Patients' ages ranged from 19 years to 48 years. The mean age was 37,6 years (Table 3). The sample's average education level was Std 5, but it ranged from not having gone to school at all, to having completed Std 10. None of them have had a post-matric education.

Table 3

Social characteristics of the fourteen patients in the study

Subject	Age	Sex	Educ Level	Occupation	Marital	Residence Temporary	Permanent	Date(s) of Transplant	Dependents
1*	42	F	Std 4	Domestic Worker	Single	Crossroads	Transkei	1986; 1995	2 Kids
2	48	M	-	Driver	Married	Nyanga	Transkei	1995	4 Kids& wife
3*	47	M	Std 6	Unemployed	Married	Gugulethu	Gugulethu	1992; 1993	1 Daughter
4	27	F	Std 9	Unemployed	Single	Gugulethu	Transkei	1994	-
5	46	F	Std 6	Childminder	Divorced	Khayelitsha	Khayelitsha	1994	4 Kids
6*	45	F	Std 6	Domestic Worker	Married	Rondebosch	Transkei	1982; 1983	2 Kids
7#	42	M	Std 6	Packer	Single	Gugulethu	Gugulethu	1993	-
8*	32	F	Std 5	Unemployed	Single	Crossroads	Transkei	1988; 1996	1 Kid
9*	47	M	Std 10	Preacher	Married	Langa	Ciskei	1992; 1993	4 Kids
10	38	M	Std 4	Unemployed	Married	Khayelitsha	Transkei	1990	4 Kids
11	31	F	Std 9	Unemployed	Married	Khayelitsha	Transkei	1993	dep on Husb
12*	33	F	Std 10	Cook	Single	Hermanus	Transkei	1983;87;93	-
13	30	M	-	Labourer	Single	Simonstown	Transkei	1994	-
14#	19	F	Std 6	Student	Single	Gugulethu	Gugulethu	1990; 1992	-

PROCEDURE

Patients were initially contacted telephonically (those who had telephones), as a means of introducing them to the researcher and briefly orientating them to the study. As a follow up, a letter was written to patients, both in Xhosa and in English (Appendix 1 and 2). The letter was giving more information about the study, and formally requesting patients' participation. Patients were made aware of their right not to participate. Informed consent for inclusion in the study was obtained from all patients prior to interviews. Closer to the respective dates of the interviews, patients were contacted telephonically again, to confirm the respective appointments.

Given the availability of subjects for the study at hand , 18 patients were selected and 14 participated. Two patients died shortly before the interviews commenced and two more did not turn up for their interviews. The study made use of a qualitative method of research. A semi-structured in-depth interview was conducted with each of the 14 patients. Appendix 3 contains an outline of questions explored. Because of the open-ended nature of the in-depth interviews, questions in Appendix 3 were asked only to facilitate lengthy and elaborate responses from patients, and to explore their answers further. Interviews were conducted at the Renal Unit, in Xhosa - the first language of all the patients. Each interview lasted between 60 and 90 minutes. The interviews were not tape recorded, but notes were taken during each interview. After each interview, a summary of that interview was written up. This summary also contained notes on non-verbal gestures and the general atmosphere during the interview.

It must be borne in mind that this study was retrospective; patients were journeying back several years. This was an attempt to re-present and perhaps re-capture patients' thoughts, feelings and reasons for their behaviour patterns at the time of their illnesses. This retrospective nature of the research produces a re-construction and, to some extent, a re-formulation of their past, as they narrate their past. It is these narrations to which we now turn, in the next chapter.

CHAPTER 3: FINDINGS

INTRODUCTION

The present study's aim has been to ascertain how kidney transplant recipients attribute meaning to the transplant experience. Findings from this exploration will be discussed under five major themes that emerged. They will be discussed in order of importance, as narrated in the interviews. The themes are: religion and indigenous belief systems; the role of the extended family; and feelings about the actual transplant. In addition, the patients' contact with the hospital was explored, in terms of different routes that patients took to end up in hospital; and experiences in the hospital. Towards the end of this chapter, additional general emerging trends will be discussed.

It must be borne in mind that while the interviews were conducted in Xhosa, they are represented in English in this text. This may have implications on the kinds of words used, as translated from Xhosa to English. Furthermore, the process of translation may have implications for the amount of information lost.

1. RELIGION AND INDIGENOUS BELIEF SYSTEMS

A general belief that God is in control of all that unfolds in the world and in individuals' lives in particular, emerged from the interviews. Some of the patients mentioned that it is for this reason that He was seen to have been in control of all that transpired during the transplant. He is said to have known what was to come to pass and it was He who carried the process through. Two patients talked of God as the physician of all physicians. That God uses doctors as His instruments seems to complement Lysaught's (1993) argument that to some extent, the hospital team is symbolic of co-creators with God, as they labour hard to re-kindle 'life' in individuals. The concept of doctors restoring life seems to carry with it power, command and authority. It seems that it was in this light that doctors were seen to be God's messengers by the recipients in this study.

It was God's power that endowed doctors with the knowledge and sophistication that brought about healing. In fact the general perception was that it was God who healed, using doctors as

His instruments. This concurs with Idowu (1973), who asserts that God is perceived to be having an indefiniteness about Him that allows Him to be the Almighty.

Although there seems to have been a uniform perception of God's role in the transplant and healing process, along a continuum patients located themselves in terms of the practicalities of how God, as the centre of the supernatural world, worked with and around the latter to bring about healing. Three main categories emerged from this continuum.

FUNDAMENTAL CHRISTIANITY

This group saw their illness, pain and suffering, prior to transplant, as either a result of sin that they themselves might have committed or that others around them committed, thus indirectly impacting on them. It was patients' understanding that God allowed (but did not necessarily cause) this to happen as He is not only a provider of good things, but also One who allows for tragedy so that His people can learn from these. Patients took refuge in the thought that the illness is momentary, spiritually and physically speaking.

Furthermore, through their pain and suffering, patients found encouragement in the lives of many men and women of God quoted in the Bible, who had to endure hardships, trials and tribulations for a reason. Mostly the reason given for such hardships was to be groomed and purged. Patients understood this process as one where they are taken through an experience of knowing God a lot more deeply than they have up until then - a 'reminder' that He is still Almighty and in control of all. In speaking elaborately about figures in the Bible three patients quoted Job and Abraham as heroic men of God in biblical times. The patients saw themselves as walking in a similar path of hardship and pain, as those gone before them. Thus, despite the pain, it was worth enduring because other more honourable men (and women) went through similar trials. Over and above the distress of illness, patients held on to a promise of eternal life in the hereafter, that was free of pain and sorrow.

It is interesting to note that in the midst of the adversity and pain that the patients were going through, they were still able to hold on unshakingly to the concept of an Almighty God who is seen to be all good and in control of all. This brings to mind Rowe's (1982) assertion that adversities and doubt bring our belief to mind, for inspection and for modification or

reaffirmation. It seems that the interviews provided a forum wherein patients could reflect and perhaps reaffirm their respective belief systems. Rowe (1982) however, would tend to see the unshaken belief systems that people held on to, as a consequence of fear of ultimate spiritual death. Rowe saw this belief in God as linked to a belief in judgement and wrath. He thus seemed to have suggested that part of patients' holding on to a 'good God' is out of fear of not being rescued from illness, by that very God. Another reason is the possibility of being condemned to spiritual death on judgement day.

Experience has it that one human's belief system is another's delusion. It seems that orthodox Christianity would be incompatible with the following more indigenous belief system.

GOD AND ANCESTORS

While the foregoing group dismissed any belief in ancestors (*izinyanya*), the overwhelming majority of the sample perceived God to be the ultimate control of all, and has chosen to work together with ancestral spirits, to bring about protection and rescue among earthlings. *Izinyanya* are spirit beings who are said to intercede to God on behalf of human kind. Though they (*izinyanya*) might know the intricate plans and purposes of God, they are a gateway to God. They have been humans, they can therefore fully identify with the suffering and the pain that comes with the human condition. At the same time they have transcended this world, and inhabit the spirit world. The latter is said to give them some power to impact directly or indirectly on the lives of their loved ones on earth. It was many patients' belief that through the transplant, *izinyanya* have been 'praying' for patients, pleading with God for healing. Mbiti (1969) has mentioned that from time to time, *izinyanya* themselves may be given a 'mandate' by God to come and 'take death away'. This belief was demonstrated by one patient who spoke of having been visited by one of her ancestral spirits in a dream, at a time when she was most sick and had lost all hope of ever surviving kidney failure. She believed that visit had come about to rescue her from death.

The role of *izinyanya* in the lives of patients, similar to Christianity, seems to be yet another unshaken symbol of belief. Though one may agree with Raum (1972) and Round (1982) that belief systems are constantly impacted upon by sociocultural change, and therefore constantly being modified and changed, the present group of patients seem to have contradicted this. A

belief in *izinyanya* seems to suggest that even through adaptations and changes, some aspects of certain belief systems stand the test of change. This argument then concurs with Idowu (1973) and Gumede (1990), that in the face of instability and adversities, African people turn to their own belief systems as a refuge.

Another part of African belief systems seems to be witchcraft.

WITCHCRAFT

A small group of patients, though believing in the supremacy of God and in the power of *izinyanya*, believed that their respective illnesses came from bewitchment (the Nguni word for this is *ukuthakatha*). Thus the beginning of any kind of healing would start with finding out who is responsible for the illness itself. This would be escertained from *isangoma. Isangoma* is a diviner, one who has been endowed with the power to see beyond the natural, into who has done what to whom, in terms of bewitchment, as to who is responsible for the patient's illness. As Gumede (1990) has described, *isangoma* plays the role of the diagnostician, prior to any form of treatment. Some of the aetiological understandings given to patients by *izangoma* follow below:

* *Udlisiwe:* The patient was given poison (to consume). This is said to have caused the patient to fall ill.

* *Unyathelile*: A patient is said to have stepped on something, either visible or invisible (along a pathway) that has been put there specifically for him/her, to cause ill health.

* *Amabekelo*: Similar to *ukunyathela* above, *amabekelo* are said to be entities that when one touches, one falls ill. These may take the form of objects or appliances.

It is interesting to note that the concepts of *udlisiwe, unyathelile* and *amabekelo* are similar to those discussed by Ngubane (1979). Though Ngubane's (1979) work was based on Zulu customs specifically, these belief systems seem to be part of the lives of many traditional African societies, as demonstrated in the present study of Xhosa speakers. However, due to language differences in Africa, similar concepts are named differently. For example, the Xhosa word *"unyathelile"* is translated into Zulu as *"weqile"*, as Ngubane (1979) has discussed.

Patients felt that bewitchment is untreatable by medical doctors in particular, much less by western medicine generally. This is because the latter cannot recognise the 'poison' as a separate and more potent entity than the presenting symptoms which are altogether too familiar to the western medical practitioner. A forty-two year old man explained how he had been bewitched by a girlfriend who did not have the courage to break up with him. The 'poison' (udliso), which she is said to have put in his food, manifested a few months later as a painful lump towards the left of his chest. Doctors are said to have operated on the lump and removed a yellowish substance (prior to transplant). However, a few months after a successful transplant, a similarly painful lump emerged, which was again removed. This convinced the patient that no matter how hard doctors can work and celebrate momentary successes of having treated patients adequately, bewitchment is invincible. This belief was further reinforced when the patient's first kidney transplant failed.

Literature has tended to see witchcraft in Africa as a kind of false belief, that could be understood in the western perspective as a consequence of social 'stress' or neuroses, or dis-ease. Hallem and Sodipo (1986) see the so-called witch, usually a woman, to be a victim of the social forces that are beyond her control, an involuntary scapegoat who is forced to confess to excesses that are patently empirically impossible, thereby highlighting in an indirect manner the underlying social problems for which the society must victimise her. In a reciprocal manner, having such people to blame helps society to cope with and to control the underlying, hostile social forces (Hallem et al., 1986).

It is for this reason perhaps that some theorists in the field have suggested what Parrinder (1970) -cited in Hallem et al. (1986)- refers to as social engineering programmes that will 'enlighten' society into seeing beyond the myths that inform the collective experience of the world. Parrinder (1970), quoted in Hallem et al (1986) further suggested improved medical services and religious beliefs that place greater emphasis upon spiritual values (e.g love) that are somehow antagonistic to the fearful atmosphere in which the witchcraft phenomenon thrives.

Parrinder (1970), as quoted by Hallem et al. (1986) seems to have underscored the power and purpose of such social constructions of the world. These seem to allow societies, and particularly individuals within those societies, to survive and thrive. It does not seem that it is necessarily out of a wide array of world views that people choose to hold on to particular belief systems (as Parrinder suggests people should choose other 'better' ones). Instead, it seems, as Rowe (1986) suggested, that world views and belief systems are adhered to as a result of unfolding of

individuals' experiences and hence a consolidation of those respective experiences into world views. This is to keep stable and secure, the internal and indeed the external world of the individual. Thus to introduce education programmes in the name of shifting world views may be an ambitious task, that indirectly denigrates, disregards and downplays individuals' frameworks of meaning. This may be particularly the case when one considers Rowe's thought that "Metaphysical beliefs seem to be held with greater certainty than rational beliefs" (1986, p.48).

It is interesting to note that in the light of patients' entrenched belief systems, some of which did not appear to be compatible with the medical model (e.g the invincible lump on the 42 year-old man's body), patients seem to have acted according to the medical explanations of what was seen to be wrong with them (i.e. coming regularly for treatment). Be that as it may, these medical explanations did not erode, much less have the same weighting as those that have formed part and parcel of patients' meaning of life with and or without illness. Once again the findings seem to suggest a desperate need to hold on or to appeal to a force bigger and more mystical than scientific explanations that could possibly rescue beyond the physical endeavours of the doctors. Idowu (1973) suggests that for the sake of people's psychological well being, they need something more and beyond the the Europeans' mere 'coloured water' or mere pills. It is worth mentioning Idowu's conclusion that in matters concerning providence, healing and general well-being, most Africans still look to 'their own religion' as 'the way'.

Ngubane (1979) agreed with Idowu (1973) and went on to say that the concepts of illness and healing in the African context are closely linked with African culture in its entirety. Given African culture and frameworks of meaning therefore, it seems appropriate that transition from these to a western medical world view may be a stressful process, as Schlebusch (1985) purported. The process of transition may be particularly stressful because in traditionally African settings, the frameworks of meaning are shared communally and thus form and enhance a collective experience of the world (Mbiti, 1969). Individuals are constructed by their respective societies at large, and by the family relations in particular. Thus individuals cannot conceive of themselves in isolation. It is for this reason, it seems, that the role of the (extended) family became the second most salient factor in the study.

2. THE ROLE OF THE (EXTENDED) FAMILY

In African families individuals do not make decisions in isolation; instead elders in the family hold the authority to make decisions (Raum, 1972). This is done either in the absence of a family meeting or when the decision to be made is seem to be too big for the younger generation of the family. Thus even when a family member is far from the home base (s)he may still need to report home as a way of respecting the family order and structure.

In the present study all but four of the patients originally come from the rural areas of the Eastern Cape, as discussed in Chapter 2. Most came to Cape Town on account of job hunting. Thus the (family) roots of the patients are said to be entrenched in the rural life style and its values. All patients from the rural areas reported that none of the family members (back home) knew about the concept of organ transplantation. Thus when patients broke the news of the possibility of a transplant to the family, family members, particularly those who are senior in the family ranking, were horrified and even resisted the possibility of their son/ daughter going through a process they had never heard of. Some family members are said to have tried to sabotage the process. Elders particularly suggested and insisted on repeated visits to traditional healers, even though in most cases these visits had proven to be without much benefit.

This finding is in line with Fernandez' et al. (1991) findings that elders seem to have more of a say in a family member's life who is ill, irrespective of their (elders') insight or lack thereof, about the illness itself. However, what is unique about the patients in this study is that most have been physically removed from the extended family structure. Thus patients seem to have had more of autonomy than they would have, had they been based permanently in their respective families. This autonomy however, seems to have been at a cost of some family relations.

Many patients took the decision of having a transplant on their own, away from home. This in itself seems to have created tension between patient and family. This was particularly the case when the patient was seen by the family as having little say, if any at all, in important matters that have to do with life and death. This tension seems to be an inherent factor in rural patients moving away from their respective home bases to urban areas. As Schlebusch (1985) pointed out, the transition from a rural to an urban (i.e from traditional to modern) way of living is a process of letting go of the one and embracing the other. In the light of this transition, Uyanga (1983) argued that there is a marked difference in disease beliefs and related health care behaviour between rural and urban residents. Shangase, Randeree and Schlebusch (1993) confirmed this notion and went on to assert that the reason for this is that each society has its own distinctive cultural pattern that

is acquired according to its own history of cultural contact with other societies. It is this contact, they say, that has dichotomised urban and rural black people's conception of healing. Western medicine and traditional healing respectively are said to be regarded by urban and rural dwellers as superior. This argument seems to throw some light on one of the possible causes and nature of tension between patients in this study, who have now been urbanised, and their rural-based families. However, while patients were seen to break ties with traditional values, they still carried with them some parts of that world view. For example, many held on to God and ancestors, as has been demonstrated in the discussion on the role of religion above.

In most cases family members were told about the transplant procedure afterwards. There was more than one reason for this. Patients felt they needed to protect themselves against criticisms of not having conformed to the norms and values of the family (namely taking the route of traditional healers).This may have been an attempt to minimize the already present tension, as discussed above. Furthermore, patients reported the need to protect the family from anxiety and distress about the uncertainty of the outcome of the procedure.

Thus in most cases patients felt unsupported, particularly by the family, betrayed by their own 'flesh and blood' and alone. The voice of Sara Joseph, in a poem titled **Someone Alone**, seems to capture the essence of patients' loneliness (see Appendix 4). In some of the cases, the major source of loneliness was the fact that patients had appealed to the family members for organ donation, but members refused, on the basis that they themselves feared not waking up after the procedure. More importantly, family members could not understand how they would be able to live a normal life, having had a part of their body taken out. There seems to have been a general understanding that human beings are created whole, with sufficient body parts to allow them to engage fruitfully with the world. Therefore, an attempt to disrupt that natural process is to bring death much nearer than it originally was.

It is perhaps partly this perception that accounts for the low rates of organ donation among Africans. Hence vigorous attempts are made to break through language and communication barriers in order to educate some of these communities. However, it may, be important to consider Washington's (1993) argument that language is not the only obstacle to people understanding and even accepting the concept around transplant. Instead, embedded in language, there are an array of sociocultural symbols and underlying sets of meaning. It seems therefore that the implications of education may, to some extent, be a sacrifice of one world view, to be

replaced by another. Be that as it may, in the present sample patients seem "torn" between the two world views, namely the urban, modern and the rural traditional, of which their families are still part.

It seems that family members' own fears about the 'unheard of' transplant made them resistant to letting patients go through with the procedure. Patients' feelings of aloneness and alienation seemed to have been an act of sacrificing some aspects of their indigenous belief system for the sake of trying out other avenues that seemed more promising in terms of restoring their health. However, this was met with further resistance from the sociocultural context from which the patients came. Hence the tension between the individual and his/her sociocultural context seemed to have been amplified, particularly in the light of Mbiti's (1969) argument that individuals can only be defined as part of a collective.

One important aspect of these patients' experiences of the transplant, was thought to be how they landed up in hospital. This was probed in the interview.

3. TRACING THE ROUTE TO HOSPITAL

Patients took several different routes, they tried several avenues and options open to them. In order to appreciate these different routes fully, one has to consider how patients first discovered they were ill and how they responded to this.

A number of patients reported that they had been suffering from high blood pressure (HBP), long before the onset of kidney failure. In fact a 46 year-old woman attributed her kidney failure to the many types of medication she had been using for HBP and the high stress levels she had been under (recently divorced). Thus when patients saw symptoms such as the swelling of the body, and particularly swelling of the legs, high blood pressure patients thought it to be related to their chronic condition. The majority of the patients remembered having one or more of the following symptoms: Swelling of the body, as mentioned above; intense and acute back ache; persistent headaches; shortness of breath; onset of visual problems, particularly short-sightedness; vomiting; and urinating blood. One 45 year-old woman remembered having recurrent nose bleeds. A 48 year-old man said family members had told him that on occasion he had gone through a phase of

making inaudible utterances when spoken to. Because he could not remember this, they thought of him as momentarily having lost his mind.

Several women developed symptoms of swelling of the body during pregnancy (mainly between the sixth and the seventh months of pregnancy). Many reported having had to deliver prematurely as either their heart and/or kidneys were said to be swollen and thus 'squeezing' the unborn baby. A woman who had symptoms of back pain immediately after delivery, said she attributed her symptoms to the possibility that "things might have gone wrong during the delivery".

Patients were worried about the progressive loss of weight. The latter seems to have been a metaphor for existential depletion, especially since the community at large would comment on how terrible they looked. One patient who had been rushed to the hospital and had spent several days in bed, woke up to look at himself in the mirror. He reported being horrified by the image he was staring at. It looked nothing like the person he had been, prior to admission. He went on to describe vividly how he stared for a long time at the mirror, needing to absorb and integrate this image into his sense of self: a pair of huge, protruding eye-balls looked like they were about to fall from his forehead, cheek bones were as prominent as they could be under the delicately hanging skin. This was to be one of the many moments where this patient came face-to-face with death.

In keeping with the norms and values of their respective sociocultural backgrounds, most patients went to several *izangoma* (plural for *isangoma*) - to get a diagnosis and an etiological explanation of what had brought the illness about. The purpose for going to more than one was in order to verify and thus validate whatever explanation was given in the first instance. From *isangoma*, patients in this route went to an *inyanga* -one who heals with traditional medicine, based on the presenting symptoms. The treatment consisted of one or more of the following procedures:

* *Ukusela:* The direct transplantations of this word is 'to drink'. The patient is given what is called *ibhotile* (literally meaning ' bottle'). This represents different types of medicine (*umuthi* in Xhosa) that the patient drink.

* *Ukuhlamba:* This word translates as 'to wash'. A patient is given medicine to wash him/herself with. This is either done at *inyanga*'s place or the patient takes it home with him/her and follows the given instructions, depending on how ill the patient is.

* *Ukufutha:* An equivalent word for '*ukufutha*' is 'to steam'. The patient's face is held over a pot of boiling water, and the inhalation of the steam is said to be part of the healing process.

Once again these concepts are equivalent to those used by Ngubane (1979) and Gumede (1990), when discussing forms of healing among the Zulus. However, once again, though the concepts are the same, Zulu and Xhosa words differ.

Following the treatment, patients either got better for a little while, or nothing changed, or they got worse. Thus, having explored all forms of traditional healing and found no help, patients resorted to western medicine. Contrary to Idowu (1973) and Gumede (1990), who purported that in the face of adversity, African people seek refuge in their respective traditional medicine, patients in this group ventured to the hospital setting when all else failed. Patients seem to have held on to their religiocultural ways of explaining their illness and their healing, yet faithfully went to hospital for treatment.This oscillation between their traditional world view and behaviour that does not concur with that world view, points to a process of adapting to sociocultural changes, both for the world views and the individuals located within them. In the midst of social change and adaptation, particularly of some traditional African practices, Africans seem to be exploring beyond the boundaries of what indigenous customs have advocated for generations. But with this process of venturing beyond the known, inevitably there is stress and tension, as several authors have pointed out earlier in the discussion on religion and indigenous belief systems and in the role of the family.

The second route that some patients took was to go to the local clinic, in the light of the symptoms (i.e headaches and back aches) not being severe enough to warrant an indigenous aetiological explanation. This concurs with Ngubane's (1979) argument that health seeking behaviour depends on the severity of the symptoms, among other variables. Ngubane went on to say that the less severe the symptoms, the less likely patients are to consult *isangoma* for

diagnostic purposes. Most of the patients following this route reported being referred from one clinic to another. Not much was explained to them in the process, while the symptoms were progressively getting worse. In the light of patients' lack of understanding and anxiety to get rapid relief from symptoms, this group then went to traditional healers to seek a second opinion. Most patients reported being told by traditional healers to stop western medication, and the healer started them on indigenous medicine, most of whose relief lasted no more than a year. Again the treatment was made up of different variations of *ukusela, ukuhlamba* and *ukufutha.*

That traditional healing did not have lasting effects in patients, confirms a perception that traditional healers are not efficient in their healing practices. Joubert (1984) argued that the commonest cause of acute poisoning among Black South Africans is traditional healing, second to paraffin. Sherwood (1995) later said "I cannot conceive of how we can be seen to support people who concoct '*medicines*' that include human parts and parts of wild animals...". These general perceptions of what traditional healing is about, is based on patients who experienced traditional healing as a failure. It must be acknowledged that patients who present in hospital following a failed traditional treatment, are a small proportion of patients who go to traditional healers. The majority of patients attending traditional treatments may not present to the hospital as they may have benefitted from the former. Sue Derwent of Mail and Guardian (July, 1996), estimated that 80% of South Africa's population consult traditional healers. Derwent went on to say that so little is known about this neglected field because in the past authorities dismissed it as witchcraft. The researcher makes the point that though patients in the present study did not find help in traditional healing, the latter cannot be devalued and dismissed. It still seems to have cultural importance.

Another sub-group of patients attended western forms of treatment (clinics and hospitals) concurrently with attending traditional treatments. At times patients were faced with a dilemma as to which form of treatment to give up: traditional or the western. This was because the two forms of treatment are said to have been incompatible, and often gave contrasting prescriptions. For example, several patients were told by a medical doctor not to drink too much water as the kidneys would not be able to regulate the excretion of this water. The traditional healer on the other hand prescribed that the patients drink as much water as possible in conjunction with

ibhotile, discussed above, so as to rid the body of the 'infection'. The dilemma of which form of treatment to choose may have carried with it, the tension that comes with having to sacrifice one framework of meaning for another, as discussed by several authors (Idowu, 1973; Rounds, 1982; and Gumede, 1990).

A few patients consulted only the western medical practitioner. It is interesting to note that this group coincides with those who strongly adhered to an orthodox Christian religion. When asked reasons for not exploring other options like traditional healing, these patients dismissed the latter as primitive and inaccurate as the practitioners have not been formally trained to perform some of the duties that they do. One patient dismissed traditional healing as mere filth.

An overall observation was that the patients that seemed to have done the most 'touring' and 'shopping' around for the most appropriate form of treatment, were also the ones that seemed to have idealised the medical profession more. This idealisation may have come from the sudden relief from a chronic condition that patients may have thought was their cross forever.

4. FEELINGS ABOUT THE TRANSPLANT

In unpacking the patients' feelings about the transplant, three broad themes will be discussed: pre-transplant thoughts and feelings; the actual transplant experience; and post-transplant conceptualisation of all that had come to pass.

PRE-TRANSPLANT

Patients, while on dialysis, were told briefly about the process of awaiting a kidney transplant and the implications (i.e that there was uncertainty about when any donated kidney would arrive). Furthermore, even when a donated kidney had arrived, its blood type would need to be compared with that of the patient's in order to match them correctly. There may also be a waiting list, as

the demand historically has been greater than the supply. In the mean time, they were told their companion would be the dialysis machine. Patients were urged to be in a state of readiness, as a kidney could be available at any time. This news, however warmly and reassuringly it was said to be broken to patients, usually by doctors and/or nursing staff, seems to have left the patient in a state of uncertainly and grimness about what the future holds.

The same patient who felt he had come face-to-face with death while staring at his thin self in the hospital mirror, painfully narrated a second, more intense experience. During one of his several admissions to the ward, he remembered doctors assembling around his bed, curtains drawn, and how they quietly broke the news that they could do no more for him, especially as there did not appear to be a donor in sight. For him it had become obvious that the doctors had done all that they could, but perhaps they did not have the resources to save his life. Here the taste and feel of death seemed worse than the physical pain and anxiety he so wanted to escape. It seemed at this point that the only determining factor would be God Himself.

Most patients heard that they finally had a donor, **when they least expected it.** Some received phone calls, summoning them to come to hospital urgently, as a kidney was available for them. Others who were not reachable by phone were pleasantly surprised to see a hospital car coming to fetch them. Immediate emotions that patients reported were those of disbelief, thinking that they were dreaming and they would probably wake up. Other feelings were relief, mixed with ecstasy, yet anxious about the thought of all this being a rude joke. One woman summed it up by saying for her, it was Christmas day - all would be well, the worst was over. Patients' feelings on hearing the news seemed to point to the realities discussed by Macdonald (1993): that patients often have no time to absorb, ponder and reflect on the meaning of what is about to take place. In this instance too, patients were taken by surprise and could only respond to events as they unfolded. Patients did not have a forum to reflect upon the implications of having a kidney donated, and of finally having a transplant. There was a general sense of not having had adequate time and space to prepare themselves, much less their families. Given the nature of traditional African families, as discussed earlier, one may assume that to absorb the news on transplantation may take more time than the availability of a kidney.

A pattern that emerged among the patients hearing the 'good news' is that those who had a transplant before, and were about to have a second and sometimes a third, were rather sceptical and hesitant to take up the offer. But the thought of having to come to dialysis three times a week seemed to have been one of the only motivating factors to go through with the procedure. A 33 year-old woman who has had three transplants reported constant anxiety about the possibility of her 'third kidney' failing. She wondered if the hospital would be prepared to give her another chance, as she might be perceived as wasting opportunities for others whose bodies might hold the transplanted kidney better.

Another pattern that emerged is that the longer the patients had been ill, the more they seemed to have valued the kidney. They seemed to have been more analytical about the transplant process in the context of their lengthy illness. This seems to suggest that through the process of them being submerged in the grimness of what it means to live with a chronic illness, patients had to continuously rethink and reconstruct the experience in such a way that they were better able to live with and survive it. Furthermore, the patients that had been ill longer seemed to have had to grapple with the reality and proximity of their death more readily than others in the sample. This in turn forced them to ask questions about the meaning of life, the purpose of existence and what it means to be non-existent. It was perhaps this process of continual evaluation that gave the rich analytical flavour in the interviews of those who had been ill for much longer.

Over and above the different patterns that emerged while patients were awaiting transplants, there seemed to have been a general surrendering of patients to the natural (or maybe unnatural) unfolding process that was to determine their fate. Newnes (1991) suggested that the awareness of one's personal death has a potential of acting as a spark that shifts one from one mode of existence to a higher one. This is symbolised in a patient, whom, prior to yet another admission, silently said to himself "if I meet my death now, God will have willed it" (This is paraphrased from Xhosa). This is quite close to Noyes' (1978) findings on people's interpretations of near death experiences. He reported that at a certain level of surrender to death, there is no more anxiety, no trace of despair, no pain, but rather calm seriousness, profound acceptance, and a dominant mental quietness and a sense of surety. In a similar sense the patient under discussion paid off most of his bills, went to church to re-dedicate himself and re-united with his religion. But most

importantly on the day of admission, he specifically asked his wife to prepare a large meal for him and the family. This was to symbolise for him, his last exit from his home. The final ritual seemed to carry with it a kind of dignity that suggested that he had said his farewell, however indirectly.

Ironically, it seems that it was this quiet surrender to the inevitability of death that gave patients the resilience and emotional resource to face each passing day. Maybe the adjustment to this frame of mind contributed to them being shocked to the point of disbelief when they heard of the news of the eventuality of a transplant.

ACTUAL TRANSPLANT

Twelve out the fourteen patients expressed a feeling of fear of the possibility of not waking up after the operation. The operation was seen as a process of 'dying', while doctors worked on one's body. Then gradually one is expected to come back when the doctors were finished with the procedure. The process of coming back seemed to have been the most frightening part of the whole operation. Patients spoke of this process lasting anywhere from an hour to several hours. Patients believed that much as the doctors were in control of the operation procedure, the responsibility of 'coming back' was said to be left with the patient. This was said to have been one of the times that patients needed God and *izinyanya* the most. This fear of the possibility of not waking up corresponded with the general belief systems adhered to by the patients' family contexts - a fear of annihilation, an experience beyond the known. One patient said he cracked an anxious joke just prior to the transplant procedure: "it's time to go to the slaughter-house now".

Much as patients experienced an intense fear of death and dying, they experienced feelings of urgency to escape the pain of months and sometimes years of dialysis. Patients would have more autonomy and control over their lives, no longer having to come to the hospital for dialysis, for most of their time in the week. So with the transplant, life promised to be more 'normal'.

Thus the build-up to the transplant and the actual experience seem to have been approached with ambivalence. While relieved that 'the moment of truth' had arrived, patients were equally scared

of the possibility of the procedure being the last experience they would ever have. For all, it was a risk worth taking.

POST-TRANSPLANT

Most patients spoke of the feeling of rejuvenation, that they have been given a second chance in life. Some of the reasons stated for this second chance was to make right all that they might have neglected, and to live life to the full and be more appreciative of the little things that make life what it is. For example: the ability to urinate freely without thinking about the complications that came with the illness was mentioned by many. One man spoke of feeling that he had experienced a re-birth. Through the power of this conceptualisation, he planted a garden patch. As he watched it grow, it symbolised his own growth in the new life.

A 42 year-old woman saw the whole process of her illness and eventual healing as God's way of allowing her to touch the absolute foundation of suffering and loss of any hope, so that she could be taken to greater heights emotionally, spiritually and even materially. In her words, paraphrased in English: "... God has brought suffering to my life so that through this suffering I can gain riches on this side of eternity. Who would have known that I would be able to feed my children? Who would have known I would be able to buy uniform for them? My enemies stand amazed at the miracle of my having been revived from the dead...". As she spoke, her eyes welled up with tears, demonstrating how far she has come, with God on her side. This sense reiterates how other patients, with similarly chronic, illnesses conceptualise their lives. Ruderman (1979), in writing about his experience as a cancer patient, said "If life could be measured in 'units of experience', I am sure that the number of units has increased significantly since my encounter with cancer" (1979, p. 14).

Literature has suggested that in African communities, individuals are defined in the context of a collective (Mbiti, 1969; Raum, 1972; Idowu, 1973). However, the following finding seems to suggest a shift. Many patients felt overwhelmed by and grateful for the transplant 'miracle' that had befallen them. They wished that there could be some educational programmes that tell the

world of their experiences. Be that as it may, the majority of patients were reluctant to talk about their experience in their immediate neighbourhoods and respective communities. There seemed to have been a need to preserve a kind of privacy about their process of suffering and subsequent physiological well-being. Coupled with this was a sense of self-consciousness about being the focus of attention, particularly in the light of many people in their respective communities not knowing much about the concept of a transplant. One woman said she avoided speaking about the transplant as she was weary of people feeling sorry for her, out of a lack of clarity and deeper understanding of what had happened to her life.

Contrary to what the literature has suggested about the collective experience of sharing in some African societies (Mbiti, 1969), findings in the present study perhaps demonstrate that as individuals move from their traditional sociocultural contexts, they adapt to new situations as these present themselves. They seem to have kept more to themselves than they might have, had they been in their families and more closely knit sociocultural contexts. An example of this is that in urban settings people come from varied sociocultural contexts, for example, different rural settings. Because of this, urban settings may be a less communal milieu. As a result of the lack of a sense of communality, people may tend to be more individualistic in their daily living. This concurs with an aspect of Idowu's (1973) assertions that social change comes with sociocultural adaptation and the modification of world views. The findings differ from Idowu's subsequent argument that in the midst of this change, people resort to ways of old. Perhaps if the latter were the case, patients would not have had the transplant.

In terms of the donor, all patients but one would have wanted to know where the kidney came from. Patients would have liked to thank the respective families and the actual donors if they were still alive. For most, that they did not know did not matter much, what mattered was that they themselves were well and they had been given a second chance in life. However God chose to bring that second chance about was least of their worries. This finding contradicts most literature that speaks of recipients' guilt feelings about the deceased and, though grateful to be alive, they do not feel justified to have survived (Macdonald, 1993). The present sample gave reasons for why they thought they had been given a second chance in life, namely to make right what was not, and to be more appreciative of the simple things in life.

5. EXPERIENCE IN THE GROOTE SCHUUR HOSPITAL (GSH)

Though patients reported varied experiences within the hospital system, ranging from excellent, satisfactory to poor, and having many anecdotes to validate their perceptions, two main themes emerged from most narrations. These are: that the hospital was invariably associated with pain; and that the hospital was held in high esteem for what it had done for them.

Patients invariably associated the hospital with pain, as many were on dialysis for a long while before they received transplants, as discussed above. In fact one man made mention of the fact that his daughter had begun to refer to Groote Schuur as 'daddy's hospital' because of the amount of time he spent there. For many the hospital had become their second home.

Patients further reported having acute anxiety on days when they had to come for treatment. Though patients knew this was good for them, they had a somewhat punitive image of what the hospital represented in their lives. Several patients spoke of how much of an effort it was in winter when they had to brace the cold and the rain, just for the sake of faithfulness to their health. At times there would be spontaneous taxi fights and it would be virtually impossible to get to hospital, but against all odds, patients had to make means. Much as the hospital was perceived to be persecutory, it was a better evil than skipping one visit and having many near-death experiences at home (suffocation, and swelling of the body due to intake of fluids without sufficient excretion).

Coupled with feelings of anxiety about and towards the hospital, patients seemed to hold the hospital in high esteem. Several patients spoke of the historical importance of Groote Schuur as it was the first hospital to perform a heart transplant. Thus because of its legacy, patients saw themselves as being in capable hands and thus had more space to worry about their day-to-day coping rather than the quality of the treatment they were getting. Furthermore, patients tended to compare the kind of treatment they were getting at Groote Schuur with that which they had received on their respective routes of trying to find healing. Against that background therefore,

the hospital seems to have been idealised. One Christian patient metaphorically labelled the renal unit team 'preachers of the good news of healing', because of what they had helped bring about in his life.

Only two patients reported that they needed a translator, as they could not understand what the medical staff were trying to communicate to them. This was despite most of the patients having an average education level of Std 5. This finding goes against literature that see language and education levels having an impact (negatively) on the communication between patients and staff (Bisceglie et al., 1983; Gold et al., 1992). This is a communication barrier that is so often observed in the hospital setting. There were a few patients who had colleagues who had either suffered from kidney malfunction, and are said to have oriented the patients to the general procedures that would most likely be followed in the hospital setting. This seems to have compensated for the possible misunderstanding of the unfolding processes.

6. OTHER GENERAL TRENDS

EMOTIONALITY

In most interviews patients narrated their journeys with marked emotional intensity. Five patients broke down and cried as though reliving the stress of the transplantation period. At the same time they seemed to have been looking back in time through tears of celebration for having endured and survived. Whatever meaning attributed to that intensity, the interviews seem to have allowed patients to unravel new insight as they re-presented their lives and as they thought through questions. Owen (1996) argued that interviews in sensitive areas of people's lives do more than just collect and accumulate data: at times they serve as a forum for catharsis for the emotionally laden topic at hand. This rather unique interview process may therefore alter, to a greater or lesser extent, frameworks of meanings. This however, is not to say that whatever information has been gathered under these circumstances is invalid and even unreliable. What it does suggest though is that in different contexts and different types of atmosphere, a researcher will gather types of information that are flavoured by the interviewee's current state of mind.

INTERVIEW CONTEXT

Another theme that follows directly from the above is that of the physical space where interviews were conducted. As mentioned in Chapter 2, interviews were conducted at the Renal Unit in Groote Schuur Hospital. Given the associations that patients have made with the Unit and the hospital at large, it could be argued that the milieu, impacted, either directly or indirectly, on how patients re-presented their narratives. It is interesting to note that in most interviews patients spoke of their journeys as though they were 'reporting' back to the hospital (in the person of the researcher) how far they have come in life. What the researcher is purposely labelling as 'reporting' seems to have been the direct result of patients glorifying the hospital and seeing it as an inherently good object, despite the many months and years of pain and suffering.

MEDICAL DISCOURSE

Despite patients' education level (mean = Std 5) and the fact that they were all Xhosa speakers, they were familiar and conversant with the medical jargon around renal function and failure. What seems to have been an internalisation process of the discourse, may have been a result of patients having been ill for many years. Thus through frequenting the hospital and having several procedures conducted on them, they may have had an experiential understanding of the unfolding process. In fact there seems to be a relationship between the length of illness and the level of familiarity with hospital proceedings and the medical discourse.

COMMUNALITY

Patients within the sample seemed to know each other well. There seemed to have been a sense of community among patients, particularly during their months on dialysis. Kalish (1979) labelled this sense of communality among patients as a sub-sub-sub-culture, that has its own culturally shared dynamics. It is perhaps this sub-sub-sub-culture that has allowed patients to see each other

during post-transplant treatment. Many patients reported that they use the latter as an opportunity to catch up on what has come of fellow patients' lives. Several patients spoke of how they shared information among themselves (mainly during the four hours of dialysis), about their experiences and coping strategies around their illness. It is in such 'meetings' that patients would learn of others who gave up on dialysis, returned or went to traditional healers and subsequently died. Still others died while on dialysis. This seems to have generated anxiety levels among those still on dialysis.

Kalish (1979) went on to argue that patients' 'watching' of each other, forces them to come to terms with themselves as ill and possibly soon-to-die individuals. Kalish further quoted Rosemary Gordon who suggested that the death of the other inevitably evokes awareness of one's own future death, and each death may evoke renewed reflection about one's own stand in relation to it and may force one to re-examine one's own conception of life and the value and meaning of it, or lack thereof.

One patient spoke of how he watched two fellow patients go home happily, a few days following successful transplants, while his newly transplanted kidney showed signs of malfunction. Thus the established rapport with fellow suffers seemed to have been a barometer by which patients measured their progress and/or well-being. Furthermore, the communal atmosphere forced patients to face issues of death more readily and regularly than they would have, had they been on their own. This seemed to have been particularly more of an issue for patients who had more than one transplant.

GENDER DIFFERENCES

It was the researcher's impression that in the interviews rapport seems to have been established more readily with female than with male patients. Furthermore, women seemed to have been a lot more prepared and willing to talk about their experiences in the transplant process than their male counterparts. Inevitably therefore the researcher's gender identity impacted on the findings. This assertion was vividly demonstrated by a 48 year- old man who asked the researcher if she was

married or not, as there were certain themes he would not be comfortable speaking about, in the name of respecting 'another man's woman'. On the other hand, if the researcher were not married, the interviewee would wonder how she could understand certain intricacies. These questions seem to have accounted for the interview being one of the least informative, in terms of the meaning(s) attributed to the transplant process.

SOCIO-ECONOMIC FACTORS

There seemed to have been a relationship between patients' current socio-economic status/ difficulties and the way they perceived the transplant experience. Though generally patients were struggling to make ends meet, some struggled more than others. Those who were uncertain about where the next meal would come from and when this would be, seemed to have had less of a coherent and systematic framework of meaning attributed to the transplant. In fact one 27 year-old woman made mention of the fact that the transplant took place in1994, that was then and life goes on, there are more important things to worry about.

SUMMARY

The present study sought to investigate the subjective frameworks of meaning that African patients attribute to the transplant process. In order of importance, the following factors had a bearing on patients' frameworks of meaning:

Their varied religious and indigenous belief systems allowed patients to explain their illnesses and process of healing. Patients' religio-cultural understanding of the transplant process had its basis in patients' respective family backgrounds. This shared world-view did not embrace the concept of transplantation easily. Thus patients oscillated between traditional understandings of illness yet, attended western forms of medicine. Attending western medicine, particularly the transplant itself, seems to have caused tension between patients and their (traditional) families. Part of this tension seems to have been a result of family members insisting that patients should persist with traditional

treatment, even though patients themselves did not see much success in it.

In terms of patients' feelings about the actual transplant, most were relieved that they would finally get a transplant. However, they expressed fear about the possibility of not waking up after the transplant. After the successful transplant, patients felt that they had been given a second chance in life and left the hospital with determination to engage fruitfully with the world.

Several additional observations were made: most patients gave their narrations with marked emotional intensity, due to the sensitive nature of the topic at hand; there seemed to have been a relationship between patients' length of illness and their familiarity and command of the medical jargon, despite generally low education levels; there was a sense of communality among patients; males seemed to have been more withdrawn than their female counterparts in narrating their experiences; and finally, there was also a relationship between patients' socio-economic status and the amount and level of analysis given to the transplant process.

CHAPTER 4: CONCLUDING REMARKS

Having explored frameworks of meaning of African transplant patients, some aspects of the research methods need to be highlighted:

Only fourteen patients were interviewed for the study. Though the sample was small, it seemed to have been a representative reflection of the African patient population in the Groote Schuur Renal Unit. However, as mentioned in the findings, these patients are only a proportion and not a reflection of the general population of African patients suffering from kidney failure. The literature has demonstrated that over 80% of patients consult traditional healers and thus never present to western medical practitioners.

Another point to be highlighted in the research methods is that interviews were conducted in patients' home language (Xhosa). This seems to have allowed patients to narrate their stories more freely and, in some instances, they seem to have felt empowered to use language-specific metaphors to express themselves. These Xhosa narrations had to be translated into English for the present text. As indicated in the discussion, there may have been implications for the amount of information meaning lost during the translation process. However these implications are inescapable given that the study aimed to ascertain patients' stories in a form that is as close to their respective frameworks of meaning as possible. Thus conducting interviews in patients' own language seemed to have been the most appropriate means of getting their stories.

It must be borne in mind that the present study was retrospective. Patients were re-presenting their experiences of the past. This also had a bearing on the nature of the findings at hand. However, this is not to say that findings are inaccurate and therefore unreliable. Instead it suggests that at a given time, patients' narrations seem to be flavoured by their mind-set at the time of narration. Over and above narrations having been retrospective in nature, patients' transplants had been successful. This further contributed to the moulding of patients' frameworks of meaning about and around the transplant process. It seems that patients' respective meanings may have been different had the transplants been unsuccessful.

What further confounds the findings is that the study was conducted at one fixed time in history. For 60 or 90 minutes patients tried to capture the past. A longitudinal study would have been preferable. This would have allowed patients to narrate in the 'here and now', as the transplantation process unfolded. Although this was not a longitudinal study, it still tells us something about the issues that patients had to grapple with at the time, for example: anxiety about the possibility of not waking up after the transplant, the fear of death, and after the transplant; the meaning of being healthy again.

The strongest theme that emerged in the study is that of religion. Religious belief systems seemed to have constructed and shaped the patients' worldviews, not only about transplantation, but also about life in general. Although there was a variation in patients' religious frameworks of meaning, they invariably believed that God, the Almighty, was in control of all that unfolded in the transplantation process. Patients held on to their respective religio-cultural understandings even though at times these belief systems appeared to have been incompatible with the western medical model. For example at the time of interviews some patients saw illness through witchcraft as untreatable by western medicine. However, these patients, some of whom believed that they were bewitched, faithfully attended post-transplant treatment.

The foregoing demonstrated the tension that exists between traditional and western ways of understanding illness and healing thereof. The incompatibility between the two frameworks forced patients to oscillate between the two at any given time. Thus through this oscillation patients had to embrace one mode of operation and sacrifice the other. Moving from traditional to western ways of understanding illness and healing was impacted upon by patients' (extended) families. These families, who were based in the rural areas of the Eastern Cape, held on unshakingly to traditional belief systems. Partly because of their belief systems (about illness and healing), family members tried to resist and at times sabotaged patients' attempts to seek western medical help. Thus patients found themselves sacrificing familial relationships and setting out to seek help in the west. Be that as it may, patients still gravitated back towards traditional understandings of what had happened to them. Thus, it could be argued that the patients' framework of meaning are not fixed in any one paradigm, but rather are in a process of modification, in the context of a broader sociocultural transition and adaptation.

IMPLICATIONS FOR FURTHER RESEARCH

Patients seem to be engaged in a process of paradigm shifting from customs and practices that had been part and parcel of their world-view and had formed the greater part of their sense of being as individuals and as a collective. These patients, are shifting towards more modern and western ways of seeing the medical field. Future research may need to take a closer look into the mechanims involved in the process of transition from one framework of meaning to another. It is still unclear as to what keeps patients cohesive and unfragmented while constantly needing to move from one mode of understanding their illness to another. Future research may need also to consider what keeps patients cohesive in the context of having to adjust their frameworks of meaning to accommodate that which the socio-cultural context demands.

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APPENDIX 1

UNIVERSITY OF CAPE TOWN

Child Guidance Clinic

University of Cape Town · Chapel Road
Rosebank 7700, Cape, South Africa
Telephone: (021) 650-3901
Fax: (021) 689-1006
E-mail: cgcdir@protem.uct.ac.za

October 1996

Dear

RE: RESEARCH ON AFRICAN RECIPIENTS OF KIDNEY TRANSPLANT

My name is Phyllis Ndlovu. I am an Intern Clinical Psychologist, at the University of Cape Town.

I am conducting a study in the Groote Schuur Renal Unit, on African patients who have undergone a successful kidney transplant in the Unit within the past five years.

It is for this reason then that I request you to be part of the study (i.e to form part of the sample that is to be interviewed).

All information shared and discussed in the interview will be held in strict confidence. The researcher will be the only one who has access to the interview transcripts.

However, should you not wish to participate in the research, you reserve the right not to do so. This however will not jeopardise your (further) relation with the Renal Unit specifically and Groote Schuur generally.

In the case of your willing to participate in the research, a provisional time and date have been set for your interview. Times and dates may be adjusted to your convinience, within the confines of the time available for the study.

DATE:
TIME:

Please respond to the above request by writing back to me at the address stated below, or phone me at 685-1607.

ADDRESS: 401G Forest Hill
Osborne Road
Mowbray
7700

Thanking you in advance

Phyllis Ndlovu
Intern Clinical Psychologist

APPENDIX 2

UNIVERSITY OF CAPE TOWN

Child Guidance Clinic

University of Cape Town · Chapel Road
Rosebank 7700, Cape, South Africa
Telephone: (021) 650-3901
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October 1996

Dear

UPHINDO LOPHANDO KUBANTU ABAMNYAMA ABAFUMENE IZINTSO KWABANYE ABANTU

Igama lam ndingu Phyllis Ndlovu. Ndingumfundi we Psychology e Yunivesiti yase Kapa.

Ndiqhuba uphando esibhedlela sase Groote Schuur, kwicala le zintso, kwizigulane ezimnyama eziye zaphumelela kufakelelo lwe zintso, kwiminyaka esihlanu edlulileyo.

Kungoko ndicela intsebenziswano yokuba ube yinxalenye yo phando (ukwenzela ndifumane inani labantu endizakuqhuba uphando kulo).

Lonke ulwazi ekuthethwe ngalo kolu phando soze lwaziwe ngomnye umntu, esi sisiqinisekiso. Umphandi wolu luphando uzakuba nguye yedwa onolwazi lokuba isigulane ngasinye sithethe ntoni.

Ukuba ngaba awufuni kuthatha nxaxheba kolu phando, lilungelo lakho ukuba wenze njalo.Loo nto soze yenze ukuba ungabi nabudlelwane necala lezintso, kunye nesibhedlele sase Groote Schuur ngokubanzi.

Xa uthe wafuna ukuthatha inxaxheba kolu phando, umhla ne xesha lo dliwano ndlebe nawe, selibekiwe. Ukuba ngaba awufumaneki ngexesha onikwe lona, elinye ixesha nomhla onokufumaneka ngawo uzaku lungiselelwa.

UMHLA:
IXESHA:

Ngicela uchaze ukubana uzothabatha inxaxheba na, ngokuthi ubhalele kwe dilesi elandelayo, okanye ufonele le nombolo 685-1607.
IDILESI: 401G Forest Hill
Osborne Road
Mowbray
7700

Ndiyabulela

Phyllis Ndlovu
Intern Clinical Psychologist

APPENDIX 3

INTERVIEW SCHEDULE

Tracing the route to the Groote Schuur unit

* When did you first realise you were ill? How?
* Did you speak to anyone about it?
* (If yes), Who did you talk to about this?
* Did you seek professional help?
* (If yes), who did you contact?

If Traditional healer:

* How did (s)he treat you?
* For how long?
* How did (s)he explain your illness?
* Why did you not consult a medical doctor (first)?
* What made you go to the traditional healer (first)?

If Medical doctor:

* What did the doctor do?
* How did (s)he explain your illness?
* How did (s)he treat you considering your illness?
* Did you consult other different sources for help after seeing the doctor?
* If yes, what other help did you seek?
* What was the reason for that?

General experience at the Groote Schuur Renal Unit

* How did you lend up at Groote Schuur Hospital?

* Whose choice has it been for you to come to the hospital?
* What made you to come to Groote Schuur?
* How were things explained to you (if at all) about the unit and your stay in it?
* Did you know what to expect?
* What did you believe was wrong with you at first?
* How did you think you could be cured?
* Has the belief of what is wrong with you changed?
* What has changed that belief(if it has changed)?
* When were you told you were to have a transplant?
* Who told you?
* How were you told?
* Did you understand what was said?
* Did the staff discuss the transplant with you?
* If yes, what was the discussion specifically about?
* What were your thoughts while waiting for the procedure?

Actual experience of transplant

* When did you have the transplant?
* Did you enquire about the details of the transplant; Why/(not)?
* If yes, how did the explanation make you feel?
* Did you enquire about where the kidney you were about to receive, came from; Why/(not)?
* If yes, how did the knowledge thereof make you feel?
* What has changed in or about you beyond the physical changes?
* How does your family (and community) understand what has happened to you?
* Did they have any influence on the transplant process?

* Do they understand it the same way as you do?
* If not, what is/are their understanding?
* How is/are their understandings different from yours?
* How does that make you feel?

Post transplant

* What thoughts have pre occupied you about the transplant?
* What thoughts have pre occupied you about life generally?
* How does your family and broader community understand the transplant?
* Do you feel supported by them (family and community)?
* How so/why not?
* How has life changed since the transplant?
* What is different about life now?
* Are you having continuous post-transplant treatment?
* Do you understand its function and purpose?
* Do you have any problem with the treatment?
* Has your understanding of kidney function changed?
* If yes, what has caude the change?
* How do you understand their function (now)?

APPENDIX 4

someone all alone

by Sarah Joseph

A thoughtless mind joined onto a body
Alone, unwanted and left to think for itself
A family contented with love and affection
Not even noticed, an outcast
Their hearts filled with happiness
Mine seeking to be wanted
To be LOVED
Each step is a lonely one, leading to sadness
The happy playing, the joyful laughter,
Which I once used to know, has deserted me.
What brought about this tragedy?
An error made by a human mind,
An innocent victim of temptation
The heart seeks for love,
The mind for companionship,
There is a corner, there is a man.
A little help warms the heart, and a smile appears
But I must repay as always.
A step too far, leaves a frightened mind,
And the depression is unbearable
There is a whisper, but into the wrong ears
A degrading and shameful end is its result
And now that mind suffers deeply for its mistake,
Torn away from love,
I cannot bear that feeling;
A bottle once filled with pills
Now, empty like me,
A sad and slow end.