WITH GREAT POWER COMES GREAT RESPONSIBILITY: EXPLORING IDENTIFIED FACTORS THAT INFLUENCE NON-COMPLIANCE BEHAVIOUR IN THE SOUTH AFRICAN LIVER TRANSPLANT POPULATION

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COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: Signed by candidate

Date:______________________________________

ABSTRACT

The non-compliance to a strict medicine regimen is a significant problem in transplant patients across the world, and we suspect also in South Africa. Despite the magnitude of the problem and the potentially life-threatening consequences of non-compliance, no research has focused on the South African liver transplant population. The following influencing factors on non-compliance were selected to be explored further in the South African context: beliefs about medicine; perceptions about one's condition; the effect of transplantation; and family dynamics and finances. The aims of the present study are to explore the possible relationships between patients' beliefs about their illness; beliefs about their medicine; feelings of guilt regarding the donor; feelings of responsibility to the transplant team and donor's family; low attendance records for clinics; family functioning and compliance. Twenty-five liver recipients over the age of 12 were recruited from Red Cross War Memorial Children's Hospital and Groote Schuur Hospital. Data were collected via four questionnaires. Analysis revealed that the more concerns patients have about the potential adverse effects of taking immunosuppressive medications, the less compliant they are likely to be. In addition, poor compliance is associated with the recipients' beliefs that their condition severely affects their life, and this has a strong emotional effect on them. Data also indicated that family functioning had an effect on compliance behaviour; balanced (balanced emotionally/socially/psychologically and easily adaptable to different situations) families were associated with higher levels of compliance. A positive finding from the present study is that a feeling of responsibility towards the transplant team and the donor's family indicated a higher level of compliance. The results suggest that there is a further need for post-transplant education and support for families and transplant recipients from medical or government structures. Transplant recipients indicated a need for education, support and information, especially those recipients from low socio-economic communities.

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CHAPTER ONE
INTRODUCTION

Background

Non-compliance in transplant recipients and it's manifestation in the context of South African transplant recipients

Organ transplantation: this once-experimental procedure now gives those affected a new lease on life. In the early 1980s, the medical world was experimenting with the techniques and medication involved in the transplant process, but now the reality is that individuals with various fatal organ diseases have a new opportunity to live with the help of this intervention (Bradford, 1997; Millar, Spearman, McCulloch, Goddard, Raad, Rode, Kahn & Cywes, 2004). When evaluating the effectiveness of any intervention process, including that of liver transplantation, it is important to take into account various parameters. These include physical, psychological and social aspects of the functioning of the patient both before and after a transplant (Bradford, 1997). These precautions are especially important when a new treatment procedure is being developed.

Although non-compliant behaviour from different transplant populations will be discussed, the present study will focus on liver transplant recipients. In 1988, a successful adult liver transplant programme was initiated at the Groote Schuur Hospital (Millar et al., 2004). After the success of the programme, it led to attempts at paediatric liver transplants. The first successful paediatric liver transplant in South Africa was performed at the Red Cross War Memorial Children's Hospital[1] Paediatric Liver Transplant Unit in November 1991 (Millar et al., 2004). Since then, 17 years have passed, and most of the patients who received a transplant in their infant or adolescent years are still developing and growing. This means that potentially there is a vast amount to learn from these early "scientific experiments". The rapid development of medical techniques of organ transplantation has not been matched by the understanding of other important areas such as the psychological and social aspects

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[1] Henceforth referred to as Red Cross Hospital.

(Bradford, 1997). An increase in knowledge and understanding of the influence of psychological and social aspects can broaden the understanding of the problem of medicine non-compliance and give another dimension to this well-established problem.

Not all patients diagnosed with an end-stage liver disease qualify for a transplant. Potential patients could be overlooked due to their poor medical condition in favour of someone who is in better health (Millar et al., 2004). In a review study of the liver transplant centre at the Red Cross Hospital, data indicated that since 1985, 225 patients have been referred, but only 146 were accepted for transplantation. Of the 146 patients accepted into the transplant program, 33 died prior to transplant (Millar et al., 2004). Table 1 indicates that the 2008 National Waiting List had 55 patients waiting for an available liver.

Few chronically ill patients qualify for and receive an organ transplant (S. Volschenk, personal communication, May 26, 2007), therefore it is important to educate the small number who will receive a transplant on how to respect and take care of the new organ. Volschenk, director of the Cape Town office of the Organ Transplant Organisations, provided the statistics presented in Table 1. Due to the advances in medical technology and drug pathology, the problem of non-compliance has come to the fore (Bradford, 1997). In the early stages of organ transplantation the design of immunosuppresion, medications were more experimental, but with the passing year's drug pathologists have developed immosuppresion drugs that work very well. Due to the increase in better designed immunosuppressive drugs that protects transplant patients from graft failure non-compliance have since been identified as a big problem and revealed the impact of non-compliance and the negative effect human error has. According to Millar et al. (2004), compliance in the liver transplant population would be a common assumption, but this is not the case. It seems reasonable to assume that patients would not do something that would harm their new organ and new lease on life by for instance neglecting to follow prescribed medical regimens or attending clinics post-transplant. However, according to older as well as recent literature, non-compliance is one of the leading problems causing mortality after the first year of transplantation and is a phenomenon still poorly understood by researchers (Friedman, & Litt, 1987; Dobbels, Van Damme-Lombaert, Vanheacke & DeGeest, 2005).

Patients who receive a transplant have already gone through various selection processes. These individuals can be considered fortunate to have survived thus far, although the post-operative stage is not always without incidents (Millar et al., 2004). After the transplant has taken place, there is a lifelong need for the recipient to undergo immunosuppressive therapy. Unfortunately, this therapy is accompanied by consequences, such as side-effects of the medication. These side-effects cause major changes in the body, which can lead to non-compliance by recipients with their therapy regimens (Meyers, Thomson & Weiland, 1996; Neuberger, 2003).

Studies have shown that aftercare of a transplant patient is essential to the complete and healthy recovery of the patient. Aftercare includes a medicine regimen, blood tests and regular check-ups with the patient's specialist (Laederach-Hofmann & Bunzel, 2000; Wainwright & Gould, 1997). Complying methodically to an aftercare regimen for post-transplant patients is essential for a successful post-operative life. Butkus, Dottes, Meydrech and Barber (2001) found that the most predictive post-transplantation factor for graft survival was pre-transplant compliance. Therefore, it's considered important to evaluate the compliance of pre-operative transplant patients to be able to consider the best candidates to receive a graft. There is no guarantee that patients, who have methodically complied with pre-graft treatment during a period of sickness, will continue their high level of compliance. Various studies have reported that although transplant patients are aware that it is necessary for them to continue their immunosuppressive regimen to maintain their organ in good health and prevent rejection, many of them do not take their medication as prescribed (Wainright & Gould, 1997; Falkenstein, Flynn, Kirkpatrick, Casa-Melley & Dunn, 2004; Engle, 2001). These acts of non-compliance can include patients not taking medication as often as required, not taking the correct dose, or not taking it at the right times. These actions can be either deliberate or unintentional, but it does place them at a high risk for organ rejection (Laederach-Hofmann et al., 2000).

Table 1. *National Waiting List Statistics 2008*

TRANSPLANT CENTRE	HEART			HEART / LUNG			LUNG			LIVER			KIDNEY/LIVER			KIDNEY			KIDNEY / PANCREAS			PANCREAS		
	C	AD	A	C	AD	A	C	AD	A	C	AD	A	C	AD	A	C	AD	A	C	AD	A	C	AD	A
CAPE TOWN																								
Groote Schuur Hospital & Red Cross Children's Hospital	0		1							7		1				12	7	177						
Tygerberg Hospital																		53						
Netcare Group - Christiaan Barnard Memorial Hospital	1	1	2															57						
JOHANNESBURG																								
Johannesburg General Hospital																4		158						
Netcare Group - Milpark Hospital, Garden City Clinic & Olivedale Clinic			7						30								1	78			4			3
Donald Gordon Medical Centre										9	2	27				9	4	124		1	9			
PRETORIA																								
Pretoria Academic Hospital																		57						
Netcare Group - Jakaranda Hospital																	2	53						
George Mukhari Hospital																		61						
KWAZULU-NATAL																								
Inkosi Albert Luthuli Hospital																1	10	206						
Netcare Group – St Augustines Hospital																1	1	85						
Life Healthcare - Entabeni Hospital			4			8			10									12						
BLOEMFONTEIN																								
Universitas Hospital																		60						
TOTAL	1	1	[illegible]	0	0	8	0	0	40	16	5	30	0	0	0	27	25	1182	3	1	14	0	0	

Note: C = CHILDREN; AD = ADOLESCENTS; A = ADULTS; CD = CADAVER; RLD = RELATED LIVING DONOR; NRL = NON-RELATED LIVING DONOR (Organ Donation Foundation Statistics, 2007).

With this problem of non-compliance in mind, Wainwright et al. (1997) suggested that there was an urgent need for research to be carried out to examine patients' beliefs and perceptions in relation to their condition after they have received their transplantation, and with regard to the continuous treatment they will be receiving for the rest of their lives. Transplants are not limited to specific socio-economic groups or ages – infants, toddlers, young adolescents, adolescents or adults can all be recipients. The age of the transplant patient is, however, a contributing factor that can shift the responsibility of ensuring that immunosuppressive medication is taken, to another family member (Wainwright et al., 1997; Falkenstein et al., 2004). The shifting of responsibility usually happens in the case of minors. This could be where the origin of non-compliance lies, and it raises the involvement of family dynamics in the issue of compliance and non-compliance.

A non-compliant patient will have a poor attendance record at scheduled clinic and laboratory appointments, may delay notifying doctors of problems, and may show poor compliance with their diet and regular medicine schedule (Laederach-Hofmann et al., 2000). A broader definition by Laederach-Hofmann et al. (2000) divides non-compliance into four different categories which are descriptive of the type of compliance. Clinical non-compliance consists of rejection episodes, organ loss, and mortality rate. Sub-clinical non-compliance refers to those patients who are non-compliant, but do not yet show or experience signs of clinical non-compliance. Thirdly, in what is called a "drug holiday", patients who are on a strict medicine regimen abruptly stop taking their immunosuppressive medication for more than 24 hours and just as suddenly start again. Finally there is a subtle type of non-compliance called "white coat adherence", when patients neglect to take their immunosuppressive medication and abruptly restart just before they visit the hospital or clinic (Laederach-Hofmann et al., 2000).

There are various methods available for measuring medicine compliance, and specifically, immunosuppressive compliance. These methods include self-report questionnaires, pill counts, pharmacy refill data, ciclosporin[2] blood levels, and electronic monitoring (Butler, Roderick, Mullee, Mason & Peveler, 2004c).

Pill counts, pharmacy refill data and monitoring of ciclosporin blood levels are treatment methods that require the combined effort of a pharmacist and doctor from the transplant team. These methods were more difficult to assess in the present study because the transplant team are very protective of the confidentiality and records of all transplant patients. In a literature review by Butler et al., (2004c), 36 research studies on the impact of non-compliance with immunosuppressive therapy was identified. Of these 36 studies, the majority still relied on self-report questionnaires or interviews. Electronic monitoring was used, but only in two of the studies.

Although electronic monitoring is the most sensitive measure of non-compliance, it is not always feasible to implement as there are many new variables that need to be included, such as altered patient behaviour and the misuse of the monitoring device. Ciclosporin blood levels are also used as an indication of compliance level, but this method reveals itself to be unreliable because it only discloses present compliance levels and cannot be used to predict future non-compliance behaviour (O'Carroll, McGregor, Swanson, Masterson & Hayes, 2006; Laederach-Hofmann et al., 2000). Self-report is known to be limited by the respondents' reluctance to disclose any negative information, however, it is still regarded as the most cost-effective method for monitoring and detecting an element of non-compliant behaviour.

For the purpose of the present study, non-compliance will be defined as the attitude that patients show towards the authority of doctors, parents and regular medicine regimen they have to follow. Three different methods of measuring compliance and related behaviour were selected: data from attendance records were recorded from the hospital database; four questionnaires (Beliefs About Medication Questionnaire BMQ, Brief Illness Perception Questionnaire IPQ, Transplant Effects Questionnaire TxEQ, Family Adaptability and

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[2] **Ciclosporin** is an immunosuppressant drug widely used in organ transplantation to reduce the activity of the patient's immune system and hence the risk of organ rejection. Ciclosporin was initially isolated from a Norwegian soil sample and has since been studied in transplants of skin, heart, kidney, lung, pancreas, bone marrow and small intestine (Dox, Melloni, Eisner & Melloni, 2002).

Cohesion Evaluation Scales FACES-IV) were administered, and a brief structured interview was conducted with respondents. The present study was partially modelled on a Scottish pilot study monitoring compliance in their liver transplant population. Concepts shared by the Scottish study and the present study were the assessment of attendance and the four questionnaires used. O'Carroll et al. (2006) acknowledged that no perfect measuring instrument for compliance had been identified, therefore three different methods were used to measure compliance in their study. Behavioural data included attendance records of clinic appointments, biochemical data consisting of immunosuppressive trough levels and evidence of cellular rejection six months post-transplantation. The psychological assessment of non-compliance consisted of five self-report questionnaires (Rivermead Behavioural Memory Test, IPQ, BMQ, TxEQ and MARS). Biochemical data were only used as a surrogate marker of compliance because O'Carroll et al. (2006) acknowledged that there were many unknown variables involved in biochemical data. Self-report data contributed to the bulk of the data of the present study and it was stated that self-report data show very good concordance with electronic monitoring (Garber, Nau, Erickson, Aikens & Lawrence, 2004).

The present study focused on the liver transplant population of the Red Cross and Groote Schuur Hospital Transplant Units. The study focused on psychological and social factors that were previously identified in research. This research was the first of its kind to give insight into what was occurring in the lives of the liver transplant population.

The following sections are generalised contextualisations of the problems of non-compliance, including literature from various organ (heart, lungs, corneas, pancreas, kidney and liver) transplant studies. This literature includes both **international non-compliance literature and South African non-compliance literature**. The kidney and liver post-operative patients share many of the same type of symptoms, except for dialysis which is undergone only by kidney patients. For this reason, this literature review will also include non-compliance research concerning the kidney transplant population. At the Groote Schuur Hospital, kidney and liver transplant patients recover in the same ward (F. McCurdie, personal communication, June 17, 2007). There is a more common link between the renal and hepatic organs compared to the other organs (heart, lungs and corneas) that can be transplanted. The link can be ascribed to the specific filtering function of the renal and hepatic organs. This link is a further reason for which non-compliance research on kidney recipients is included in the review. Non-compliance research in the kidney transplant population plays an important role in this review as the frequency of kidney transplantation is much higher and more common than liver transplantation. Much of the non-compliance research is drawn from this section. In South Africa in 2007, 195 renal transplants were performed compared to 35 liver transplants (Organ Donation Foundation Statistics, 2007). In the South African literature, only one study discussing non-compliance levels and the liver transplant population was found (Millar et al., 2004), in comparison to five studies that specifically focused on non-compliance and influencing factors in the kidney transplant population. For this reason, research from liver patients and renal research on non-compliance also constituted a large part of this literature review.

There are many reasons and factors that have been linked to non-compliant behaviour. The literature below identifies and analyses these factors. The following research is introduced: international research focusing on the transplant population and non-compliance; non-compliance in the renal transplant population; non-compliance in the liver transplant population; and finally, non-compliance research in the South African transplant population. Research from South Africa unfortunately only included studies examining non-compliance in renal transplant patients.

It is considered very difficult to identify non-compliance in patients and the majority of non-compliant behaviour goes unnoticed. Friedman et al. (1987) concluded that the occurrence of non-compliant behaviour was at times only raised after an incident revealed the manifestation of negative clinical effects that indicated that patients have been non-compliant towards their medicine regimen or other treatment procedures.

Despite all the pharmacological advances made in the field of immunosuppression, the greatest weakness in the therapy chain is undoubtedly the human element (Douglas, Hébert, Arbus, Pool, Kores & Koren, 1997). Even though transplant patients and their families were informed that the consequences of non-compliance could lead to disaster, patients tended to neglect treatment regimens, to their detriment, without realising what they were doing. Douglas et al. (1997), who reported specifically on non-compliance with ciclosporin, reported that 21% of adolescents took less than 80% of their prescribed ciclosporin dose and 26% indicated that they missed three or more successive days of ciclosporin. This non-compliance in the face of the possible consequences was not abnormal and had been documented in patients suffering from other chronic illnesses such as cancer, diabetes mellitus, heart transplants and bone marrow transplants (Douglas et al., 1997).

Dobbels et al. (2005) found that adolescents aged 11-19 years had a higher survival rate than paediatric recipients aged younger than 11 years one year post-transplant. However, in contrast, several research groups indicated that in the long term, the outcome of adolescent transplant recipients more than five years post-transplantation was considerably worse than that of paediatric recipients. This could have been ascribed to medical interference during their transition from childhood to adulthood. Adolescents naturally have a hard time in dealing with the changes in their bodies. Migrating from dependence to independence can be a gruelling task and even more so for transplant recipients who have to accept the new organ into their body and the responsibility that this accompanies (Dobbels et al., 2005). Research from various sectors regarding the compliance behaviour of adolescents identified this group as the most troubled and with the highest frequency of non-compliance. Mortality post-transplant, due to non-compliance, was also more predominant in the adolescent age group (Berquist, Berquist, Esquivel, Cox, Wayman & Litt, 2006; Douglas et al., 1997; Falkenstein et al., 2004; Foulkes, Boggs, Fennell & Skibinski, 1993; Friedman et al., 1987; Hsu, 2005; Meyers et al., 1996; Rianthavorn, Ettenger, Malekzadeh, Marik & Struber, 2004).

Bunzel and Laederach-Hofmann (2000) attempted to identify predictors for post-operative non-compliance by reviewing the literature. Schweizer, Rovelli, Palmeri, Vossler, Hull and Bartus (1990) and Blowey, Hebert, Arbus, Pool, Korus and Koren (1997) concluded that non-compliance was usually not predictable, and that not even doctors and nursing staff who were working closely with recipients could predict the compliance behaviour of the recipients. It was, however, concluded that there are pre-operative factors that could be used to predict post-transplantation non-compliance behaviour with a high degree of probability. The following pre-operative predictive factors were identified: demographics (proximity of recipient's home to hospital and ability to travel); psychological (recipient's psychological state pre-transplant and preparation for transplantation); psychiatric (whether psychiatric problems are present or were diagnosed pre-transplant); poor social support; pre-transplant non-compliance; obesity; and substance abuse (Schweizer et al., 1990; Blowey et al., 1997). It is important to stabilise the recipient's psychological state pre- and post-transplantation, since transplantation can be a traumatic and stressful event for any person, and post-traumatic stress post-transplant has been noted in paediatric recipients (Engle, 2001; Shemesh, Lurie, Stuber, Emre, Patel, Vohra Aromando & Shneider, 2000). Laederach-Hofmann et al.'s (2000) literature review revealed the factors recipients disliked most about their medication: side-effects (64%); cost (16%); long-term effects (15%) and difficulty of preparation of medication (14%).

On the topic of alcohol liver disease and recidivism, Neuberger and Tang (1997) stated that it has been well established that patients receiving transplants as a result of an alcohol-related end-stage disease had similar survival rates to those of patients receiving transplantations for other medical reasons. However, it was still recognised that patients with a history of alcohol-related disease had a higher possibility of recidivism (Neuberger et al., 1997).

In the following paragraphs, non-compliance research focusing on liver transplant recipients is discussed. As previously mentioned, the non-compliant behaviour of the adolescent age group receives slightly more attention, because the literature identified this age group as problematic in non-compliance research. The following paragraphs serve to illustrate the problem of non-compliance, specifically in the adolescent age group.

Berquist et al. (2006) researched the behaviour of 97 (one year post-transplant) adolescent recipients. Their non-compliance rate was 38.1%. The non-compliant respondents were more likely to be female, older than 18 years and to reside in a single-parent household. This trend was also established in female renal patients (Frazier, Davis & Dahl, 1994; Berquist et al., 2006). Non-compliance was also associated with low socio-economic status (SES) (Moshokoa, Ndlovu & Modiba, 2000; Thomson, 1997a; Berquist et al., 2006), older age at transplant and late acute rejection episodes (Berquist et al., 2006).

When a young patient receives a liver graft, their parents must take responsibility for compliance (Falkenstein et al., 2004). The authors stated that the problem of non-compliance in children should be re-evaluated. This problem was evaluated using the families of 234 liver transplant recipients. The transplant recipients gave the following as reasons for non-compliance: that they had forgotten it and that the medicine regimen did not fit into their schedules. These answers could have been expected. Considering the fact that most of the families had suboptimal levels of inter-familial communication even before the children had received a liver transplant (Falkenstein et al., 2004). The family plays an equally important role in the successful adaptation of the liver recipient's life post-transplant. This is one of the reasons why **family dynamics** was included as a variable in the present study.

Immunosuppressive medication has many adverse effects. The most devastating one for adolescents is the effect it has on their appearance. This factor contributes to an increase in non-compliance in the adolescent phase (Dobbels et al., 2005; Wainwright et al., 1997; Neuberger, 2003; Falkenstein et al., 2004). Kelly (2003) stated that the future for the development of an ideal immunosuppression drug for adolescents was still open. Transplantation, like all fast-evolving fields, will always have stages of the therapy process lagging behind. In the case of immunosuppression therapy, many drugs are available and effective, but have various side-effects.

The psycho-social environment plays a critical role in fostering or inhibiting compliance. As reported from other illnesses, the family plays an equally important role in the field of organ transplantation with respect to survival and morbidity. Coping with the challenges of a chronic disease can be very stressful for children, adolescents, and their families. It is important to understand and manage these stresses because parents who are highly stressed will have difficulty in supporting their child. Bunzel et al. (2000) demonstrated that the support from a spouse was one of the utmost important factors in predicting the success of heart transplantation. During the illness, transplant and adjustment period, families find themselves under immense pressure, including emotional, financial and psychological. It is not uncommon for families to fold under these pressures, but prevention of the dismantling of the family is advised because this disruption will only intensify the stresses of the family. The US divorce rate has tripled in the last 50 years and there will be a 50% chance that a person's first marriage will end in divorce (Walsh, 2003). South Africa is not quite in the same situation, but data from 1996-2006 provided a view of the divorce trend in specific population groups. During that period, the divorce rate fluctuated amongst Mixed[3], African and White groups, constituting 0.5%, 20.9% and 44.6% of the number of divorces respectively. Currently, the trends are changing. The divorce rate has increased for both Mixed (2.0%) and African (29.1%) marriages and declined for the White (35.4%) population group (Statistics

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[3] White refers to marriages between individuals from the white population group in South Africa. African refers to marriages between all other recognised population groups in South Africa and Mixed refers to marriages between individuals from different population groups (Statistics South Africa, 2007 December).

South Africa, 2006). With rising divorce rates, and poverty, compliance rates are placed under even more pressure. These factors will have an effect on all age groups and members of the family, irrespective of whether the liver recipient is a child or an adult.

O'Carroll et al. (2006) carried out a pilot study on compliance levels of liver transplant recipients in Scotland, using mainly psychological self-report measures. Their findings confirmed that **beliefs about health and medication** play an important role in non-compliant behaviour. The key to resolving this situation is identifying vulnerable patients' pre- or post-transplant, and designing and developing a cognitive behavioural intervention programme specific to the individual and his/her community of origin and socio-economic state (O'Carroll et al., 2006).

Krahn and DiMartini (2005) stated that over the last few years, the survival rate of liver recipients has been increasing to 86% for one year post-transplant and 72% to five years post-transplant, but non-compliance is still responsible for 25% of belated deaths post-transplant.

When non-compliant behaviour leads to rejection and graft loss, the only option left for a liver recipient is for a second graft. This presents a major problem not just in South Africa, but across the globe. As can be seen in Table 1, the South African waiting list includes more than 100 patients, while in reality fewer than 40 transplants take place nationally in a year (Neuberger, 2003).

The following paragraphs focus specifically on **non-compliance research from South Africa**. In the six South African studies that were examined, three discussed kidney transplantation, two discussed non-compliance in the kidney transplant population and one the establishment of the liver transplant programme at the Red Cross Hospital.

Four studies followed the renal transplant program at the Paediatric Transplant Unit in the Johannesburg Hospital. The first two studies by Meyers, Weiland and Thomson (1995) and Meyers et al. (1996) had focused their non-compliant research on the identified problem groups in their transplant programme, namely, paediatric and adolescent recipients. Meyers et al. (1996) followed the post-transplant development of 56 renal recipients aged between 2 and 21 years, and their families. Previously, non-compliance in this Paediatric Transplant Unit ranged between 20–25% (Meyers et al., 1995). Meyers et al. (1996) reported that 21.4% were non-compliant. From this non-compliant group, 50% admitted to forgetfulness, while 23% of the compliant group admitted that they occasionally forgot to take their medicine. The non-compliant group admitted to missing clinic appointments, forgetting about their medicine, administering too much medicine, and they remembered fewer of their medications' names. Non-compliant patients also knew less about their illness, allograft and immunosuppression (Meyers et al., 1996).

Meyers et al. (1995) revealed that the majority of the sample used in that study fell into the high- risk adolescent group. Male recipients were more non-compliant. This finding is contradicted by the majority of research that suggests that female adolescents are more at risk for non-compliant behaviour (Frazier et al., 1994; Berquist et al., 2006). During the developing adolescent phase, the possibility of having more non-compliant female recipients increases, due to the side-effects ascribed to steroids (acne, facial swelling, mood swings, and hirsutism[4]), ciclosporin (coarse facial features, hirsutism) and other immunosuppressive medications. These side-effects increase the possibility of non-compliant behaviour. Patients that are already in a difficult phase of their life find it difficult to deal with the changes in their physical appearance.

Meyers et al. (1996) initiated the compliance research at the Johannesburg Hospital and ten years later, Pitcher, Beale, Bowley, Hahn and Thomson (2006) reported on a 20-year review study of the renal transplant program at the Johannesburg Hospital. Non-compliance was not measured, but a comparison was made between compliant recipients and their families, and non-compliant patients and their families. The general knowledge of the non-compliant recipients and their families about the disease and the need for a transplant was significantly less than that of compliant recipients and their families. Most of the non-compliant patients were in their adolescent years; male and Black patients were also over-represented in this non-compliant group (Meyers et al., 1996; Pitcher et al., 2006).

Race was not included in most of the international non-compliance literature reviewed, but featured in two of the South African studies. A study originating from the United States stated that Black families were less likely to be engaged in discussing donation-related issues than

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[4] **Hirsutism** is defined as excessive hair growth in women in locations where the occurrence of terminal hair normally is minimal or absent. It refers to a male pattern of body hair (androgenic hair) and is therefore primarily of cosmetic and psychological concern (Dox et al., 2002).

White families. Black families had less knowledge about their family members' wishes, and expressed less favourable attitudes towards organ donation and the healthcare system, and were significantly less likely than White families to donate organs (Siminoff, Lawrence & Arnold, 2003). As Siminoff did not explore why the behaviour of these race groups differ so much from each other, we can only presume that factors such as SES must have played a role. Although Siminoff's focus in this respect seemed to be on race, it only served to illustrate the ill-effect of low SES conditions and the extra challenges involved in low SES communities. In South Africa to date, the Black population group represents more than 80% of the population. With the 2008 mid-year population estimates for South Africa reaching 48.69 million (Statistics South Africa, March 2007), and the unemployment rate of the population group aged 15-64 years at 23,6% (Statistics South Africa. July 2008), it is clear that low SES conditions are widespread. It is therefore also understandable that the Black population are more represented in the non-compliant groups. It is clearly important to educate the families and patients that need to undergo organ transplantation.

The fate of Black South African children receiving renal transplants were discussed in a study by Thomson (1997a). Thomson (1997a) highlighted the fact that more Black children have received a second transplant and that a high level of poor compliance was recognised in recipients from lower socio-economic status. This research group had a problem with decreased graft survival rate. To improve this situation, the hospital continued with ongoing education for post-transplant patients. The poor socio-political situation was also directly linked to the death of a recipient. Although there were many identified problems in this research population, the recipients' survival rates were still satisfactory at 84.1% and 76.7%, and graft survival of 54.3% and 38.2%, at 5 and 10 years, respectively (Thomson , 1997a).

Mokotedi, Modiba and Ndlovu (2004) and Moshokoa et al. (2000) specifically examined the attitudes and non-compliance of Black renal allograft recipients and reached the same conclusions as the study by Pitcher et al. (2006). Mokotedi et al. (2004) also revealed that patients under pressure to accept an organ donation from a living family member could be more susceptible to non-compliance.

Moshokoa et al. (2000) specifically researched non-compliance in Black South African renal allograft recipients at the Medical University of Southern Africa (MEDUNSA). A random sample of 35 recipients, with a functioning graft, was used as the research sample. Non-compliance was assessed by missed scheduled outpatient follow-up appointments. Information was obtained from hospital records. Ciclosporin levels were not useful in screening for non-compliance. Ciclosporin trough levels were measured, but these served only to illustrate the unreliability of blood levels in determining non-compliance. The ineffectiveness of the method of measurement was clearly illustrated as only one patient had a trough level below the normal range of 50-300ng/mL, while other data plotted the non-compliance of this group at a high 54.3% (Moshokoa et al., 2000). The ineffectiveness of the blood level analysis could be ascribed to "white coat adherence" where patients neglected their medication regime and abruptly restarted just before they visited the clinic. The results of the present study were alarming. Of the 35 recipients, 19 were non-compliant. The present study made an estimate that 18%–22% of transplant recipients were non-compliant with their immunosuppressive drugs. This study confirmed that although strict selection criteria existed, non-compliance could still have occurred in the renal transplant programme. In that study, the following factors were rated to contribute to non-compliance: poor education; unemployment; long-distance travel; crime; being male; and time lapsed since their transplant (Moshokoa et al., 2000).

Mokotedi et al. (2004) researched the mind-set and attitudes of Black South Africans towards living-related kidney trasnplantation. The study affirmed what many other South African studies also indicated (Moshokoa et al., 2000; Thomson, 1997a; Pitcher et al., 2006). Socio-economic status and the challenges involved in low-SES conditions played an enormous role in the morbidity and compliance of the recipients. Mokotedi et al. (2004) also concluded that patients living in peri-urban and rural areas suffered from a higher incidence of morbidity and mortality before transplantation. In that case it was very likely that after transplantation, recipients would have settled back into their normal routines. This could easily have led to a fall-back relapse into a non-compliant pattern, due to various problems such as finances, housing and transport, which are rife in low SES communities.

One study focusing on the South African liver transplant population was found (Millar et al., 2004). The study gave a review of the liver transplant programme at the Red Cross Hospital and the medical advances and challenges that have been achieved so far. South Africa, like many other countries, has a problem with the scarcity of donor organs. This means that some patients on the donor waiting list have to be overlooked in favour of patients in better health (Millar et al., 2004). The probability of re-transplantation is also rare because of the scarcity of donor organs. Although non-compliance in low SES conditions has been featured in a few studies, doctors of the liver transplant team stated that they have frequently been impressed by parents that had very limited resources, and still managed to take care of their child in the required attentive way (Millar et al., 2004). The role that a competent social worker played in the transplant unit was essential to the successful post-transplant adaptation period of a transplant recipient. Regarding compliance, the article only stated that follow-up appointments and a regular medicine regime were an absolute requirement for success (Millar et al., 2004).

The preceding paragraphs contextualised the universal problem of non-compliance in the organ transplant population and gave a perspective review of the prevalence of non-compliance and non-compliance research in South Africa. The reviewed studies have identified an array of factors that have influenced non-compliance: **finances** (Chrisholm, Vollenweider, Mulloy, Jagadeesan, Wynn, Rogers, Wade & DiPiro (2000); negative clinical effects that have occurred (Friedman et al., 1987); the difficult adolescent phase (Dobbels et al., 2005); medical interference (Dobbels et al., 2005); psychological problems (Schweizer et al., 1990; Blowey et al., 1997); psychiatric instability (Schweizer et al., 1990; Blowey et al., 1997); poor social support (Schweizer et al., 1990; Blowey et al., 1997); pre-transplant non-compliance (Schweizer et al., 1990; Blowey et al., 1997); obesity (Schweizer et al., 1990; Blowey et al., 1997); substance abuse (Schweizer et al., 1990; Blowey et al., 1997); medicinal side effects (Laederach-Hofmann et al., 2000); cost (Laederach-Hofmann et al., 2000); long-term effects (Laederach-Hofmann et al., 2000); difficulty of preparation of medication (Laederach-Hofmann et al., 2000); females older than 18 years (Frazier et al, 1994); resident in a single-parent household (Frazier et al., 1994); low SES (Moshokoa et al., 2000; Thomson, 1997a; Berquist et al., 2006); older age at transplant (Berquist et al., 2006); family reasons for non-compliance such as forgetfulness (Falkenstein et al., 2004); did not fit into their schedule (Falkenstein et al., 2004); families that have suboptimal levels of communication (Falkenstein et al.,2004); physical appearance (Krahn et al., 2005); the socio-political situation (Thomson, 1997a); poor education (Moshokoa et al., 2000; Thomson, 1997a); poverty (Moshokoa et al., 2000; Thomson, 1997a); long distances to travel (Moshokoa et al., 2000; Thomson, 1997a); work and study pressure (Moshokoa et al., 2000; Thomson, 1997a); general knowledge about the disease, medicine and the need for transplantation (Meyers et al., 1996; Pitcher et al., 2006); unemployment (Moshokoa et al., 2000); crime (Moshokoa et al., 2000); male recipients (Moshokoa et al., 2000); and the amount of time that had lapsed since the transplantation (Moshokoa et al., 2000).

From this long list of identified contributing factors, five were chosen to be researched in this present study: beliefs about medication; illness perceptions; effect of transplant; family dynamics and finances. The study by O'Carroll et al. (2006) served as inspiration and guideline for the design and selection of the questionnaires. Each of the questionnaires collected data for one of the five factors. The main difference between the present study and O'Carroll et al.'s is the addition of the family dynamics factor and FACES-IV questionnaire. The five factors are discussed below to provide a more detailed context of the problem surrounding each factor and how it relates to non-compliance and the current research available.

Beliefs about medicine

All people have different experiences, different education and their own heritage with their own beliefs and convictions. Most people develop their belief system around the following influencing factors: culture, tradition, religion, and education, and these factors combined will weigh heavily on recipients' beliefs about their medicine.

> *...not only are religious views to be acknowledged, but also cultural norms are to be ascertained, for the human body and body parts convey social meaning and are loaded with cultural symbolism. Deeply ingrained cultural values and beliefs may initially outweigh the favourable stance on organ donation of the religious group to which the family belongs.*
>
> *(Gilmann, 1999, pp. 21-22)*

Lingam and Scott (2002) stated that the mental state and beliefs of recipients, compared to the physical and medical side-effects of transplant, can be equally important in predicting non-compliant behaviour. Regarding the issues around opposition to organ donation, Chapmann, Deierhoi and Wight (1997) observed in their book *Organ and tissue donation for* *transplantation* that problems usually arise when the emotional, spiritual and cultural views of patients are ignored.

In an ever-evolving field such as organ transplantation, new research is always needed. Bhengu (1995) wrote a Master's research dissertation on the beliefs and perceptions of organ donation and transplantation within Zulu culture. Although the sample was relatively small (47 participants), Bhengu listed the following factors to explain the shortage in organ donations: ineffective harvesting techniques; ignorance; cultural norms that direct and determine attitudes; and social factors. From the sample the following factors were added: cultural differences due to diverse traditions; beliefs; values; norms and preferences in a pluralistic country like South Africa (Bhengu, 1995). Bhengu found that 72% (34 out of 47) of the respondents were supportive of the proposal of organ donation and transplantation. These results were not supported by the traditional healers as 67% (6 out of 9) were against the notion of organ donation and transplantation.

Many Black South Africans subscribe to a belief system that emphasises the belief in ancestral power, natural medicine and traditional healers (sangomas). Thomson (1997b) wrote about the identification of renal problems in Black South African children, and thought that acute renal failure stemming from enemas given by traditional healers to children with renal problems, containing various toxins such as cantharides or extract from the Callilepis laureola[5] tuber, still seemed to be an unfortunate but common occurrence (Thomson, 1997b).

Research done by Van den Berg (2005) for his Master's dissertation in theology confirmed the fact that more information needed to be given to the public about organ donation and transplantation. Van den Berg (2005) focused his research on the Baptist community and from there he could establish that as with previous studies (Moshokoa et al., 2000), ignorance played a significant role in the reluctance of living organ donors to come forward. This reluctance included the unwillingness of relatives to donate the organs of their deceased.

The following three paragraphs focus on the link between organ donation and beliefs held by the public from a religious and cultural viewpoint. These different viewpoints serve to

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[5] **Callilepis laureola** is a perennial herb with tufts of stems about 600 mm tall arising from a large woody tuber (Dox et al., 2002).

illustrate the effect of different belief systems. Organ donation is the start of the process of organ transplantation and can therefore be linked with beliefs about medication. It is considered to be an important preceding step to the development of beliefs about medication.

Horne's theoretical model regarding beliefs about medication distinguishes between beliefs contiguous to medication in general and beliefs contiguous to prescribed medication. Normally, doctors only consider the effect of the medication they prescribe on primary diagnosis and do not consider the effect it will have on the other aspects of a patient's life (Horne, Weinman & Hankins, 1999b). Turk and Rudy (1991) acknowledged that two different cultures collide during an illness, namely the recipient's culture and the culture of the healthcare system. Patients' beliefs about their disease and medication are crucially important when trying to understand their compliance behaviour. The various factors that influence this belief system about medication can lead to misunderstandings between doctors and patients. Feelings of doubt and fear regarding the medication arise when patients are not properly informed about their medication, its side effects and its function. Communication between doctors and patients is very important as a language barrier can result in poor health outcomes (Monsivais & McNeill, 2007). This is especially relevant to South Africa where there are 11 official languages, but where most of the professionals speak predominantly only English or Afrikaans. In confusing situations, patients might be tempted to alter their dosage, to avoid certain side-effects that interfere with their normal life after the medical intervention (Turk et al., 1991).

Studies done by Horne suggest that early discontinuation of medication is related both to side effects and to perceiving medication as ineffective (Horne et al., 1999b; Horne, Graupner, Frost, Weinman, Siobhan & Hankins, 2004; Horne et al., 1999b). These conclusions were drawn by studying antidepressant users whose initial side-effects had subsided or who had experienced a treatment response. Pound, Britten, Morgan, Yardley, Pope, Daker-White and Campbell (2005) found that patients did not follow prescription orders due to their concerns about the immediate side-effects and also the long-term effects these medications would have on their lives. It is not uncommon for patients to take matters into their own hands by altering the dosage and minimising the intake of the medication. It is also not unusual for patients to dislike taking medication, which could stem from a fear of dependence in general and dependence on medication (Pound et al., 2005).

Horne and Weinman (1999a) studied 324 patients who suffered from various chronic illnesses. The study found that there are better predictors for compliance than clinical or socio-economic status data. The patients studied listed the following two factors as the most important predictors of non-compliance: belief in the necessity of the medication prescribed and the amount of concerns raised, due to medication side-effects.

The relevance of these possible predictors was explored by administering the Beliefs about Medication questionnaire in the present study.

Illness Perceptions

> *"Two thirds of what we see is behind our eyes"*
>
> *(Wolpert, 2007, p.92)*

Horne et al. (1999a) stated that it is crucial to understand patients' perceptions about their disease and medicine in order to understand their compliance behaviour. Understanding patients' perceptions about their illness/condition and medicine is also very important. A patient's perception involves understanding the reality and context that they find themselves in. It is therefore important to understand the recipient's frame of reference, and the beliefs and perceptions recipients have towards their illness/condition and medicine (Wainwright et al., 1997). An understanding of the recipient's frame of reference can lead to the design of tailored intervention and education methods for individuals or troubled groups (Wainwright et al., 1997).

Wise (2002) explored the child's perception of living with a liver transplant. The researcher approached paediatric liver recipients with the request to give, in their own words, a reflection of their feelings and emotions involved in this process. Recipients showed a high level of empathy towards their parents' feelings, regardless of their age. Transplant recipients could comprehend that their parents were under a great deal of stress, because of their fragile state and situation.

From the literature it was concluded that there is a definite need to understand the recipient's point of view and current mental state surrounding their illness/condition. The need to be assessed and debriefed pre- and post-transplant was also raised (Wainwright et al., 1997). Patients who have received a liver transplant are defined as patients with a chronic illness. Melloni's illustrated medical dictionary defines a chronic illness as an illness that is long-lasting or recurrent (Dox, Melloni, Eisner and Melloni, 2002). Post-transplantation recipients are removed from their previous life of illness. Patients find it difficult to identify with the fact that they still have an illness, because they feel healthy, but transplant recipients suffer from a chronic illness and this is evident because of their lifelong reliance on immunosuppression therapy (Dox et al., 2002). These definitions and labels cause negative feelings within the maintainable chronic disease patients (Wainwright et al., 1997). Patients do not want to be reminded of their illness and their mortality when they are feeling well.

In the present study, perceptions of transplant recipients were explored by administering the Illness Perception Questionnaire.

Transplant Effect

How do you measure the effect of the experience of organ transplantation? A study by Griva, Ziegelmann, Thompson, Jayasena, Davenport, Harrison and Newman (2002) approached this research question by measuring the impact that an organ transplant had on the recipient's health-related quality of life. The research population included living related donor (LRD) and cadaver (CAD) transplant recipients. LRD transplants recipients had expressed stronger feelings of guilt towards the donor compared to CAD. In this study, the type of transplant did not have a significant effect on the health-related quality of life. In fact, patients who had received an organ from an LRD transplant would have been more likely to stay in contact with their donor (Griva et al., 2002).

Archillea, Ouellettea, Fourniera, Vachona and He´bertb (2006) researched stress, feelings of indebtedness and guilt in transplant recipients and the relationship between these feelings and compliance. The research reported that recipients who had a low rate of compliance reported more distress than patients who had high compliance rates. The research also reported that feelings of indebtedness could have improved medication compliance, because the study revealed that compliant patients reported more intense feelings of indebtedness. Recipients had perceived feelings of guilt and indebtedness as separate emotions with unrelated impact on compliance.

It can be concluded that contact between the transplant recipient and LRD donor has positive effects on compliance levels (Griva et al., 2002). Archillea et al. (2006) concurred that feelings of indebtedness towards the donor were more common with compliant patients. Research suggested that unfortunately feelings of indebtedness also led to stress and this had a detrimental effect on compliance behaviour, it was therefore imperative to investigate other intervention methods. One such intervention method had suggested encouraging a relationship between the donor/donor's family and recipient in LRD and CAD. Feelings of indebtedness towards donor LRD or donor's family CAD may well have improved compliance. It could be seen as a means of honouring and respecting the gift they have received (Archillea et al., 2006).

After a transplant, various new changes and challenges enter the lives of transplant recipients. The effects of the transplant were explored by administering the 'transplant effects' questionnaires in the present study.

Family Dynamics

> *Family life is full of major and minor crises - the ups and downs of health, success and failure in career, marriage, and divorce - and all kinds of characters. It is tied to places and events and histories. With all of these felt details, life etches itself into memory and personality. It's difficult to imagine anything more nourishing to the soul.*
>
> *(Thomas Moore, 1779-1852)*

Contemporary paediatric medicine sets out three goals when treating a sick child: treat the disease, prevent interference with the child's general development, and attempt to prevent adversely affecting the family functioning (Bradford, 1997). The establishment of these three goals stems from paediatricians' becoming aware of the need to treat the family as a whole and to understand the complexity of children and their families when paediatric problems are presenting (Bradford, 1997). During different developmental stages, there are various challenges to overcome and lessons to learn in order to progress successfully into another developmental stage (Wait, Meyer & Loxton, 2005). Penn, Bunch, Olenik & Abouna (1971) researched the developmental state of pre-transplant children suffering from a chronic liver disease. The research indicated the prevalence of general developmental delays in these children.

The adolescent development phase is difficult, as it is an important transition period during which children must progress from childhood to adulthood by mastering development tasks. One of the most important tasks during this transition period is the development of a child's own identity separate to that of their parents (Rianthavorn et al., 2004). This is especially important for transplant patients. Transplant patients must at a certain age start to take responsibility for the management of their illness, in order for them to live a fulfilling life. In many ways, the transplant patient is forced to grow up faster, but in contrast some developmental tasks lag behind the norm, because of over- protectiveness of their parents and guardians (Falkenstein et al., 2004).

A literature review by Bradford (1997) concluded that children who received organ transplants can show deficits in a broad range of cognitive functions as a result of transplant intervention. These developmental problems are interlinked with family dynamics because cognitive and developmental challenges add to the already-strenuous situation in which a family with a transplant recipient find themselves.

The onset of an end-stage disease disrupts normal family functioning and alters the roles that family members play, indefinitely (Engle, 2001). The return of a transplant recipient to his/her home involves adjustment: new roles and responsibilities must be taken on by siblings and family members. There are many new stresses on the parents, and the family as a whole must take time to re-evaluate themselves and that which is important for them (Engle, 2001).

There are four stages of emotional crisis that parents could encounter when their children suffer from a life-threatening illness: hazardous event, the vulnerable state, the precipitating factor and the state of active crisis (Brown, 1999). The diagnosis and knowledge of a possible liver transplantation becomes the hazardous event for these families. Parents feel an ongoing sense of vulnerability even after the transplant. This can be ascribed to the uncertainty of this hazardous event. Children disclosed that they did not share their feelings about the transplant with their parents, because they knew that this would have been upsetting to them (Brown, 1999). When transplant recipients return home, parents are the primary carers of the children and this often causes them to enter a stage of hyper-vigilance (Brown, 1999). Vigilance implies that survival is seen as possible, but not certain. Transplant recipients recognised that their parents' moods shift together with their level of health (Brown, 1999). This connection could cause a level of concern, because things that previously would go by unnoticed, now awaken a sense of heightened awareness and tension (Wise, 2002).

Siblings of children who have been diagnosed with a life-threatening disease reported that the functioning of the family and their own behaviour changed as result of the diagnosis and treatment of their sibling's disease. Changes influenced their own behaviour and the behaviour of their parents, such as siblings being worried about their parents' emotional well-being, and their ill sibling's physical and emotional well-being. Healthy siblings reported that they received less attention from their parents (Menke, 1987). These changes set in because parents become worried, get tired and are unsure, most of the time, about the future of their ill child.

Studies that researched the impact of these changes on the siblings reported different outcomes. Some studies showed that the impact of these changes had a detrimental effect on siblings, leading to internal and external behavioural problems (Barbarin, Sargent, Sahler, Carpenter, Copeland, Dolgin, Mulhern, Roghmann & Zeltzer, 1995). Janus and Goldberg (1995), however, demonstrated the resilient behaviour of siblings. Both negative and positive changes occurred in a family where there was an ill sibling, regardless of the ages of the healthy siblings. Older siblings had reported positive effects of the illness, such as supportiveness, patience and understanding of the ill sibling. Support from family friends and members increased the maturity and independence of the remaining siblings (Barbarin et al, 1995).

The disruptive change an illness brings into the family unquestionably spills over to the siblings. Siblings must deal with these changes without the support of their family, because their family is preoccupied with their ill sibling (Menke, 1987). Adjustment depends strongly on the age of siblings and these changes can also cause a disruption in the flow of their natural developmental growth. When some time has passed after the diagnosis and treatment of the patient, adequate support re-enters the siblings' daily life. The initial psychological reaction to the illness that leads to academic and emotional strains can decrease and the siblings can move into an adjustment period and manage a normal level of functioning (Menke, 1987).

Family dynamics are measured in the present study using the Family Adaptability and Cohesion Evaluation Scales (FACES-IV). Although the FACES-IV questionnaire has not been used in the liver transplant population, the following four studies illustrate how this measure has been implemented in the organ transplant sector.

Foulkes et al. (1993) conducted a study examining compliance in 32 renal transplant patients by observing the relationship between family functioning, social support and medication compliance. The results indicated that a decline in non-compliance was associated with informed fathers who gave emotional support and were more informative towards the recipients. Younger recipients from families that experienced multiple stressors were also found to be less compliant. In a comparison between younger and older children, younger children were found to be less compliant (Foulkes et al., 1993).

Lunsford, Simpson, Chavin, Mensching, Miles, Shilling, Smalls and Baliga (2007) used the FACES measure to determine familial closeness and the probability that a family member will ask another family member for a living donation. FACES were administered during a pre-transplant information and education session. FACES were used to assess the individual perceptions of the family structure. Of the 328 potential renal recipients included in the sample, 61% were African American and 39% were Caucasian. Of the sample, 50% were willing to ask a family member for a living donation. The FACES measure the individual's perception of family cohesion and adaptability. FACES indicated that most family scores were mid-range with optimal cohesion and adaptability. FACES scores did not, however, associate familial closeness with willingness to ask for a living donation from a family member. An individual who was single and had never been married was half as likely to ask for a living donor. Race and family type were not related to a potential recipient's willingness to ask for a living donation (Lunsford et al., 2007).

Soriano-Pacheco, Lopez-Navidad, Caballero, Leal, Garcia-Sousa and Linares (1999) researched the psychopathology of bereavement in the families of CAD organ donors. Eightyseven families were interviewed and completed the FACES questionnaire. Data collected suggested that families going through the bereavement process scored high on cohesion and low on adaptability. The FACES measure has been used as an important measure in the bereavement process to help identify individuals suffering from complicated bereavement, although more than 50% do ask for counselling from the transplant centre (Soriano-Pacheco et al., 1999).

Barrera, Boyd Pringle, Sumbler and Saunders (2000) researched the topic of quality of life and behavioural adjustment after bone marrow transplantation. Measures were taken pre- and post-transplantation and the following data were recorded. Mean pre- and post-scores from FACES was within the expected range for the normal functioning families' scale of FACES. However, a significant reduction in family adaptability was recorded and this could indicate a decrease in flexibility of a family post-bone marrow transplantation. The level of family cohesion/connectedness remained constant across testing (Barrera et al., 2000).

To conclude: this section gave an overview of family dynamics, development, change, adaptation and application of the FACES-IV questionnaire. It is important to illustrate that not only will the life of the transplant recipient change after transplantation, but also the life of the family and the family dynamics. To understand the dynamics of a family, we need to understand that a family consists of various individuals with different personalities. In the present study we specifically focused on families that were under stress because of an organ transplant in the family. Stressful environments increased the chances for non-compliant behaviour and to understand the relevance of these possible predictors for non-compliance, the Family Adaptability and Cohesion Evaluation Scales were used to evaluate the family dynamics for each respondent.

Finances

Scheweller (1997) stated that the United States continued to be one of the only industrialised countries, besides South Africa, to see healthcare as a privilege for its population rather than as a right, as it is regarded in many countries. This attitude of both nations impedes many from seeking healthcare and consistently leads to poor healthcare in the lower income groups, and late diagnosis, which usually increases the costs of treatment. Millar et al. (2004)

acknowledged that liver disease had been generally underestimated as a cause of death in South African children. After a decade of research and publications the predominance of liver disease leading to mortality were evident in South African children. Miller et al. (2004) recognised that a significant amount of mortalities could have been prevented by a liver transplant.

Annually, in the United States, medication for a year of immunosuppressive therapy will typically cost more than $10 000 (Scheweller, 1997). Even though the US Government subsidises two-thirds of the cost of immunosuppressive medication for the first three years post-transplant, many patients still cannot afford to pay the remaining ⅓ of the cost (Scheweller, 1997).

Millar et al. (2004) stated in their study that it was difficult to estimate the exact monetary value of a transplant operation, but after careful costing of some patients, they could state that an uncomplicated transplant operation would cost in the region of US$ 20 000 for the first three months and US$ 500-1000 per month for the first year. These estimates are from a South African point of view. These estimated costs included the medication, the procedures and the pathology test, and could accumulate to a substantial amount which would continuously increase. Table 2 can give the reader an idea of the cost involved for a monthly supply of immunosuppressive medication and this will definitely not be the only medication prescribed for the transplant recipient. The prices given in Table 2 are also the subsidised prices and in reality this medicine is much more expensive.

Non-compliance is not just a micro-level problem that is experienced only by the patient. High levels of non-compliance lead to an increase in the healthcare costs of transplant recipients and may even lead to the cost of a re-transplant (Cleemput & Kesteloot, 2002). The situation will be very different between countries that have national healthcare systems and countries that do not have these systems. South Africa does not have a national healthcare system. However, patients can receive medicine for free or at subsidised rates if they can prove that they cannot afford it. The only other option in South Africa is to belong to an expensive medical aid scheme.

Table 2. ***Estimated monthly cost of various immunosuppression medication from the Groote Schuur Hospital Pharmacy June 2007***

Immunosuppressive medication	**Dosage available**	**Price**
Cyclosporin	100mg	R 658.35/50
	25mg	R 184.33/50
Tacrolimus	500ug	R 993.83/50
	1mg	R 2202.71/100
	5mg	R 5437.12/50
Azathioprine	Tabs 50mg	R 145.25/100
Sirolimus	1mg	R 1094.74/30
Daclizumab	20mg/5ml	R 2793.00/vial
Basiliximab	20mg/5ml	R 8785.90/vial

Note: Information was provided by H. Vreemde, a pharmacist at the Groote Schuur Hospital (H.Vreemde, personal communication, 17 June 2007).

The current healthcare system in South Africa does allow for the following benefits: free healthcare for children under the age of six, as well as for pregnant or breastfeeding mothers. People who find themselves in financial crises may join the queue at any state hospital. According to the South African constitution, no person may be denied medical attention when they need it (National Health Act No. 61, 2003). Depending on the patient's financial situation (for which they have to provide their financial statements as proof of a deficit of funds), they could receive medicine for free (Coustasse, Hilsenrath & Silva Rojas, 2005).

Chrisholm et al. (2000) suggest that finances seem to be related to compliance. These authors published the first study that examined the relationship between compliance rates and free immunosuppressive medication provided to patients. They measured the compliance rate of renal transplant patients who received their immunosuppressive medication for free. Patients were generally more compliant if they had received their medication for free, but compliance tended to deteriorate to 95% after five months post-transplant, 75% after 7 months post-transplant and 48% of patients were compliant with their immunosuppressive therapy 12 months post-transplant. These findings suggest that the cost of the medication plays a role, especially in the months just after the transplant, but it is not the only influencing factor in non-compliant behaviour (Chrisholm et al., 2000). From this study it seems that finances are related to non-compliance, especially in the 5 to 10 years post-transplant recipient group.

The prescription of different dosages and types of dosages of immunosuppressive medication will depend on the weight and age of the patient. These factors and more are taken into account when specific immunosuppressive medication is chosen for a patient. A patient will not change the immunosuppressive medication he/she is prescribed, unless the doctor decides that the negative effects of the immunosuppressive medication prescribed initially are causing the patient to be ill.

A state-funded hospital can give financial support to patients who can prove that they qualify for financial help. Patients are divided into four tier groups. Patients, parents or guardians of patients are judged on the combined income of their household. All their paperwork must accompany their application for financial support. Paperwork includes payslips, bank statements and all other financial obligations. These documents will give the health department a comprehensive view of the family's current financial state. On this basis the department decides to give financial assistance to a family. In most cases, medical cost is not completely exempt, but the partial payment that is asked for is minimal in comparison to the real costs of the medication, medical expertise and medical procedures provided by the hospital.[6]

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[6] The **Financial Assistance** information was provided by Majoli Nomvuyo, a financial administrator in the Accounts Department at the Groote Schuur Hospital (Nomvuyo Majoli, personal communication, 16 May 2008).

Table 3. *Tariff category for Groote Schuur Hospital*

Tariff Charges	Monthly Income-Single	Monthly Income Family Unit	OPD/Visit Charges (Consultation)
H_0	Social Pensioners (Pensioners, Grants, disabilities, maintenance) Formally unemployed-proof provided	Social Pensioners (Pensioners, Grants, disabilities, maintenance) Formally unemployed-proof provided	Free
H_1	Less than R36 000 per annum R0.00 – R2999.00 per month	Less than R50 000 per annum R0.00 - R4166.00 per month	R.35.00
H_2	Equal to or more than R36 000 but less than R72.000	Equal to or more than R50 000 but less than R100 000	R120.00
H_3 **Private self-funded** **FULL PAYING**	Equal to or more than R72 000 per annum R8000+	Equal to or more than R100 000 per annum R8330+	R172.00

Note: H_0 patients receive all medical services for free on account that they are on old age or disability grants or have other reasons that have been acknowledged by the department. For patients on H_1, medication and procedures are included in payment (R35.00). H_2 patients have to pay for their medication and blood tests and procedures that are done. H_3 patients pay the full price for everything or send the account to their medical aid/insurance. OPD, Outpatient Department

The Present research

The Red Cross Hospital is the only paediatric hospital in sub-Saharan Africa. This is also the only hospital with a paediatric liver transplant programme. The transplant team and supporting staff are responsible for the pre-transplant preparations, transplant and post-transplant immunosuppressive therapy. Together, this multi-disciplinary team of healthcare professionals provides a high standard of medical and surgical services to their transplant patients. After a major endeavour such as a liver transplant, there are many changes that the recipient will undergo and it sometimes happens that the psycho-social rehabilitation does not receive the same attention. The need for psycho-social rehabilitation and education has become particularly relevant as advances in medical and surgical techniques have decreased the mortality rate of transplant recipients, thereby exposing the flawed human element (patient's responsibility to administer medicine) involved in the process of immunosuppressive therapy. When patients leave the hospital to return to their homes, there are many new factors that influence them and may lead to potential non-compliant behaviour. The preceding discussion in literature has made it clear that non-compliance is a serious matter for all transplant recipients, resulting in either life or death. Non-compliance research has not received much attention in South Africa: since 1995, only six studies highlighting non-compliance have been published. Of these six studies, five came from the renal transplant population and only one from the liver transplant population. The study focusing on the liver transplant population revealed only that non-compliance post-transplant was a problem that leads to unnecessary/preventable deaths post-transplant. This was the only research from South Africa that specifically focused on non-compliance in the liver transplant population and possible contributing factors.

The Cape Town setting for this research is of the utmost value, as the first adult liver transplant programme in South Africa was instituted at the Groote Schuur Hospital and the paediatric liver transplant programme is based at the Red Cross Hospital. Since there are two hospitals in Cape Town that are doing liver transplants, the area can provide the study with a reasonable sample size. The study focuses on the following factors: beliefs about medicine; perceptions that transplant patients have about their illness; medication compliance; the effects the transplant has had on them, as well as on their family dynamics and finances.

Data was gathered via the administration of four self-report questionnaires, attendance records and structured interviews. These questionnaires are discussed in more detail in the following chapter.

The following relationships between compliance and the following variables will be explored:

- Patients' beliefs about their illness;
- Patients' beliefs about their medicine;
- Patients' feelings of guilt regarding the donor;
- Patients' feelings of responsibility to the medical staff and donor's family;
- Low attendance of clinics;
- Family functioning; and
- Balanced family functioning predicts higher level of compliance.

Conclusion

The purpose of this introduction has been to contextualise the nature of non-compliance in the liver transplant population of South Africa and to provide a comprehensive background to the literature on the long-term psycho-social adjustment of liver recipients. It outlines the influencing factors that change patients' lives and influence their compliance towards their immunosuppressive medicine regimen and to the instructions and advice of the doctors of the transplant team.

According to the empirical research, the majority of transplant patients struggle with the changes in their life after their organ transplant. An organ transplant is a life-saving operation and is usually preceded by a fairly long period of sickness. After a transplant, a recipient's life is turned around, but this is the start of a new life-cycle with well-identified obstacles and challenges. A permanent commitment to immunosuppressive therapy is but one of the challenges. One year post-transplant leaves the window open for organ--rejection for no explainable reason, and these ups and downs can be very challenging not only for the patient but also for his/her extended family. Since immunosuppressive therapy is essential for the preservation of a transplant organ, the topic of non-compliance and organ transplantation is well represented in the literature. A large portion of the transplant research focused on highlighting the problems regarding compliance and the adolescent age group. Research explored this age group and specially focused on identifying influencing factors leading to non-compliance.

Many influencing factors were identified but unfortunately none of these studies was performed on the liver transplant population of South Africa. The majority of the transplant research is contributed by studies conducted in America, but because of the lack of research in South Africa we chose to include non-compliance research on kidney transplant recipients conducted in South Africa to illustrate some of the unique influencing factors that have an effect on the South African population. Research also focused on a variable rarely included in previous compliance research: namely family dynamics, and the changing influence exerted by a patient's organ transplant on the whole family.

CHAPTER TWO

METHOD

Design

The design of the present study was partially influenced by O'Carroll et al.'s (2006) study on non-compliance occurring in a Scottish liver transplant population. Both transplant units were initiated within a year of each other: the South African Liver Transplant Unit in the Red Cross Hospital opened in 1991 and the Scottish Transplant Unit in Edinburgh opened in 1992 (Millar et al., 2004; O'Carroll et al., 2006). A major difference between these two transplant units is the number of transplants performed since opening. Since 1992, the Scottish Liver Transplant Unit has performed 513 transplants, compared to the South African unit's 155 transplants since 1991 (Millar et al., 2004; O'Carroll et al., 2006).

Following O'Carroll et al. (2006), three different methods of collecting data were identified: self-report measures, qualitative interviews and behavioural attendance data. Quantitative data was collected via self-report measures. Similar measures from O'Carroll et al. (2006) were included with the exception of a family dynamics questionnaire that was not part of the Scottish measures. This data will be essential in exploring different factors such as beliefs and perceptions of non-compliance in the liver transplant population, and in making comparisons with the Scottish data. Qualitative data was gathered using a structured interview consisting of 14 questions. Thirdly, behavioural data was used to reflect on the compliance of patients. In this study, the behavioural data specifically referred to recipients' attendance record of clinic appointments. Attendance was measured by the appointments made and attended, and appointments missed without rescheduling. Data about financial assistance received from the hospital were also gathered.

Sample

Sampling criteria

To be considered eligible to participate in this research study, several inclusion criteria were proposed. These related to the organ transplantee: age of the transplant recipient at the time of transplantation; the present age of the recipient; the time elapsed since the transplantation; the geographical location of the recipient; and the availability of contact details (address, telephone number) in the folders or computer database of the hospital.

Firstly, the decision was made to include only liver transplant recipients in the present study. Although kidney and liver transplants share many characteristics, as argued above, it was considered prudent to keep the sample as homogeneous as possible in this regard. In terms of the present age of transplant recipients, it was decided to include all participants older than 12 years. This ruled out paediatric transplants, but at the same time gave enough of an age range to use age as an analytical variable. No person who had received a liver within the last year was included in the study, since many changes would still take place during that period and possible rejection that might be unrelated to compliance, tend to happen more frequently (Millar et al., 2004).

During the process of diagnosis and treatment, patients migrate closer to the hospital where they receive their treatment. This might imply moving to another province. This migration process occurs quite commonly as the Red Cross Hospital has the only Paediatric Liver Transplant Unit in South Africa. The two adult transplant programs are running at the Groote Schuur Hospital in Cape Town, which is also in the Western Cape, and the Donald Gordon Medical Centre in Johannesburg, which is in the Gauteng province.

After transplantation and recovery, some recipients choose to return to their place of origin where another physician takes over the responsibility for their care (Millar et al., 2004). In earlier years South Africa had the only liver transplant unit in Africa and performed transplants on patients from various countries in the African continent. These recipients also returned to their country of origin after they had been monitored closely for some time. This at times resulted in the loss of contact between the transplant recipients and the Transplant Unit.

Finally, with regard to personal information, recipients may be on the list of post-transplanted patients, but because of circumstances such as those mentioned above, their details have not been updated. Patients would return to their lives in other provinces or countries and would not necessarily attend clinics or hospitals, nor keep their records updated at these hospitals. When hospitals lose contact with some of the liver transplant patients, it has a limiting effect on the remaining sample population that is left to recruit from. This illustrates that there are many obstacles that limit the research on the already-small liver transplant population in South Africa.

Recruiting the sample

Recruiting the sample of liver recipients proved to be very challenging, because of the limited number of patients. It could be argued that the sample for the present study was extremely small, but after studying the number of transplants performed since 1991, there had been no evidence of a steady increase of liver transplants. The number of transplants performed each year is dependent on the availability of donor organs. This is illustrated by the fluctuation of the transplant figures for each year.

Table 4. *Combined transplant statistics from Groote Schuur and Red Cross Hospital*

Year		Liver Transplants per year	
1981			
1982			
1988		1	
1989		2	
1990		3	
1991		2	
1992		6	
1993		13	
1994		15	
1995		17	
1996		9	
1997		9	
1998		3	
1999		4	
2000		12	
2001		8	
2002		17	
2003		6	
2004		4	
2005		4	
2006		4	
2007		7	
Total		155	

Note: Number of liver transplantation operations performed during 1981-2006 period. Numbers include adolescent and adult transplant patients. Information from this table was provided by Fiona McCurdie, transplant co-ordinator at Groote Schuur Hospital (F. McCurdie, personal communication, June 17, 2007).

From 1981 to the end of 2007, 155 liver transplantation operations were performed at the Groote Schuur and the Red Cross Hospitals. Statistics were retrieved from the data in Table 4 dating from 1981 to 2006. Statistics were provided by the transplant co-ordinator at Groote Schuur (F. McCurdie, personal communication, June 17, 2007). Table 5 provides the transplant statistics for 2007 (data provided by the Cape Town co-ordinator of the Organ Transplant Organisation, S. Volschenk, personal communication, May 26, 2008).

Table 5. *Transplant statistics 2007*

TRANSPLANT CENTRE	HEART			HEART / LUNG			LUNG			LIVER			KIDNEY-LIVER			KIDNEY									KIDNEY / PANCREAS			CORNEA			TOTAL
																CD			RLD			NRL									
	C	AD	A	C	AD	A	C	AD	A	C	AD	A	C	AD	A	C	AD	A	C	AD	A	C	AD	A	C	AD	A	C	AD	A	
CAPE TOWN																															
Groote Schuur Hospital & Red Cross Children's Hospital	1		6							4		1						37	6	1	16			2							66
Tygerberg Hospital																		13			11			1							25
Netcare Group Christiaan Barnard Memorial Hospital	1		9															7		2	12			7							38
Cape Town Eye Bank																												5	7	73	85
JOHANNESBURG																															
Johannesburg General Hospital																		25			2										27
Netcare Group - Milpark Hospital, Garden City Clinic & [illegible] Clinic			8						6									9			4			4			5				36
Donald Gordon Medical Centre										5	2	21	1					11	1		9						5				55
Gauteng Eye Bank																												5	15	150	170
PRETORIA																															
Pretoria Academic Hospital																		7													7
Netcare Group - Jakaranda Hospital																		14			1										15
George Mukhari Hospital																					1										1
Pretoria Eye Bank																												1	2	56	59
KWAZULU-NATAL																															
Inkosi Albert Luthuli Hospital																				1	3										4
Netcare Group - St Augustine's Hospital																		7		1	4										12
Life Healthcare - Entabeni Hospital			1						1																						2
KwaZulu-Natal Eye Bank																												4	4	64	72
BLOEMFONTEIN																															
Universitas Hospital																															1
PORT ELIZABETH																															
Port Elizabeth Eye Bank																													1	13	14
TOTAL	2		24						7	9	2	24	1					124	7	7	57			14			10	15	29	356	688

Notes: C = CHILDREN; AD = ADOLESCENTS; A = ADULTS; CD = CADAVER; RLD = RELATED LIVING DONOR; NRL = NON-RELATED LIVING DONOR

Data that were made available for the present study were restricted, as only patients that had received their transplant at the Groote Schuur or Red Cross Hospital were included. Details of all transplant recipients were closely guarded by the doctors of the Transplant Unit. Transplant patients face a long recovery period and a lifelong connection with the hospital and transplant doctors. The protection of their details can be ascribed to the importance of transplant patients for the further understanding of the transplant process, and therefore their privacy is held in high regard (Millar et al., 2004). Every patient, irrespective of the success of the transplant, provided more information on the recovery process and treatment techniques. Detailed information on liver recipients from the Red Cross Hospital was provided by the Head of the Liver Transplant Team at Red Cross, Prof. McCulloch. Of the 90 liver transplants that took place at the Red Cross Hospital since 1991, 27 recipients were under the age of 12 and would therefore not be included in the present study. Twenty-three of the 27 recipients are deceased and 3 were re-transplanted (M. McCulloch, personal communication, 6 June 2007). A detailed list from the Red Cross Hospital indicated that there were potentially 37 patients that could have been contacted for the purpose of the present study (M. McCulloch, personal communication, 6 June 2007).

Prof. Spearman, Head of the Liver Unit at Groote Schuur, provided the study with the adult patient details, as otherwise only limited details were available. Data of the deceased patients from Groote Schuur were unavailable. Twelve names and contact details of adult liver recipients were received (W. Spearman, personal communication, 28 October 2007).

The limitation of an appropriate sample was part of the rationale behind the inclusion of the adult transplant recipients. In order to increase the sample size, both adult and adolescent liver transplant recipients were included. The liver transplant recipients studied in this research will be referred to as the patients, participants, transplant recipients, respondents, adolescents or adults while family will be referred to as caregivers, siblings, guardians and family.

Patients treated at the Red Cross Hospital were usually under the age of 13. Patients aged 13 or older were transferred to Groote Schuur if there were no conflicting circumstances such as low growth tempo or body weight. Nobody was forced to move to another hospital; if patients felt uncomfortable they had the option to stay on at the Red Cross. Patients who were considered to be too small physically had to stay on at the Red Cross until they had reached an appropriate age, weight and body mass index (BMI). (H. Church, personal communication, 17 June 2007).

A transplant list that contains the name, file number, age and other details of all liver transplant operations done at Red Cross Hospital since the opening of the unit in 1991 was provided by the Head of the Liver Transplant Team at Red Cross Hospital. This list was used to identify possible participants and eliminate participants on account of their age, year of transplant and availability. These patients on the Red Cross Hospital transplant list were all still in their adolescent years with the exception of two recipients (M. McCulloch, personal communication, 6 June 2007). After possible participants had been identified on account of their age, Prof. Millar, Head of the Red Cross Hospital, helped by identifying the patients on this list that still regularly visit the Red Cross Liver Clinic (A. Millar, personal communication, 28 July 2007).

Once access to records was granted by the Head of the Liver Transplant Team, a search of the records was conducted to obtain all contact details for the identified patients. All liver transplant recipient files are kept in the Liver Transplant Unit. A manual search of the files and the hospital computer database provided 31 addresses and telephone numbers. From Groote Schuur Hospital, 12 addresses and phone numbers were provided by the Head of the Liver Unit (W. Spearman, personal communication, 28 October 2007). The address and telephone number was obtained of a liver recipient who received her transplant in England more than 20 years ago. The recipient was contacted and informed about the present study, she then agreed to be recruited into the research programme.

Participants were recruited via three different methods (also refer to Figure 1).

1. The potential participant was contacted to arrange a meeting to complete questionnaires during their next visit to the liver clinic.
2. The potential participants with available contact details were contacted to verifying mailing addresses in order for participants to receive questionnaires through the postal service or via e-mail.
3. The potential participants that could not be recruited earlier with methods 1 & 2 due to incomplete records and contact details, were recruited at the weekly and monthly liver clinics at both Red Cross and Groote Schuur Hospital. The researcher attended the

weekly liver clinic at Red Cross Hospital and a monthly liver transplant clinic at Groote Schuur Hospital for four months (Aug 2007-Nov 2007).

Of the 31 addresses found from records at Red Cross Hospital, 9 were incomplete, telephone numbers were missing or digits were missing from telephone numbers. Of the 12 addresses and telephone numbers for adult liver recipients (provided by the Head of the Liver Unit at Groote Schuur Hospital), 6 were outdated (the telephone number was out of service). Having the telephone numbers was important to verify patients' addresses. In an attempt to recruit all 31 adolescent liver recipients and 12 adult liver recipients, a letter (Appendix A) to participants and guardians was sent to the address provided in the medical records. The letter contained an explanation and motivation for the study and also explained the importance of every liver recipient's participation, because of the limited sample. The topic of non-compliance is a sensitive one, therefore a paragraph explaining confidentiality was also included. The letter also included the researcher's telephone number, five questionnaires and a pre-paid and addressed envelope.

The low response rate could be attributed to the outdated personal details and time elapsed since transplantation. The patients' personal details that were correct were usually patients that still regularly attended the liver clinic at Red Cross Hospital. From the 25 liver recipients recruited for the present study, five were recruited at the Liver Clinic held at the Red Cross Hospital and four were recruited from the monthly Liver Transplant Clinic at the Groote Schuur Hospital.

The difficulties encountered in terms of recruiting the sample could have been ascribed to the following factors: limited liver recipient population; indirectly the small number of registered organ donors in South Africa; dispersion of liver recipients across Africa and South Africa; sensitivity surrounding the topic of non-compliance and the fact that no non-compliance research has been conducted on this population before.

The participants

Twenty-five liver transplant recipients ranging in age from 12.8 to 63.5 years (mean = 26.8 years; standard deviation = 14.6) were finally recruited to participate in the study. The mean age at the time of transplantation for the whole group was 16.8 years (range 2 – 58 years; standard deviation = 15.05). The mean length of the time that had elapsed since the transplantation and the present interview was 9.9 years (range 4.1 – 21.8 years; standard deviation = 4.6). Thirteen participants were male and 12 were female.

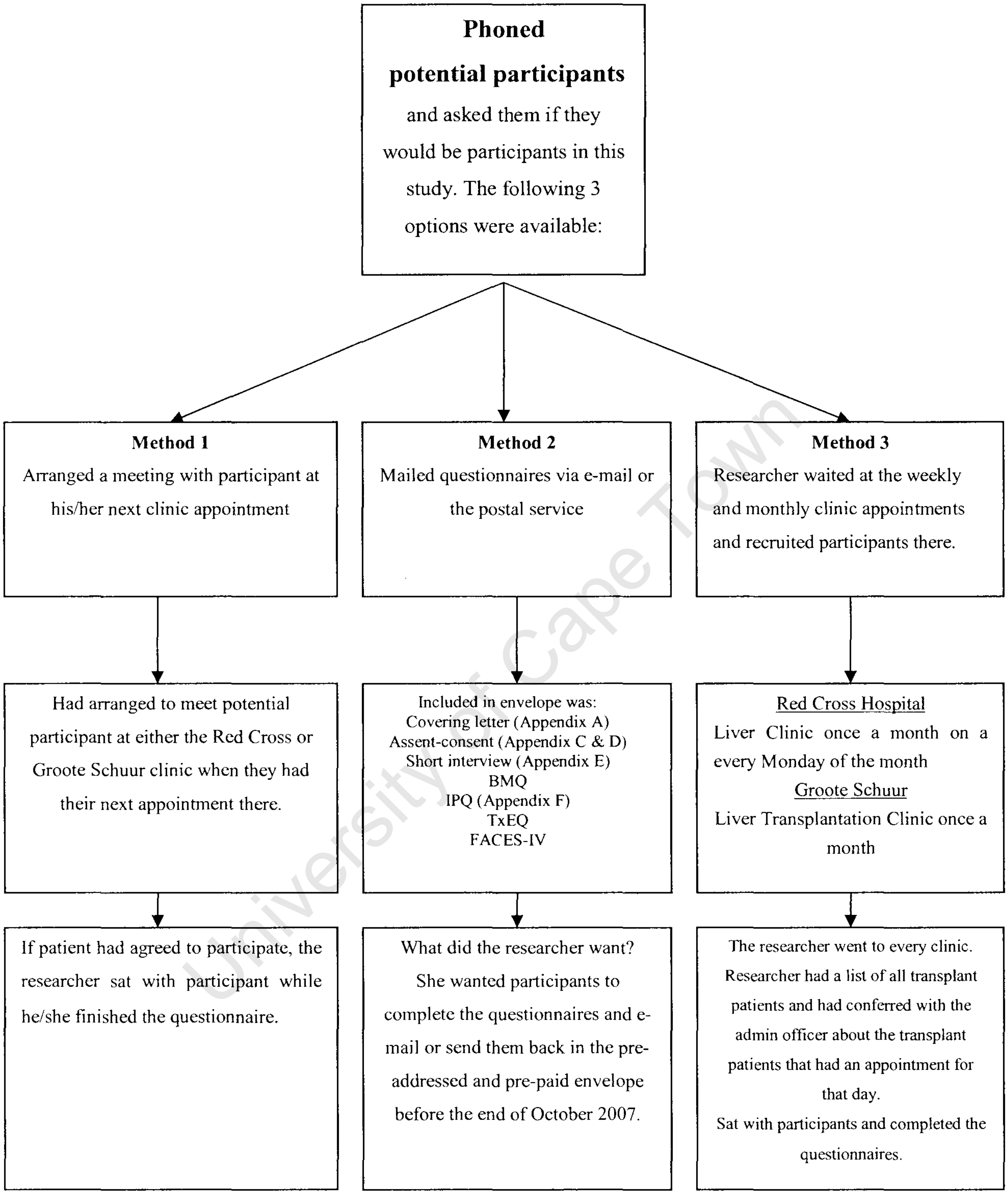
Procedure

Data were collected by recruiting participants from the transplant lists provided by the doctors from the Transplant Units at both the Red Cross and Groote Schuur Hospital. Data were captured from 25 liver transplant recipients, through four different questionnaires and short structured interviews. Only one recipient approached at the clinic declined to take part in the study. Data regarding attendance were gathered from the same hospital database used to search for contact details of transplant recipients. The interview section included a combination of 14 structured questions.

Four months were allocated to recruiting and collecting data. Firstly, participants were contacted and informed about the study. If they agreed to participate, three options were made available for them to complete the questionnaires: via an appointment with them at any chosen venue; the questionnaires were mailed to them via the postal service or e-mail; or participants were recruited when they attended the liver clinic. The last-mentioned procedure was employed when there were no address details on file for the patients and they therefore could not be contacted. The process and procedure that were followed are illustrated in Figure 1.

The data collection took place between 1 August 2007 and 30 November 2007. The Red Cross Hospital held a Liver Clinic every Monday and Groote Schuur held their Liver Transplant Clinic once a month. It took between 30 and 45 minutes to complete the administration of the questionnaires, depending on the time it took participants to complete their questionnaire and their willingness to volunteer further information. All participants were interviewed in their home language which was either English or Afrikaans.

Ten of the participants that were included in the present study were younger than 18 and needed their parents' or guardians' consent. Assent (Appendix C) and consent (Appendix D) forms were attached to the questionnaires and were completed before the data-capturing began. After the self-report questionnaires had been completed, the 14 interview questions were discussed with each participant.



Phoned potential participants and asked them if they would be participants in this study. The following 3 options were available:

Method 1
Arranged a meeting with participant at his/her next clinic appointment

Had arranged to meet potential participant at either the Red Cross or Groote Schuur clinic when they had their next appointment there.

If patient had agreed to participate, the researcher sat with participant while he/she finished the questionnaire.

Method 2
Mailed questionnaires via e-mail or the postal service

Included in envelope was:
Covering letter (Appendix A)
Assent-consent (Appendix C & D)
Short interview (Appendix E)
BMQ
IPQ (Appendix F)
TxEQ
FACES-IV

What did the researcher want? She wanted participants to complete the questionnaires and e-mail or send them back in the pre-addressed and pre-paid envelope before the end of October 2007.

Method 3
Researcher waited at the weekly and monthly clinic appointments and recruited participants there.

Red Cross Hospital
Liver Clinic once a month on a every Monday of the month
Groote Schuur
Liver Transplantation Clinic once a month

The researcher went to every clinic.
Researcher had a list of all transplant patients and had conferred with the admin officer about the transplant patients that had an appointment for that day.
Sat with participants and completed the questionnaires.

Figure 1. ***Procedure explaining three different ways in which data had been collected***

Ethical Considerations

Institutional review board approval

The proposal for this research was first presented on the 15 May 2007 to the Department of Psychology. The proposal was accepted by the Department and the ethics sub-committee of the Faculty of Humanities. Due to the nature and location of the study, approval had to be granted from various other institutions.

- The Research Ethics Committee from Red Cross and Groote Schuur Hospital formally approved the research proposal on 26 July 2007 (REC.REF: 327/2007).
- Permission from the medical superintendent of Red Cross Hospital was obtained on 8 August 2007.
- Permission from the medical superintendent of Groote Schuur Hospital was obtained on 16 August 2007.
- Permission to sit in at clinics to conduct interviews and gather data were obtained from the Head Matron of the Red Cross Hospital on 16 August 2007. The Head Matron was provided with a copy of the research proposal and all letters of approval.

Informed consent to participate in research and relinquishment of parental consent

Informed consent is one of the basic requirements for ethical practices in research, and is signed by the participants to protect their rights, their decision to take part in the study and the information they disclose during the study. Adult participants could give informed consent, but since children under the age of 21 are legally incapable of giving consent according to the Age of Majority Act of 1972[7], consent had to be obtained from their parents or guardians.

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[7] During the ethical approval process of the study, the legal age of majority was still 21 (Age of Majority Act of 1972). In July 2007 the new section of the Children's Act that lowers the age of majority to 18 came into effect. Previously with the Age of Majority Act of 1972, there was a grey area: between the ages of 18-21 you were neither a child nor an adult. Since this research study was approved before July 2007, the section on relinquishing of parental rights was kept in the methodology chapter.

Assent was also obtained from children since they are the participants and must be included in the whole process.

In order to obtain the required assent and informed consent, the nature and purpose of the study had to be explained to parents, guardians and participants. Patients that had contact details available received a letter through the post that along with the consent and assent forms, had accompanied the questionnaires. This letter (Appendix A) explained the purpose of the study. The participants who were approached at the clinic were verbally informed that this was the first study to research compliance and influencing factors in liver transplant recipients in South Africa. All participants had received an explanation of the study on two occasions by means of a letter explaining the study and/or either verbally during a telephone conversation or in person at the clinic (Appendix A).

Another ethical consideration that needed to be taken into account was the fact that data were to be gathered from minors under the age of 21. In certain cases, younger patients had arrived and were waiting with a guardian or parent. There no problem existed; participant and parent could be approached together for consent, but another problem did exist. Parents do not always accompany their children, especially if children fall into the 18-21 year group. Therefore the researcher requested permission from the Research Ethics Committee from Red Cross and Groote Schuur Hospitals (REC.REF: 327/2007) to relinquish parental consent for the potential participants that fall into the 18-21 year age group. With the approval granted by the Research Ethics Committee from Red Cross and Groote Schuur Hospitals, this request was also approved. Special circumstances as referred to above included the following: Some guardians or parents had to drop their children off, because they themselves had to go to work and could not wait with their children until they were attended to, or adolescents that no longer lived with their guardians or parents were lost as participants as they were not accompanied by their parents/guardians. From the total sample population, this had only applied to 9 potential participants. Due to the limited population, it would be to the researcher's advantage to include all of the available recipients.

Confidentiality

When capturing data of a sensitive nature such as non-compliance, a high level of confidentiality must be provided to participants in order to obtain data that are current and accurate. Therefore it was important to assure patients of the anonymity of their data. Patients may not want to disclose their indiscretions to anybody, especially not to the medical staff who cared for them (Wainwright et al., 1997). The researcher wanted to retrieve data of good quality and therefore had to assure patients of complete anonymity and privacy.

Patients were asked to complete four sets of questionnaires, of which none required the patient to disclose his/her identity. During the analysis, the questionnaires were given a reference code for the sole purpose of keeping the data organised. In this manner, there was no means of tracing data back to participants.

Access to attendance records

Research by Laederach-Hofmann et al. (2000) found a close relationship between attendance of clinic appointments and compliance with medication. The present study therefore included attendance of clinic appointments as a proxy measurement for non-compliance. Permission to use folder numbers was not given by the transplant doctors and was requested from transplant recipients themselves. In the questionnaires, the participants gave the researcher permission to use their folder number. File numbers were then used to extract attendance data from the hospital database.

As per agreement with Professors McCulloch and Spearman, the hospital file numbers were not used to identify any participant or have access to their personal medical files. The access to file numbers was therefore only used to extract computerised data related to the patients' attendance record at the hospital.

Responsibilities towards participants

South African researchers have a responsibility to provide information and updated data in studying samples such as these. In order for the hospital to address the problem of non-compliance for future reference, by designing culture-specific intervention programmes, it is necessary to conduct research and possess information on the liver transplant population. No research that has been done has specifically focused on the liver transplant population and non-compliance in South Africa.

Finding organ donors in South Africa is a problem and the supply is not sufficient for the needs of everybody on the waiting list. Thus it is essential to help the few patients who have received an organ to understand why they are taking their immunosuppressive medication, and for the researchers to understand why some patients are still non-compliant after receiving all this information.

Although the research was not directly of benefit to the participants, it would indirectly help gain insight into the problem of non-compliance. Various participants requested to receive a copy of the completed study and this will be arranged for them.

Measures and Analysis

International research (O'Carroll et al., 2006; Laederach-Hofmann et al., 2000) and local (Moshokoa et al., 2000; Millar et al., 2004) makes it clear that the use of multiple sources of information was beneficial for research on non-compliant behaviour.

George, Peveler, Heliger and Thompson (2000) and Waterhouse, Calzone, Mele and Brenner (1993) stated that self-report measures lacked sensitivity, although it had been recorded that patients were more at ease and willing to disclose information in a self-report questionnaire to an independent researcher away from a clinical setting. De Geest, Borgermans, Gemoets and Abraham (1995) stated that data disclosed at a neutral setting to an independent researcher were more accurate than data disclosed to clinical staff. Since the present study was the first of its kind, it was beneficial to gather data on non-compliance in more than one way, as this allowed the study to compare and verify compliance data from various sources.
The following five variables were included in the present study: Medication Compliance; Beliefs about medication; Illness perceptions; Transplant effect and Family dynamics. Data on each of the following variables were collected by a specific self-report questionnaire. The five variables and their questionnaires were introduced and are discussed below.

None of the questionnaires used in this study have been used on this South African population before. Therefore there is no information available regarding the reliability and validity of the instruments. The sample size of this study is too small to give a reliable indication of the reliability and validity of these instruments. However close inspection of the questionnaire did not indicate any particular item that could pose a problem.

Beliefs about Medication Questionnaire (BMQ)

Beliefs that patients have about their medication were measured by the BMQ, a self-report scale that was designed to provide the user with a cognitive reflection that patients have about their medication and the regular usage thereof. The questionnaire is copyrighted and could therefore not be included in the appendix.

The BMQ comprises of two sections: the BMQ-Specific, which assesses representations of medication, prescribed for personal use, and the BMQ-General, which assesses patients' beliefs about medicines in general. The BMQ-Specific comprises two 5-item factors assessing beliefs about the necessity of prescribed medication (Specific-Necessity) and concerns about prescribed medication based on beliefs about the danger of dependence, long-term toxicity and the disruptive effects of medication (Specific-Concerns). The BMQ-General comprises two 4-item factors assessing beliefs that medicines are harmful, addictive, poisons which should not be taken continuously (General-Harm) and that medicines are overused by doctors (General-Overuse) (Horne et al. 1999a). Participants were given 18 statements (I sometimes worry about long-term effects of my medicine, My medicine disrupt my life) and asked to give their opinion on a continuum 5-point scale of "strongly agree" to "strongly disagree."

Specific versions of the BMQ are available for a range of conditions and therapies including renal disease/renal transplant. The internal consistency of a renal sample group was assessed by Horne et al. (1999b) and reported that both the BMQ-Specific and the BMQ-General scales have satisfactory internal consistency. Reliability of the four BMQ sub-scales is as follows: Specific Necessity $\alpha = 0.55$; Specific Concerns $\alpha = 0.73$; General Overuse $\alpha = 0.77$; General Harm $\alpha = 0.83$ (Horne et al., 1999b).

Test-retest reliability of the BMQ was again assessed by Horne et al. (1999b). A sample group of asthmatic patients was used. Reliability of the four BMQ scales is as follows: Specific Necessity $\alpha = 0.77$; Specific Concerns $\alpha = 0.76$; General Overuse $\alpha = 0.60$; General Harm $\alpha = 0.78$. Further test-retest reliability of the BMQ was revealed to be satisfactory when tested by comparing scores obtained when the questionnaire was administered to patient samples at two sessions 14 days apart (Horne et al., 1999b).

The following two studies serve to illustrate the legitimacy of the BMQ for this specific research topic. Wray, Waters, Radley-Smith, Sensky, Brompton and Harefield (2006) assessed the prevalence of non-compliance to medication in adolescent and young adult transplant recipients by using the BMQ. Recipients that reported their non-compliance as unintentional were associated with high scores on the BMQ concerns sub-scale (Wray et al., 2006).

O'Carroll et al. (2006) confirmed these statements with help of the BMQ: self-reported adverse side-effects of prescribed medication and consequences on the recipient's life because of a transplant would lead to poorer compliance. The previous statement replicates the association of consequences and compliance found in patients suffering from diabetes (O'Carroll et al., 2006).

Illness Perception Questionnaire (IPQ)

The IPQ is a self-report scale that reflects the perceptions a patient has towards her/his own illness/condition. These perceptions consist of nine factors, seven of which were included in the present study: consequences, personal control, treatment control, identity, concern, emotion, illness comprehensibility, cause and timeline. Identity and cause were considered to be inappropriate for the present study and were excluded. Participants respond to each of the 38 statements on a 5-point scale of "strongly agree" to "strongly disagree." The questionnaire is included in Appendix F.

Test-retest reliability of the IPQ was assessed by Moss-Morris, Weinman, Petrie, Horne, Cameron and Buick (2002) by a sample group of renal patients. Reliability of the seven IPQ scales is as follows: Timeline (acute/chronic) $\alpha = 0.76$; Timeline (cyclical) $\alpha = 0.72$; Consequences $\alpha = 0.74$; Treatment control $\alpha = 0.63$; Personal control $\alpha = 0.46$; Illness coherence $\alpha = 0.60$; Emotional representation $\alpha = 0.70$ (Moss-Morris et al., 2002).

The following study serves to illustrate the legitimacy of the IPQ for this specific research topic. Wainwright et al (1997) had realised in his review that to promote compliance and develop intervention methods, researchers needed to understand the transplant patient. Although O'Carroll et al. (2006) and Butler, Peveler, Roderick, Smith, Horne and Mason (2004a) reported no noteworthy correlations between the sub-scales of the IPQ and compliance, the questionnaire was included, because it had been included by O'Carroll et al. (2006) in their study and because there was little else available to measure these variables.

Transplant Effects Questionnaire (TxEQ)

This questionnaire was specifically developed to measure the emotional and behavioural responses considered important to transplant recipients and especially the emotions surrounding the transplant and the organ received. The TxEQ consists of 23 statements that other transplant patients have made about their transplant experience. The questionnaire is copyrighted and could therefore not be included in the appendix.

The TxEQ contains five factors that assess the following: worry about the transplant (I am worried about damaging my transplant); feelings of guilt towards the donor (I feel guilty about having taken advantage of the donor); disclosure of transplantation (I avoid telling other people that I have a transplant); medication adherence (sometimes I forget to take my anti-rejection medicines); and perceived responsibility to do well (I think that I have a responsibility to the transplant team to do well). Participants respond to each of the 23 statements on a 5-point scale of "strongly agree" to "strongly disagree."

The internal consistency of a group consisting of a variety of transplant recipients was assessed by Ziegelmann et al. (2002) who reported that the five factors of the TxEQ have satisfactory internal consistency. Validity of the five TxEQ scales is as follows: Worry about transplant $\alpha = 0.81$; Guilt regarding donor $\alpha = 0.76$; Disclosure $\alpha = 0.86$; Adherence $\alpha = 0.79$ and Responsibility $\alpha = 0.72$.

Test-retest reliability of the TxEQ was assessed by the same sample as validity tests. One month test-retest reliability revealed the following: Worry about transplant $\alpha = 0.80$; Guilt regarding donor $\alpha = 0.69$; Disclosure $\alpha = 0.60$; Adherence $\alpha = 0.77$ and Responsibility $\alpha = 0.70$ (Ziegelmann et al., 2002).

It is important to recognise that a transplant recipient's quality of life cannot be assessed using the same measures as for a person who has not experienced similar events (Griva et al., 2002; Ziegelmann, Griva, Hankins, Harrison, Davenport, Thompson & Newman 2002). The emotional responses of the TxEQ are specifically designed for the transplant community and the different emotional stresses they endure. Griva et al. (2002) carried out a quality-of-life comparison study between organ transplant recipients who received an organ from either a living related donor (LRD) or cadaver (CAD). An overall view of the data indicated the following: worry about a transplant is the key determinant for healthy quality of life (HQoL); emotional wellbeing of both LRD and CAD recipients was indicated to be very important for HQoL. The following relationships were linked with increasing age of recipients: less worry regarding your transplant, less guilt, higher compliance with medication and perceived responsibility to do well (Griva et al., 2002; Ziegelmann, 2002). Griva et al. (2002) also stated that the number of collective negative conditions was positively correlated with more disclosure from the recipients. Relationships between TxEQ sub-scales that could suggest associations between the emotional and behavioural aspects of post-transplantation adjustment were also found. Strong feelings of guilt correlated with: worry about transplant; higher perceived responsibility; lower disclosure and poorer medication compliance (Griva et al., 2002). Worry about the transplant had correlated with feelings of greater responsibility to do well and less disclosure about the transplant (Griva et al., 2002).

Family Adaptability and Cohesion Evaluation Scales (FACES-IV)

The Family Adaptability and Cohesion Scales (FACES-IV) is a self-report measure based on the circumplex model of marital and family systems (Olson, McCurbin, Barnes, Larsen, Muxen & Wilson, 1985). The FACES-IV was designed to survey families across the family life-cycle and all family members, including children 12 years old or older. The circumplex model is based on a curvilinear understanding of family functioning and includes two dimensions, cohesion and flexibility. A circumplex implies a correlation relationship among variables.

The basis for the circumplex model lies in the correlation relationship among the variables, which then can be graphed in a circular pattern to represent this correlation relationship, rather than in the graphic representation itself (refer to Figure 2). The circumplex model suggests that families that function best fall in the centre (balanced) between curvilinear extremes on the dimensions of cohesion and flexibility. When applying this model, families that are too cohesive (enmeshed) or too distant (disengaged) are less functional. On the flexibility dimension, families that change too much (chaotic) or do not change enough (rigid) are less functional.

The Family circumplex model and the FACES-IV instruments are proven tools for investigating family functioning in many fields of study. FACES-IV was developed in an attempt to tap the full continuum of the cohesion and flexibility dimensions from the circumplex model of marital and family systems.

The circumplex model consists of three operational dimensions: cohesion; flexibility; communication and a fourth dimension, satisfaction, which assesses the satisfaction of all three of these dimensions (Olson, Gorall, & Tiesel, 2006c). Cohesion is defined as the emotional bonding that family members have toward one another. Flexibility is defined as the amount of change in family leadership, role relationships and relationship rules. Communication is defined as the positive communication skills utilised in the couple or family system. Communication is a facilitating dimension – it is through the use of positive communication skills that couples and families alter their levels of cohesion and flexibility. Satisfaction is defined as the degree to which family members feel happy and fulfilled with each other.

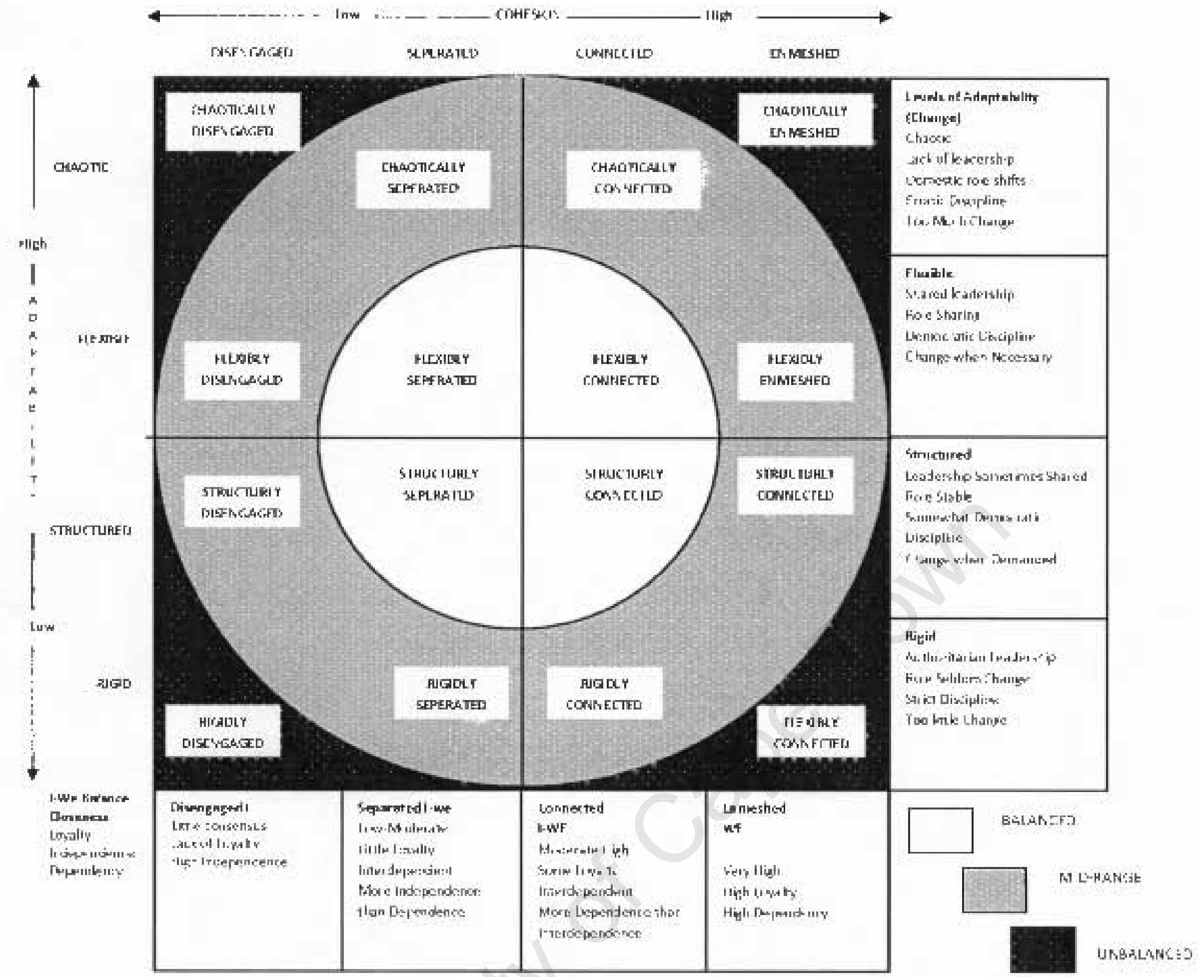

Figure 2. ***Circumplex Model of Marital and Family Systems***

FACES-IV is a self-report assessment designed for the circumplex model of couple and family systems. It contains 62 items that provide a comprehensive assessment of family cohesion and flexibility dimensions. FACES-IV taps both balanced (healthy) and unbalanced (problematic) aspects of family functioning. FACES-IV scales include balanced cohesion; enmeshed; disengaged; balanced flexibility; chaotic and rigid. All items are answered in a five-point Likert-type scale, ranging from 1 "almost never" to 5 "almost always."

The four dimensions of the circumplex model consist of sub-scales. Communication and satisfaction have no sub-scales, but both cohesion and flexibility have two sub-scales. The sub-scales included were developed to measure the high and low extremes of cohesion and flexibility. There are three scales for both cohesion and flexibility. The scales for cohesion are balanced cohesion; disengaged; enmeshed. These scales are designed to measure the balanced and extreme low and high measures of cohesion. The scales for flexibility are balanced flexibility; rigid; chaotic. These scales are designed to measure the balanced and extreme low and high measures of flexibility.

The main hypothesis of the circumplex model is: Balanced levels of cohesion and flexibility (low to high levels) are most conducive to healthy family functioning, while unbalanced levels of cohesion and flexibility (very low or very high levels) are associated with problematic family functioning. When referring to Figure 2, balanced families will be represented on the inner circle and unbalanced families will fall on the outer circles with higher or lower scores on either cohesion or flexibility dimensions. Family dynamics will be measured using FACES-IV. It also includes questions on socio-economic status. The questionnaire is copyrighted and could therefore not be included in the appendix.

An alpha reliability analysis was conducted by Olsen et al. (2006c) to examine the internal consistency of the six scales. Alpha reliability analysis of the validation scales is included for comparison purposes. Reliability of the six FACES-IV scales is as follows: Balanced Scales: Balanced Cohesion $\alpha = 0.89$; Balanced Flexibility $\alpha = 0.80$. Unbalanced Scales: Disengaged $\alpha = 0.87$; Enmeshed $\alpha = 0.77$; Rigid $\alpha = 0.83$; Chaotic $\alpha = 0.85$. Thus reliability is acceptable for research purposes.

Both family satisfaction and communication are new scales to the FACES-IV. Olsen et al. (2006c) assessed the reliability of both by cronanbach alpha and test-retest analysis. A separate sample of n=2465 individuals was used to evaluate the validity and reliability of these scales. The internal consistency is as follows: Family communication $\alpha = 0.90$; Family satisfaction $\alpha = 0.92$. Test-retest reliability of these two FACES-IV scales was assessed. Reliability of the two scales is as follows: Family communication $\alpha = 0.86$; Family satisfaction $\alpha = 0.85$. Finally, there is currently no test-retest data to establish the reliability of the scales and dimensional scales over time (Olson et al., 2006c).

The FACES-IV package includes a formatted spreadsheet that was used for scoring the questionnaire data. The spreadsheet automatically scores the questionnaire data for each of the six FACES-IV scales (cohesion, flexibility, enmeshed, disengaged, rigid, chaotic) and a total score for each scale is calculated. This total score is converted into a percentile score, using the percentile conversion chart. Percentile scores will be used to plot onto the FACES-IV Profile plotting chart illustrated in Figure 3. These percentile scores plotted onto the chart in

Figure 3 will be used to divide families into different family types with specific characteristics that define them. A further two scales were also scored: family communication and satisfaction. These two scales do not form part of the scores needed to divide participants into their appropriate family types.

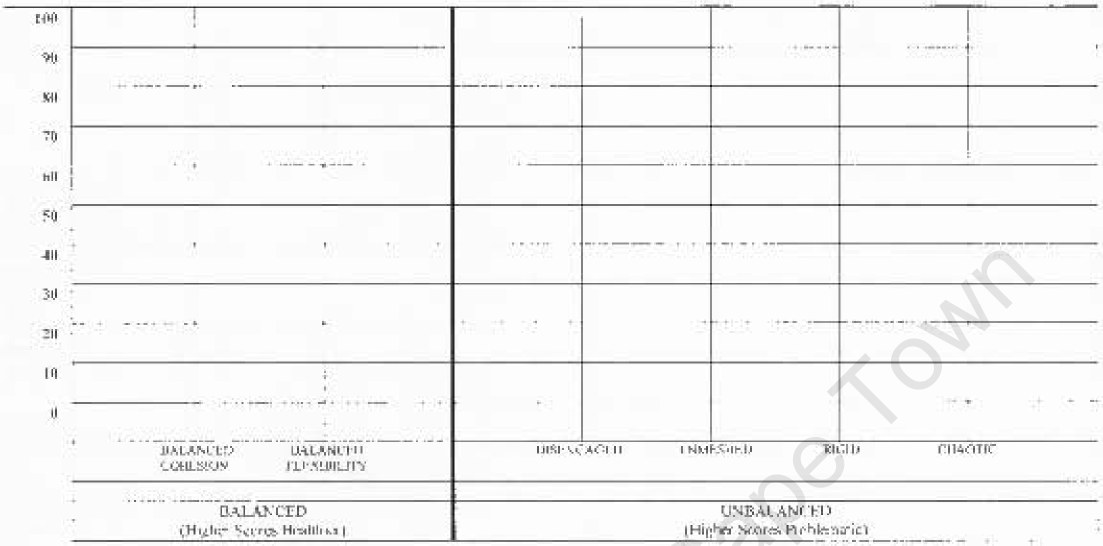

Figure 3. ***FACES-IV Profile plotting chart***

Percentile scores for all sub-scales (cohesion, flexibility, enmeshed, disengaged, rigid, chaotic) for every participant were plotted onto the chart illustrated in Figure 3. There are six different types of family relationship system that can be identified with the FACES-IV scale and each has unique characteristics. These percentile scores were rated from very high, high, moderate, low to very low. The percentile scores were then used to plot onto the chart in Figure 3. This chart is then used to identify and classify participants into one of the six family types.

The six family types

The classification of the family types is a separate part of the FACES-IV analysis. The percentage scores of the dimensions (cohesion, flexibility, communication, satisfaction) and sub-scales of cohesion (enmeshed, disengaged) and flexibility (rigid, chaotic) are plotted on the chart illustrated in Figure 3. The characteristics of the six family types will be discussed and illustrated below (refer to Figures 4–9).

Participants categorised into the 'Balanced' family type will characterised by the following scores: highest scores on the balanced sub-scales of cohesion and flexibility; lowest scores on unbalanced sub-scales disengaged, enmeshed and chaotic; except rigidity where the scores are near the lowest. These scores indicate a family with high level of healthy functioning and low levels of problematic functioning. These families don't have difficulty in handling daily stressors and changes in the family (Olson, Gorall & Tiesel, 2006b).

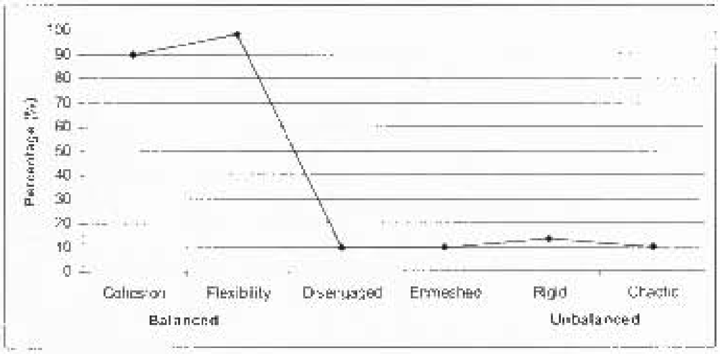

Figure 4. ***Characteristics of the 'Balanced' family type plotted on the FACES-IV profile plotting chart***

Participants categorised into the 'Rigidly Cohesive' family type will characterised by the following scores: high cohesion and rigid scores; moderate flexibility and enmeshed scores; low disengaged and chaos scores. These levels indicate a family with a high level of emotional closeness and rigidity, but the high level of rigidity may cause situational and development changes to be forced by situations or developments in the family (Olson et al., 2006b).

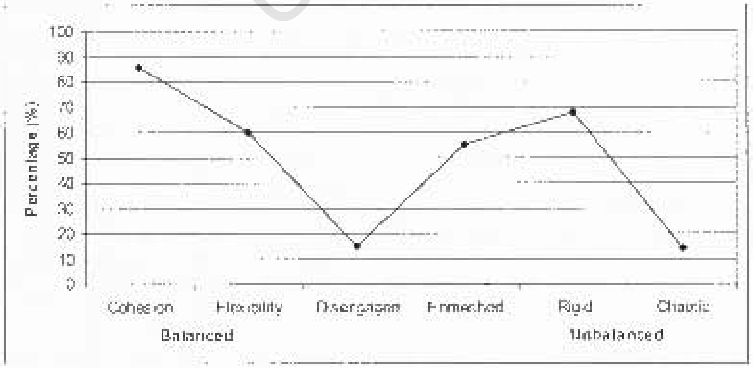

Figure 5. ***Characteristics of the 'Rigidly Cohesive' family type plotted on the FACES-IV profile plotting chart***

Participants categorised into the 'Mid-range' family type will characterised by the following scores: moderate scores on all of the sub-scales with the exception of the rigid sub-scale. The rigid values will fall into either the high or the low group, even for this mid-range family. These levels indicate a family that functions adequately, but does not have the strengths of the high scores of the balanced scale or the difficulties linked to high scores in the unbalanced sub-scales (Olson et al., 2006b).

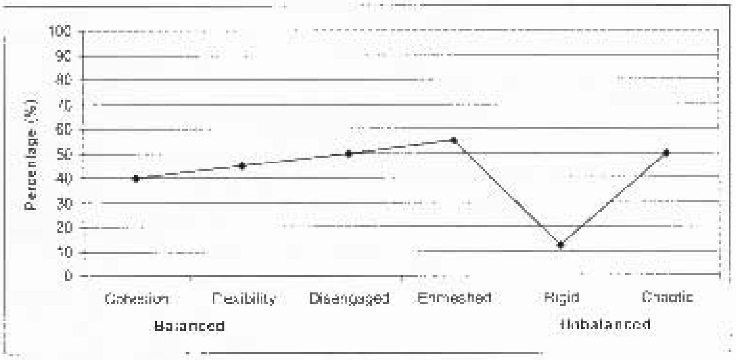

Figure 6. ***Characteristics of the 'Mid-range' family type plotted on the FACES-IV profile plotting chart***

Participants categorised into the 'Flexibly Unbalanced' family type will characterised by the following scores: high scores on all sub-scales except cohesion, where moderate to low scores are characteristic. The high score on the unbalanced scales and low scores on cohesion would indicate problematic functioning in a family, but because of high scores on flexibility these families will be able to alter problematic levels when necessary (Olson et al., 2006b).

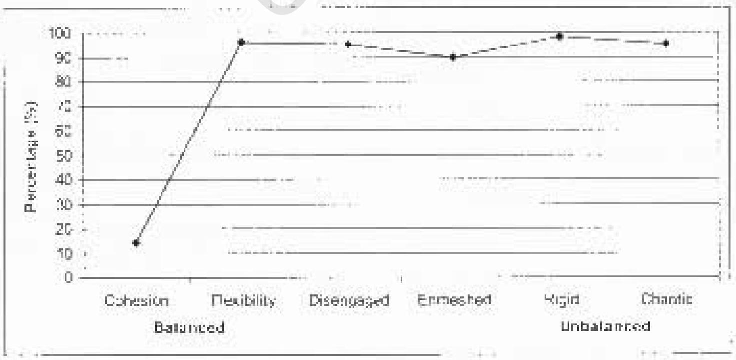

Figure 7. ***Characteristics of the 'Flexibly Unbalanced' family type plotted on the FACES-IV profile plotting chart***

Participants categorised into the 'Flexibly Unbalanced' family type will characterised by the following scores: low scores on the balanced sub-scales; low scores on the enmeshed and rigid sub-scales; high scores on the chaotic and disengaged sub-scales. Families will have problems with a lack of emotional closeness, because of their low cohesion scores and high disengaged scores, and the high degree of problematic change indicated by the high chaos and low change scores.

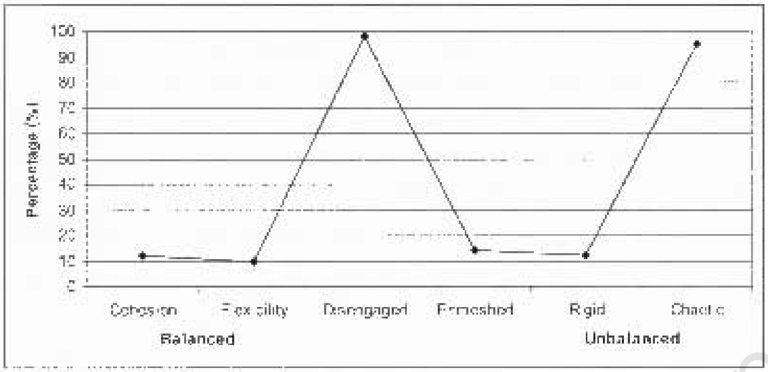

Figure 8. ***Characteristics of the 'Chaotically Disengaged' family type plotted on the FACES-IV profile plotting chart***

Participants categorised into the 'Unbalanced' family type will characterised by the following scores: high scores on all four of the unbalanced sub-scales; low scores on the two sub-scales of balanced. These families are likely to have many problems due to a lack of strength, cohesion and flexibility. These families are an exact mirror image of the balanced families.

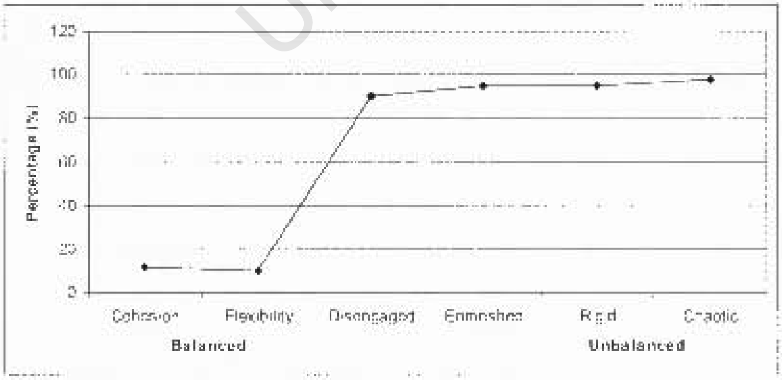

Figure 9. ***Characteristics of the 'Unbalanced' family type plotted on the FACES-IV profile plotting chart***

Although the FACES-IV questionnaire has never been used specifically in the liver transplant population, previous research implemented this measure on transplant populations and transplant- related research topics: organ donation (Lunsford et al., 2007); bereavement in the families of organ donors (Soriano-Pacheco et al., 1999); and bone marrow transplantation (Barrera et al., 2000). Research by Foulkes et al. (1993) did however illustrate that it has been used as a measure in a study focusing on non-compliance in renal transplant patients.

Structured Interview

The four questionnaires were accompanied by a brief structured interview. The interview consisted of fourteen questions (Appendix E). The interviews were not recorded, but the interviewer did make detailed notes during her conversation with participants. If the respondents choose to discuss any other problems relating to non-compliance, it would also have been recorded and included.

CHAPTER THREE
RESULTS AND DISCUSSION

Introduction

The results of the attendance records, questionnaire findings and interviews are presented in three main sections. The analysis of the behavioural data will be presented first, followed by the presentation of the quantitative and qualitative data.

Behavioural Results

Attendance records for clinic appointments

Previous studies indicated that attendance can be linked to a patient's compliance level (Laederach-Hofmann et al., 2000). Patients missing or cancelling more than 25% of their clinic appointments would be coined as non-compliant (O'Carroll et al., 2006).

Attendance data from only 10 of the total research sample of 25 were found. It is unfortunate that the attendance data from the Red Cross Hospital were incomplete and statistically unusable. Nevertheless, these data are included to give an idea of the compliance behaviour using attendance as a proxy measure, even though the quality of the data is so poor. They will not form part of the analysis.

Table 6. *Attendance record of liver transplant patients that could be recovered from hospital*

Patient No.	Clinic Appointments Made	Appointments Not kept	Appointments Cancelled on day	Appointments Cancelled by hospital	Appointments Cancelled by patient	Attendance percentage (%)
1	12	5	1			66.67
2	2					100.00
3	79	5				94.00
4	13	3				81.30
5	39	12				76.50
6	6	2				75.00
7	87	24		2		77.00
8	117	36		1		76.00
9	3	1				75.00
10	56	10		1	1	82.35

Note: Attendance data recovered from computer database at Red Cross Hospital.

Patients will be classified as non-compliant if they missed more than 25% of their appointments.

Quantitative Results

The BMQ, IPQ, TxEQ and FACES-IV was analysed, inter-correlated and discussed individually. The FACES-IV percentile scores was also plotted on the FACES-IV profile plotting chart to identify the specific family type that best represents each participant. These family types have specific characteristics. The relationship between each family type and compliance was also explored.

Beliefs about medication

Scores obtained for the individual items within each of the four sub-scales are added to give a scale score. Higher scores indicate stronger beliefs in the concepts represented by the scale. Total scores for the BMQ-Specific scales (necessity and concerns), range from 5 to 25. The BMQ-General scales (overuse and harm) range from 4 to 16.

In studies of patients from several illness groups (including asthma, diabetes, kidney disease, heart disease, cancer and HIV) it was found that necessity beliefs and concerns were related to reported compliance. Patients with stronger beliefs in the necessity of their medication (high scores on the BMQ–Necessity scale) were significantly more compliant. Those with stronger concerns (high scores on the BMQ-Concerns) scale were significantly less compliant (Horne, 1997). Low scores on the Necessity scale may simply be a reflection of the fact that patients who do not perceive their medication to be important may be more likely to forget to take it. General medication beliefs (Harm and Overuse) seem to have less influence on compliance than specific beliefs (necessity and concerns). However, general beliefs may be important when a new and unfamiliar treatment is prescribed and the patient may not have formulated strong concerns or necessity beliefs (James, 1999; Horne, 1997).

Table 7. ***BMQ sub-scales: mean, standard deviation and correlation to compliance***

	Mean ($\bar{x}$)	SD (s_n)	Tx (r^2)
Specific Necessity	20.88	4.44	$r^2 =$ .063, $p > 0.05$
Specific Concerns	13.88	5.21	r^2 -.417*, $p < 0.05$
General Overuse	3.03	3.03	r^2 -.144, $p > 0.05$
General Harm	2.89	2.89	r^2 -.167, $p > 0.05$

Note. *. Correlation is significant at the 0.05 level (2-tailed).

The mean scores obtained on the four sub-scales in the present study appear in Table 7. To link the scores to compliance behaviour, scores were correlated with the scores on the compliance sub-scale of the TxEQ. The complianceTxEQ is the primary scale for compliance in the present study, as it was for Carroll et al. (2006). The following mean scores were obtained for the sub-scales: high mean scores for specific necessity; moderate mean score for specific concerns; and low mean scores for both general overuse and general harm.

Correlation analysis with complianceTxEQ and sub-scales revealed a single statistically negative correlation with specific concerns. This seems exactly what would have been expected: the more concerns you have, the less compliant patients will be (O'Carroll et al., 2006).

To conclude, the mean values signified an agreement with the concept of necessity of medicine. Moderate levels of concern and low levels of harm and overuse concluded that patients believed that doctors know what they are doing and are not over-prescribing medicines that can be harmful to them. From the data retrieved, it can be argued that this is the type of data that could have been expected. The necessity of medicine and concerns surrounding medicine indicated an increasing level of compliance, but the effect of general overuse and harm had no significant effect on compliance behaviour of recipients.

Associations between sub-scales of BMQ

In order to investigate possible relationships between the sub-scales of the BMQ, correlation coefficients were calculated and revealed the following.

Table 8. ***Correlation matrix of BMQ scales***

Scale	I.	II.	III.	IV.
I. Specific Necessity	1.00			
II. Specific Concern	.222	1.00		
III. General Overuse	.342	.587**	1.00	
IV. General Harm	.233	.599**	.732**	1.00

Note. **. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

The significant correlations between specific concerns and general overuse indicated that patients' concerns regarding the adverse consequences of their prescribed medication are positively related to their personal beliefs that doctors place too much emphasis and trust in medicines and thus overuse and prescribe them.

Significant correlations between general overuse and general harm indicated that patients' personal beliefs regarding the extent of doctors' emphasis and trust in medicines had a positive relationship with the personal beliefs patients had about the fundamental properties of medicines and the degree to which medicines are perceived as essentially harmful.

Significant correlations between general harm and specific concerns indicated that patients' personal beliefs regarding the fundamental properties of medicines and the degree to which they are perceived as essentially harmful, had a strong positive relationship with patients' concerns regarding the adverse consequences of their prescribed medication.

Correlation analysis between sub-scales of BMQ are as one would have expected, and in line with other research (Horne, 2000; Wainwright et al., 1997; O'Carroll et al., 2006).

Illness Perception analysis

Scores obtained for the individual items within each scale were summed to give a scale score. Higher scores indicate stronger beliefs in the concepts represented by the scales. High scores on the identity, timeline, consequences, and cyclical dimensions represent strongly held beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, the negative consequences of the illness, and the cyclical nature of the condition. High scores on the personal control, treatment control and coherence dimension represent positive beliefs about the controllability of the illness and a personal understanding of the condition (Moss-Morris et al., 2002).

Total scores for the IPQ sub-scales: (timeline, consequences, personal control, emotional representation) range from 6 to 30; (treatment control items, illness coherence items) range from 5 to 25 and (timeline cyclical) range from 4 to 20. High scores on the sub-scales would indicate the following perceptions surrounding their illness: a strong emotional response to the illness; perception that the illness is chronic; perception that the illness is cyclical in pattern; perception that the illness has serious consequences; and perception that control or cure of the illness is possible.

Table 9. ***IPQ sub-scales: mean, standard deviation and correlation to compliance***

	Mean (x)	**SD (s_D)**	**Tx (r^2)**
Timeline	21.68	5.16	$r^2 = .376, p > 0.05$
Consequences	17.8	4.31	$r^2 = .173, p > 0.05$
Personal control	20.8	3.71	$r^2 = .273, p > 0.05$
Treatment control items	17.68	3.25	$r^2 = .160, p > 0.05$
Illness coherence items	18.2	3.92	$r^2 = .262, p > 0.05$
Timeline cyclical	10.36	3.23	$r^2 = -.103, p > 0.05$
Emotional Representation	14.52	5.25	$r^2 = -.366, p > 0.05$

The mean scores obtained on the seven sub-scales in the present study appear in Table 9. To link the scores to compliance behaviour, scores were correlated with the scores on the compliance sub-scale of the TxEQ. The complianceTxEQ is the primary scale for compliance in the present study, as it was for Carroll et al. (2006). The following mean scores were obtained for the sub-scales: high mean scores for (timeline, personal control, treatment control items, illness coherence items); moderate mean score for (consequences, timeline cyclical); and low mean scores for emotional representation.

Correlation analysis with complianceTxEQ and sub-scales revealed no statistically significant correlation with any of the IPQ sub-scales. This was not exactly expected, however (Butler, Peveler, Roderick, Smith, Horne & Mason, 2004b) also indicated that sub-scales of IPQ did not significantly correlate with compliance.

To conclude, the mean values signified the following: high scores on timeline indicated that patients have strong beliefs about the influence of the chronicity of the condition; high scores on the personal control, treatment control and coherence dimension represent positive beliefs about the controllability of the illness and a personal understanding of the condition; moderate scores on consequences, and cyclical dimensions represent strongly held beliefs about the number of symptoms attributed to the illness, the negative consequences of the illness, and the cyclical nature of the condition; and low scores on emotional representation indicate the effect of emotional state of patient on their condition. The data retrieved provided reasons to argue that this is the type of data that could have been expected (Butler et al., 2004b).

Associations between sub-scales of IPQ

In order to investigate possible relationships between the sub-scales of the IPQ, correlation coefficients were calculated and revealed the following.

Table 10. ***Correlation matrix of IPQ scales***

Scale	I.	II.	III.	IV.	V.	VI.	IX.
I. Timeline	1.00						
II. Consequences	.057	1.00					
III. Personal Control	.021	-.007	1.00				
IV. Treatment Control Items	.009	.060	.453*	1.00			
V. Illness Coherence Items	.250	-.183	.300	.093	1.00		
VI. Timeline Cyclical	-.031	.360	-.235	-.272	-.235	1.00	
IX. Emotional Representations	-.413*	.115	.123	.092	-.524**	-.154	1.00

Note. *. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

The significant correlations between treatment control items and personal control indicated that a positive relationship exists between the beliefs patients have about the power of personal control and the effect this can have on their illness and the belief in treatment that can influence their condition.

Significant correlations between timeline and emotional representation indicated that the patients' knowledge of the timeline of their illness had negative relationship on the emotional effect that the transplant had on the recipient.

Significant correlations between emotional representation and illness coherence items indicated that the patients' understanding of the scope of their illness had a positive relationship on the emotional effect the transplant had on the recipient.

Correlation analysis between sub-scales of IPQ is as one would have expected, and in line with other research, but unfortunately no correlations between IPQ sub-scales and complianceTxEQ were found (Butler et al., 2004b; Weinman, Petrie, Moss-Morris & Horne, 1996; Moss-Morris et al., 2002; Horne et al., 1999b; Wainwright et al., 1997; O'Caroll et al., 2006).

Transplant Experience analysis

Scores obtained for the individual items within each scale are summed to give a scale score. Total scores for the TxEQ sub-scales: (worry about transplant) range from 6 to 30; (guilt regarding donor; compliance) range from 5-25; (responsibility) range from 4-20 and; (disclosure) range from 3-15. Higher scores indicate stronger beliefs in the concepts represented by the scale. Higher scores on the sub-scales of the TxEQ signify more worry about the transplant, more guilt, and more disclosure to the doctors and about their transplant, more perceived responsibility felt towards doctors and donor to do well, respectively, and greater compliance.

Table 11. ***TxEQ sub-scales: mean, standard deviation and correlation to compliance***

	Mean ($\bar{X}$)	**SD (s_D)**	**Tx (r^2)**
Worry about transplant	18.04	4.07	$r^2 = -.016$, $p > 0.05$
Guilt regarding donor	13.08	2.33	$r^2 = -.137$, $p > 0.05$
Compliance	19.48	3.10	$r^2 = 1.00$
Disclosure	7.28	3.55	$r^2 = -.289$, $p > 0.05$
Responsibility	16.04	2.52	$r^2 = .585$**, $p < 0.01$

Note. **. Correlation is significant at the 0.01 level (2-tailed).

The mean scores obtained on the five sub-scales in the present study appear in Table 11. To link the scores to compliance behaviour, scores were correlated with the scores on the compliance sub-scale of the TxEQ. The complianceTxEQ is the primary scale for compliance in the present study, as it was for Carroll *et al.* (2006). The following mean scores were obtained for the sub-scales: high mean scores for (compliance, responsibility); moderate mean score for (worry about transplant, guilt regarding donor); and low mean scores for (disclosure).

The primary compliance scale originated from the TxEQ and this can be seen in Table 11 where the compliance coefficient is 1.00. Correlation analysis with complianceTxEQ and the other sub-scales of TxEQ revealed one statistically significant correlation between complianceTxEQ and responsibility. This was exactly what was expected. O'Carroll *et al.* (2006) also indicated that sub-scales of TxEQ should significantly correlate with compliance.

To conclude, the mean values signified the following: high scores on compliance indicated that patients have high non-compliance behaviour; high scores on responsibility indicated that patients' experienced more perceived responsibility; moderate scores on worry about transplant indicated that patients did not experience worry about their transplant regularly; guilt regarding the donor indicated that patients did not feel much guilt towards the donor of their organ; and low scores on disclosure indicated that patients did not disclose information about their transplant condition easily or regularly. From the data retrieved it can be argued that this is the type of data that could have been expected (Butler et al., 2004b; O'Carroll et al., 2006).

Associations between sub-scales of TxEQ

In order to investigate possible relationships between the sub-scales of the TxEQ, correlation coefficients were calculated and revealed the following.

Table 12. ***Correlation matrix of TxEQ scale***

Scale	I.	II.	III.	IV.	V.
I. Worry about transplant	1.00				
II. Guilt regarding donor	-.005	1.00			
III. Disclosure	.145	-.254	1.00		
IV. ComplianceTxEQ	-.016	-.137	-.289	1.00	
V. Responsibility	.278	-.289	-.131	.585**	1.00

Note. **. Correlation is significant at the 0.01 level (2-tailed).

The correlation between sub-scales in the TxEQ sub-scales resulted in only one significant correlation. The significant correlation between responsibility and complianceTxEQ indicated that an increased sense of responsibility felt by recipients shared a strong positive relationship with an increased compliance of patients.

Correlation analysis between sub-scales of TxEQ is not exactly as one would have expected, but was in line with other research (O'Carroll et al., 2006).

Family Dynamics analysis

In order to identify participants into one of the six family types, the following needs to be done. Scores from the six sub-scales (cohesion, flexibility, enmeshed, disengaged, rigid, chaotic) are converted to percentile scores by using the chart provided by the FACES package. Charts are attached in Appendix G. Please refer to Table 13 for conversion of raw data to percentage scores.

Table 13. *Conversion of FACES-IV raw scores to percentage score*

Participant	Cohesion Raw scores	Cohesion % Score	Flexibility Raw scores	Flexibility % Score	Disengaged Raw scores	Disengaged % Score	Enmeshed Raw scores	Enmeshed % Score	Rigid Raw scores	Rigid % Score	Chaotic Raw scores	Chaotic % Score
1	32	86	31	93	15	24	13	18	23	50	10	14
2	27	50	26	65	18	32	13	18	21	40	16	26
3	25	35	23	50	26	64	21	40	26	64	17	30
4	26	40	26	65	26	64	20	36	26	64	22	45
5	34	95	28	75	13	18	13	18	24	55	13	18
6	15	10	21	40	19	34	12	16	20	36	17	30
7	29	69	27	70	15	24	18	32	14	20	21	40
8	29	69	26	65	17	30	18	32	25	60	9	13
9	30	76	29	83	21	40	24	55	21	40	8	12
10	31	86	28	83	15	36	15	14	24	30	15	26
11	27	81	27	75	21	24	22	24	24	55	17	24
12	29	69	28	65	17	15	20	20	18	32	18	18
13	23	25	22	45	21	40	22	45	20	36	21	40
14	33	50	34	70	17	40	21	45	33	55	7	30
15	30	12	27	50	16	13	12	15	16	36	12	16
16	31	81	25	65	15	20	21	18	22	36	18	30
17	32	69	29	75	20	30	10	36	17	32	16	32
18	29	90	26	99	11	30	14	40	18	95	13	10
19	12	10	17	20	25	60	14	20	14	20	24	55
20	31	76	26	70	14	26	13	16	20	26	17	16
21	31	81	30	88	11	15	16	26	25	60	13	18
22	29	69	29	83	18	32	22	45	21	40	16	26
23	32	86	31	93	20	36	24	55	25	60	14	20
24	26	40	24	55	19	34	20	36	21	40	17	30
25	18	81	23	60	9	24	11	40	20	45	12	32

Note. Refer to Appendix G for percentage conversion chart.

ercentage scores of each of the subscales for every participant are plotted on the FACES-IV profile plotting chart illustrated in Figure 3. This is done for every participant and the results are illustrated in Figure 10. From this graph, every participant is divided into one of the six family types. To clarify, in this sample there are no participants classified into the unbalanced family type. Therefore from here on, only five family types will feature in the analysis process. To make Figure 10 more usable, data from family types were grouped and the average for each of the sub-scales was plotted on a new graph shown in Figure 11, to illustrate a more condensed version of participants divided into their family types. Table 14 illustrates the data divided into their family types and the calculation of averages for both raw scores and percentage scores. Table 15 serves the same purpose as Table 14, but provides data only for the communication and satisfaction scales. Averages for raw scores are calculated and then again referred to balanced and unbalanced scales: in percentile scores & levels chart (Appendix G) this provides new percentage score for each sub-scale of every family type.

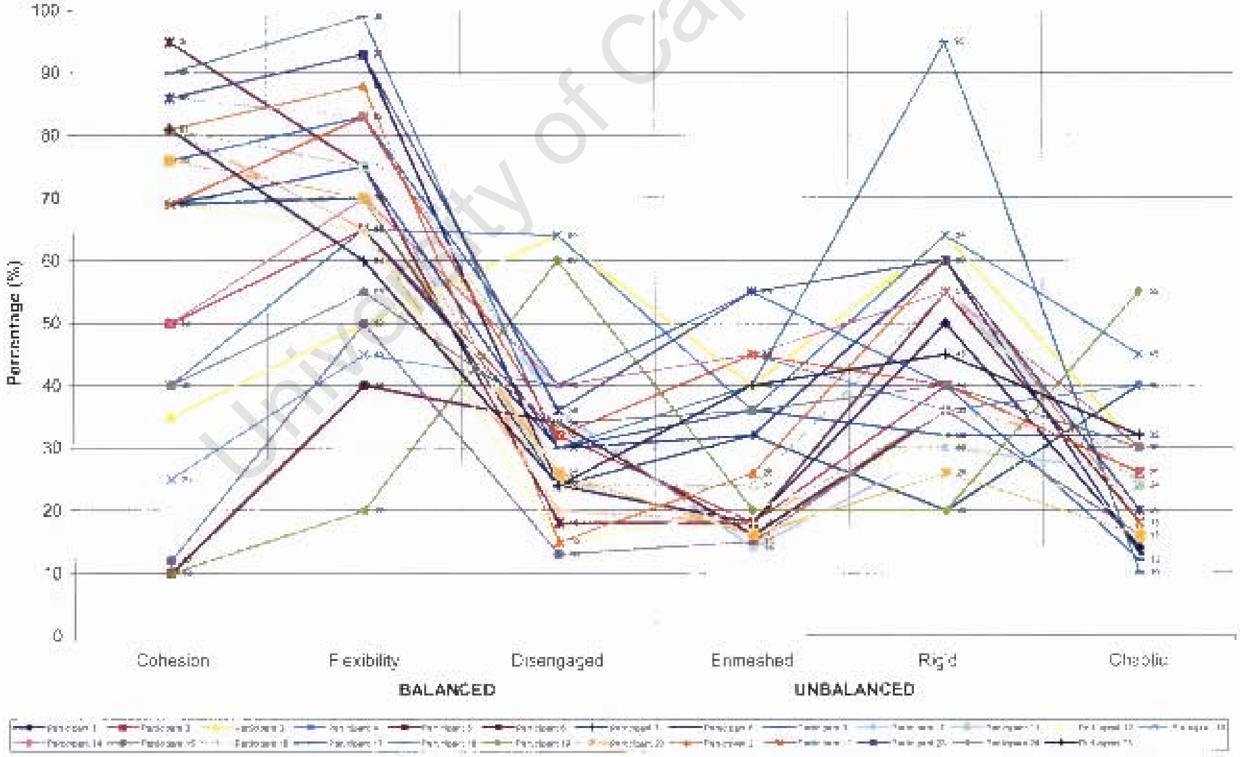

Figure 10. ***Percentage scores of 25 participants plotted on the FACES-IV profile plotting chart***

From Figure 10, five family types were identified from the 25 participants: balanced (n=12), rigidly cohesive (n=6), mid-range (n=1), flexibly unbalanced (n=4) and chaotically disengaged (n=2).

Table 14. *Conversion of raw and percentages scores into average scores for each of the five identified family types*

Participant	Cohesion Raw scores	Cohesion % Score	Flexibility Raw scores	Flexibility % Score	Disengaged Raw scores	Disengaged % Score	Enmeshed Raw scores	Enmeshed % Score	Rigid Raw scores	Rigid % Score	Chaotic Raw scores	Chaotic % Score
Balanced Family Type												
1	32	86	32	53	15	24	13	18	23	50	10	14
2	27	50	26	65	18	32	13	18	21	40	16	26
5	34	95	28	75	13	18	13	18	24	55	13	18
7	29	69	27	70	15	24	18	32	14	20	21	40
8	29	69	26	65	17	30	58	32	25	60	9	13
10	31	86	28	83	15	36	15	14	24	30	15	26
12	29	69	28	65	17	15	20	20	18	32	18	18
15	30	17	27	50	16	13	12	15	16	36	12	16
17	32	89	29	75	20	30	10	36	17	32	16	32
18	29	90	26	99	11	30	14	40	18	95	13	10
20	21	76	26	70	14	26	13	16	20	26	17	16
21	31	81	30	88	12	15	16	26	25	60	13	18
24	26	40	24	55	19	34	20	36	21	40	17	30
Averages	30	76	27	70	15	24	15	24	20	36	15	21
Rigidly Cohesive Family Type												
9	30	76	29	83	21	40	23	55	21	40	8	12
11	27	81	27	75	21	24	22	24	24	55	17	24
14	33	50	34	70	17	40	21	45	33	55	7	30
16	31	83	25	65	15	20	21	18	22	36	18	30
22	29	69	29	83	18	32	22	45	21	40	16	26
23	32	96	32	93	20	36	24	55	25	60	14	20
Averages	30	76	29	83	19	34	22	45	23	55	13	15
Mid-range Family Type												
24	26	40	24	55	19	34	20	36	21	40	17	30
Averages	26	40	24	55	19	34	20	36	21	40	17	30
Flexibly Unbalanced Family Type												
3	25	35	23	50	26	64	21	40	26	64	17	35
6	15	10	21	40	19	34	12	16	20	36	17	30
13	23	35	22	45	21	40	22	45	30	36	21	40
25	18	81	23	60	9	24	11	40	30	45	12	32
Averages	20	34	22	45	19	34	17	30	22	45	17	30
Chaotically Disengaged Family Type												
4	26	40	26	65	26	64	20	36	26	64	23	45
19	12	10	12	20	25	60	14	20	14	20	24	55
Averages	19	13	22	45	26	64	17	30	20	36	23	50

Note. Average raw scores are converted to average percentage score with the help of the balanced unbalanced scales: percentile scores & levels.

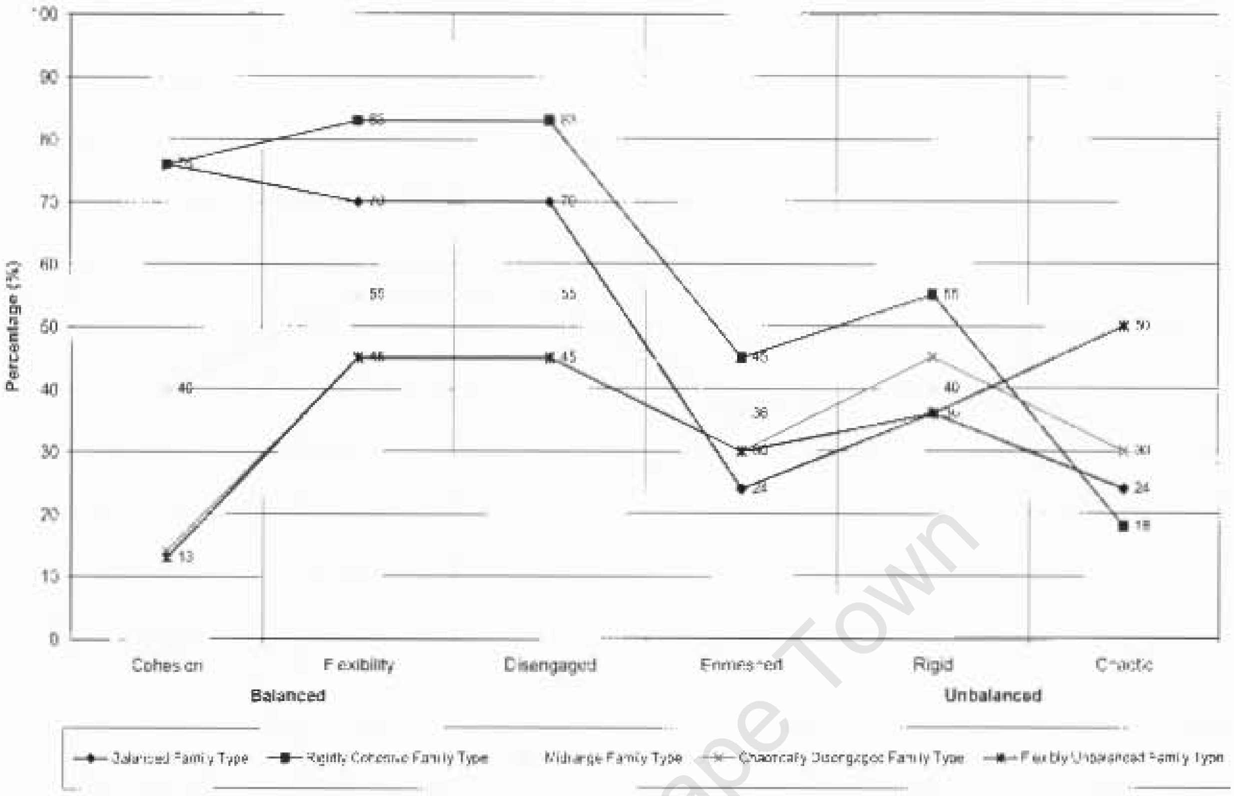

Figure 11. *Average percentage scores plotted for each of the five family types identified*

Communication and satisfaction scales are not involved in the identification of family types. They serve a different purpose. The communication scale assesses the level of communication of the family and satisfaction assesses the level of satisfaction of the following three dimensions (cohesion, flexibility, communication) (Olson et al., 2006c).

Table 15. *Conversion of raw scores of communication and satisfaction into average percentage scores f each of the five identified family types*

Participant	Communication Raw scores	Communication% Score	Family Communication Level	Satisfaction Raw scores	Satisfaction % Score	Family Satisfaction Level
			Balanced Family Type			
1	38	61	Moderate	43	79	High
2	35	44	Low	40	66	High
5	44	86	High	40	66	High
7	36	50	Moderate	38	51	Moderate
8	40	70	High	40	66	High
10	35	44	Low	39	58	Moderate
12	37	58	Moderate	31	23	Low
15	38	61	Moderate	38	51	Moderate
17	42	80	High	38	51	Moderate
18	39	65	Moderate	39	58	Moderate
20	41	74	High	40	66	High
21	40	70	High	41	71	High
Averages	39	65	High	39	58	Moderate
			Rigidly Cohesive Family Type			
9	40	70	High	35	35	Low
11	37	58	Moderate	38	51	Moderate
14	40	70	High	42	75	High
16	40	70	High	41	71	High
22	40	70	High	39	58	Moderate
23	48	96	Very High	44	84	High
Averages	41	74	High	40	66	High
			Mid-range Family Type			
24	38	61	Moderate	49	98	Very High
Averages	38	61	Moderate	49	98	Very High
			Flexibly Unbalanced Family Type			
3	37	58	Moderate	40	66	High
6	24	12	Very Low	30	21	Low
13	20	10	Very Low	28	15	Very Low
25	47	94	Very High	40	66	High
Averages	32	32	Low	35	35	Low
			Chaotically Disengaged Family Type			
4	40	70	High	35	35	Low
19	25	13	Very Low	14	10	Very Low
Averages	33	36	Moderate	25	10	Very Low

Note. Average raw scores are converted to average percentage score with the help of the communication and satisfaction scales: percentile scores & levels (refer to Appendix II).

The FACES-IV was developed to assess the full dimensions of cohesion and flexibility in the circumplex model. Six scales were developed two are balanced, cohesion and flexibility. Four are unbalanced to measure the low extremes of cohesion, disengaged and enmeshed and the low extremes of flexibility, rigid and chaotic. With these six sub-scales, five different family types were identified in Figure 11, ranging from balanced representing healthy families to unbalanced representing problematic families.

Total scores for the FACES-IV sub-scales cohesion, flexibility, disengaged, enmeshed, rigid and chaotic range from 7 to 35, while for communication and satisfaction they range from 10 to 50. High scores on the balanced sub-scales of cohesion and flexibility and low scores on the unbalanced sub-scales of disengaged, enmeshed, rigid and chaotic would indicate a family that is functioning in a healthy manner. Low scores on the balanced sub-scales of cohesion and flexibility and moderate to high scores on the unbalanced sub-scales of disengaged, enmeshed, rigid and chaotic would indicate a family with problematic unhealthy functioning.

Table 16. ***FACES-IV sub-scales: mean, standard deviation and correlation to compliance***

	Mean $(\bar{x})$	**SD** (s_D)	**Tx** (r^2)
Balanced Cohesion	27. 64	5.49	$R^2 = 0.499^*$, $p < 0.05$
Balanced Flexibility	26.52	3.60	$R^2 = 0.248$, $p > 0.05$
Disengaged	17.56	4.44	R^2 -0.377, $p > 0.05$
Enmeshed	17.16	4.43	$R^2 = -0.183$, $p > 0.05$
Rigid	21.52	4.22	$R^2 = 0.097$, $p > 0.05$
Chaotic	15.32	4.31	$R^2 = -0.477^*$, $p < 0.05$
Communication	37.64	6.40	$R^2 - 0.290$, $p > 0.05$
Satisfaction	37.68	6.61	R^2 0.328, $p > 0.05$

Note, *. Correlation is significant at the 0.05 level (2-tailed).

The mean scores obtained on the eight sub-scales in the present study appear in Table 16. To link the scores to compliance behaviour, scores were correlated with the scores on the compliance sub-scale of the TxEQ. The complianceTxEQ is the primary scale for compliance in the present study, as it was for Carroll et al. (2006). The following mean scores were obtained for the sub-scales: high mean scores for balanced cohesion, balanced flexibility, communication, and satisfaction; moderate mean scores for disengaged, enmeshed, and rigid; and low mean scores for chaotic

Correlation analysis with complianceTxEQ and the sub-scales of FACES-IV revealed two statistically significant correlations: a positive correlation between complianceTxEQ and balanced cohesion and a negative correlation between complianceTxEQ and the chaotic sub-scales. Although the FACES-IV measure has not been used for researching the liver transplant population, it can be argued that results are as expected. The significant positive relationship between balanced cohesion and compliance indicate that balanced families have a higher level of compliance. The chaotic sub-scales rarely have high scores and only score high in the most unbalanced families (chaotically disengaged family type and unbalanced family type). The significant negative relationship between complianceTxEQ and chaotic indicated that the higher the chaotic scale of a family, the lower their compliance level will be, and indirectly this also indicates that the more unbalanced the family, the lower their compliance level.

To conclude, the mean values signified that most of the families of the present study will fall under balanced umbrella (balanced, rigidly cohesive, mid-range). Of the six family types, three are identified to have balanced functioning (balanced, rigidly cohesive, mid-range) and another three are identified to have unbalanced functioning (flexibly unbalanced, chaotically disengaged, unbalanced). The first statement can be supported by the fact that mean scores signified balanced cohesion, balanced flexibility, communication, satisfaction and moderate to low mean scores on the four unbalanced sub-scales: disengaged; enmeshed; rigid; chaotic. Of the 25 participants, 19 have been identified as a family type that falls under the balanced umbrella.

Associations between sub-scales of FACES-IV

In order to investigate possible relationships between the sub-scales of the FACES-IV, correlation coefficients were calculated and revealed the following.

Olson et al., (2006c) tried to validate the FACES-IV by inter-correlating the 8 sub-scales with the family satisfaction validation scales. In the validation study, the FACES-IV correlation analysis revealed some relationships that stood out due to their large or small correlations. Relationships signified by their large correlations include those between the FACES-IV scales of cohesion/disengaged, cohesion/flexibility, chaos/disengaged, chaos/cohesion, and disengaged/flexibility. Relationships signified by their low correlations are enmeshed/disengaged, enmeshed/cohesion, flexibility/rigid, and chaos/rigid (Olson et al., 2006c). There were relatively high correlations between the FACES-IV scales and the validation scale of Family Satisfaction with the exception of the Rigid and Enmeshed scales, which had relatively low correlations with all other scales. The general trend between the FACES-IV scales and the validation scales is that the FACES-IV scales designed to measure the moderate or healthy regions of cohesion and flexibility (balanced cohesion and balanced flexibility) had large positive correlations with the validation scales, while the FACES-IV scales designed to measure the high and low extremes of family functioning (enmeshed, disengaged, chaos, rigid) had large negative correlations with the validation scales, excluding Enmeshed and Rigid.

Table 17. ***Correlation matrix of FACES-IV scales***

Scale	I.	II.	III.	IV.	V.	VI.	IX.	X
I. Cohesion	1.00							
II. Flexibility	.819**	1.00						
III. Disengaged	-.425*	-.210	1.00					
IV. Enmeshed	-.017	.182	.468*	1.00				
V. Rigid	.284	.319	.130	.438*	1.00			
VI. Chaotic	-.522**	-.553**	.417*	.148	-.304	1.00		
IX. Communication	.216	.055	-.274	-.176	.000	-.291	1.00	
X. Satisfaction	.278	-.074	-.404*	-.280	-.069	-.136	.493*	1.00

Note. *. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

Cohesion and flexibility had the strongest positive relationship. According to the characteristics of the family types, balanced families have high scores on both cohesion and flexibility, and since 12 of the 25 participants fall into this family type, a strong positive correlation is to be expected. Satisfaction and communication also shared a positive relationship, indicating that increasing levels of communication lead to an increase in the satisfaction of families. Disengaged shared a moderate positive relationship with cohesion, enmeshed, satisfaction and chaotically disengaged. Chaotic shared a strong positive relationship with cohesion, and flexibility. Enmeshed and Rigid variables characteristically have predominantly higher scores in the three balanced families (balanced, rigidly cohesive, mid-range). The present study illustrated however that of the 25 participants, 19 are from one of the three balanced family types. The data showed a positive relationship between enmeshed and rigid, due to the predominance of balanced families in the study.

Family structure and compliance

The present study predicted that family dynamics will have an effect on compliance and that balanced families will be more compliant than other family types. All compliance scores plotted on the graph in Figure 12 are mean scores for complianceTxEQ for each of the identified five family types. Compliance decreased from balanced to unbalanced family types. From Figure 11 it can be suggested that the more the scores of the balanced dimensions (cohesion & flexibility) decrease, the more the variables of the unbalanced dimensions increase and this also indicates the increase in non-compliance.

The relationship between balanced families and higher compliance levels has been illustrated by two methods. Firstly, the correlation showed that cohesion and complianceTxEQ shared a moderate positive relationship (Table 16). Characteristically, cohesion scores are higher for the three balanced family types (balanced, rigidly cohesive and mid-range) and low for the unbalanced families (chaotically disengaged and flexibly unbalanced) (Olson & Gorall, 2006a). Indeed, this was the case in the present study, as can be seen from Figure 11.

Another significant correlation (Table 17) revealed a negative relationship between the chaotic variable and complianceTxEQ. Characteristically, the scores for the chaotic variable are low for balanced families and increase in unbalanced families from (flexibly unbalanced to chaotically disengaged) (Olson et al., 2006a). Secondly, the relationship between balanced families and higher compliance levels were illustrated by Figure 12. The positive relationship between cohesion and complianceTxEQ can be observed in Figure 12 where the three balanced families all had higher average compliance levels compared to unbalanced families, visually illustrating the positive relationship between cohesion and compliance.

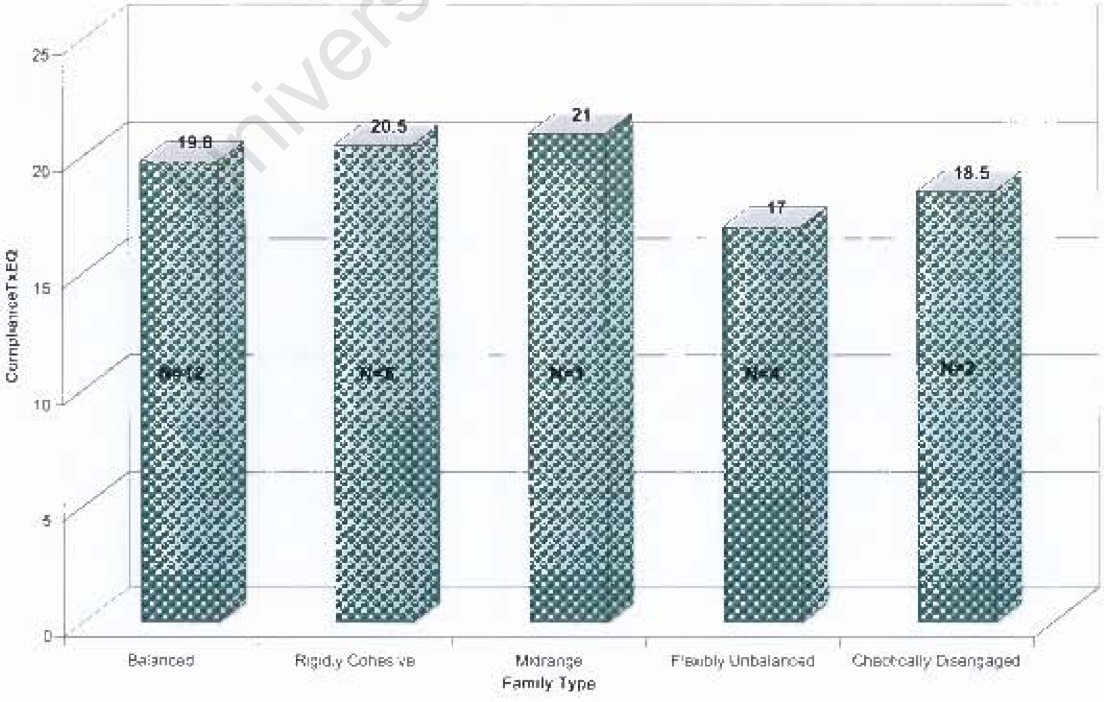

Figure 12. *Average compliance measure of family type*

Associations between family communication, satisfaction and sub-scales of FACES-IV

Scores from communication, satisfaction and complianceTxEQ scales were converted to percentage scores in order to be relatable to each other. Again, the relationship between balanced families and higher compliances levels have been illustrated by two methods: correlation relationships between sub-scales (refer to Table 17) and referring to the visual representation of Figure 13. Correlation analysis revealed the following relationships between communication, satisfaction and complianceTxEQ.

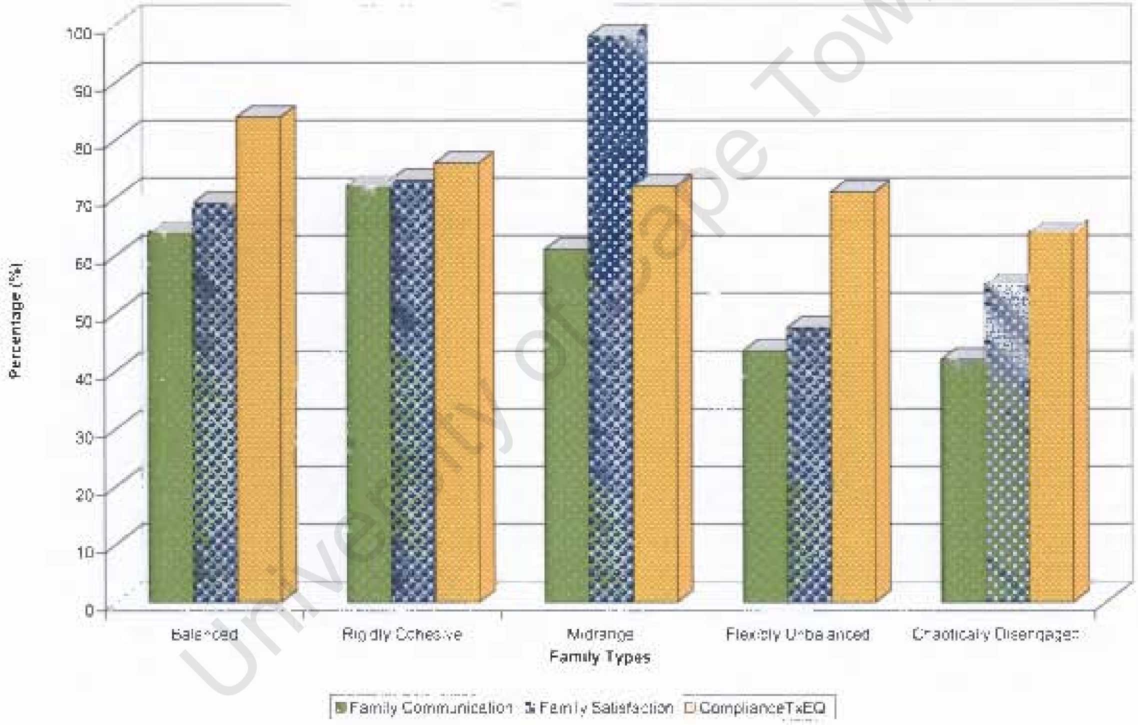

Figure 13. ***Communication and Satisfaction in relation to Compliance levels and Family Type***

A positive relationship was identified between communication and satisfaction and this relationship are illustrated in Figure 13. The three balanced families (balanced, rigidly cohesive and mid-range) had higher communication and satisfaction scores than the unbalanced families (flexibly unbalanced and chaotically disengaged). The balanced families with the higher communication and satisfaction scores also represent more of the participants (balanced n=12, rigidly cohesive n=6 and mid-range n=1) in relation to the unbalanced families (flexibly unbalanced n=4 and chaotically disengaged n=2).

The disengaged sub-scale shared a moderate negative relationship with the satisfaction sub-scales. Characteristically, the scores for the disengaged sub-scale increased from the flexibly unbalanced family type to the chaotically disengaged family type. This relationship is illustrated in Figure 13 where the disengaged scale increases from balanced to unbalanced family types and satisfaction decreases from balanced to unbalanced family types.

The satisfaction sub-scale and complianceTxEQ sub-scale also shared a positive relationship. This is not a very strong relationship but an illustration of this relationship can also be observed in Figure 13. In Figure 13, complianceTxEQ and satisfaction decrease from balanced to unbalanced family types. The mid-range family type has an uncharacteristically high satisfaction score compared to the other balanced families (balanced, rigidly cohesive), but this can be explained by the fact that the mid-range family type is not an average score because only one mid-range family was identified in the data.

When comparing the correlation relationships identified by the validation study (Olson et al., 2006c) with the present study's correlation coefficients, some differences emerged. According to the validation study, disengaged/flexibility are supposed to have a high correlation relationship, but in the present study it is low. According to the validation study, enmeshed/disengaged and rigid/enmeshed are supposed to have a low correlation relationship, but in the present study it is high and significant. The explanation may very well lie in the fact that the present study had a much smaller sample size (n=25) compared to the respondents used in the study by Olsen et al., (2006c).

Not all the correlations of the present study were significant (refer Table 17), and this might be due to the small sample size of the present study (n=25), when one compares them to correlation relationships from the validation study from Olson et al. (2006c), and in the correlation relationships from the present study some contradicting correlations were identified.

The Scottish and the South African studies

The sample size of the Scottish (n=33) and the South African (n=25) study are almost similar (O'Carroll et al., 2006). The significant correlations between the sub-scales of the BMQ, IPQ, TxEQ and complianceTxEQ of the Scottish study are: specific concerns (r^2 = -0.48, p = < 0.01); general harm (r^2 = -0.44, p < 0.01); emotions representations (r^2 = -0.38, $p < 0.05$); consequences (r^2 = -0.44, $p < 0.01$). Most of the significant correlations of the Scottish study could not be replicated in its South African counterpart. Here are the significant correlations between sub-scales of the BMQ, IPQ, TxEQ and the complianceTxEQ of the South African study: specific concerns (r^2 = -0.417, $p < 0.05$); responsibility (r^2 = 0.585, $p < 0.01$).

The Scottish study also hypothesised that feelings of guilt regarding the donor and feelings of responsibility to the medical team and donor's family would be related to their level of compliance, but this was not the case in the present study. However, significant results were observed from the South African study, which indicated that a strong relationship did exist between complianceTxEQ and the responsibility scores from the TxEQ (r^2 = 0.585, $p < 0.01$). Thus the more responsibility patients felt towards their medical team and the donor's family, the more likely they were to be compliant. The more responsibility patients felt towards their medical team and the donor's family, the more likely they were to be compliant.

Other significant relationships have been identified in the South African study, and relationships that could not be proven in the Scottish study were evident in the South African study. This just serves to illustrate that although this group shares many unique similarities, they can also be considered to be equally different due to the different variables that weigh in on the lives of liver transplant recipients from a developing country such as South Africa: socio-political situation; SES; personal finances; work; education, etc.

In conclusion, this indicates that although these two liver transplant populations share many similarities on account of the experiences they have had during their journey towards becoming a liver transplant recipient, there are still various other unidentified variables that influence the respondents. The only shared significant correlation from both SA and Scotland indicated that the more concerns they had regarding the adverse consequences of their prescribed medication, the poorer their compliance was.

Qualitative Data

Background Information of participants

Information from participants will be discussed in association with the family type of every participant and the characteristics inherent in this association. Background information of participants is displayed in Table 18.

Table 18. ***Background information of participants arranged into family type groups***

Participant no	Family Type	Education: Father/Adult transplant patient	Education: Mother	Relationship of parents you live with	Living arrangements	Family structure
1	Balanced	Some High School	Some High School	Single, widowed	With parents	One parent (biological)
2	Balanced	Completed High School	Some High School	Married, first marriage	With parents	Two parents (biological)
5	Balanced	Completed College	Advanced Degree	Married, first marriage	With parents	Two parents (biological)
7	Balanced	Advanced Degree	Completed College	Married, first marriage	With parents	Two parents (biological)
8	Balanced	Some High School	Some High School	Married, first marriage	With parents	Two parents (biological)
10	Balanced	X	X	X	X	X
12	Balanced	Completed College	Advanced Degree	Married, first marriage	With partner	Two parents (biological)
15	Balanced	Advanced Degree	Completed College	Single, widowed	With parents	One parent (biological)
17	Balanced	Completed High School	Some High School	Married, first marriage	With partner and children	Two parents (biological)
18	Balanced	Completed College		Married, first marriage	With partner	X
20	Balanced	Advanced Degree		Married, first marriage	With partner	Two parents (biological)
21	Balanced	X	X	X	X	X
9	Rigidly Cohesive	Some High School	Some High School	Living together	With parents	Two parents (biological)
11	Rigidly Cohesive	X	Completed High School	Single, never married	With child	One parent (biological)
14	Rigidly Cohesive	Completed High School	Completed High School	Married, first marriage	With parents	Two parents (biological)
16	Rigidly Cohesive	Some High School	Completed High School	Married, first marriage	With partner and children	Two parents (biological)
22	Rigidly Cohesive	Some High School	Some High School	Single, divorced	With parents	One parent (biological)
23	Rigidly Cohesive	Some High School	Some High School	Married, first marriage	With parents	Two parents (biological)
24	Mid range	Advanced Degree	Advanced Degree	Married, first marriage	With parents	Two parents (biological)
3	Flexibly Unbalanced	Some High School	Some High School	Single, never married	With parents	One parent (biological)
6	Flexibly Unbalanced	Some High School	Some High School	Single, widowed	With parents	One parent (biological)
13	Flexibly Unbalanced	Some High School	Completed High School	Married, first marriage	With parents	Two parents (biological)
25	Flexibly Unbalanced	Completed High School		Married, first marriage	With partner and children	Two parents (biological)
4	Chaotically Disengaged	X		X	Living with guardian sister of (parents died)?	One parent (guardian)
19	Chaotically Disengaged	Some High School	Completed High School	Single, divorced	With partner	One parent (biological)

Note. X – No answer was filled in by respondent.

The level of education of the caregivers is disclosed in Table 18. When moving from the balanced families to the unbalanced families, it is visible that the level of education of parents/adult transplant patients decreases.

When regarding the family structure, twelfth participants from balanced families (balanced, rigidly cohesive, mid-range) had two-parent families in their first marriage, four participants had a one-parent family and three participants did not answer. Unbalanced families (flexibly unbalanced, chaotically disengaged) had two participants with a two-parent family in their fist marriage and four participants with one-parent families.

All respondents categorised into the younger age group still live with their biological parents, with the exception of one participant who lives with a guardian, because of the death of both her parents. Single-parent families are more prominent in the unbalanced family group.

In Figure 14 the relationship between family members and income providers are explored. It is clear from Figure 14 that the total number of family members living in the household has an impact on finances and family dynamics, as the number of children and adults per family household increased from balanced to unbalanced families. In balanced families, the number of children per household is either less or equal to the adults, but in unbalanced families, the number of dependants per household is slightly more than the adults. The income providers per household do not increase with the increase of dependants per household.

The level of education indicated by the adult age group is much higher compared to the adolescent age group, but again, education decreases from balanced to unbalanced families. The adult age group consists of three family types (balanced, rigidly cohesive and flexibly unbalanced). Some of the adult patients still live with their parents and other adult transplant recipients have their own families.

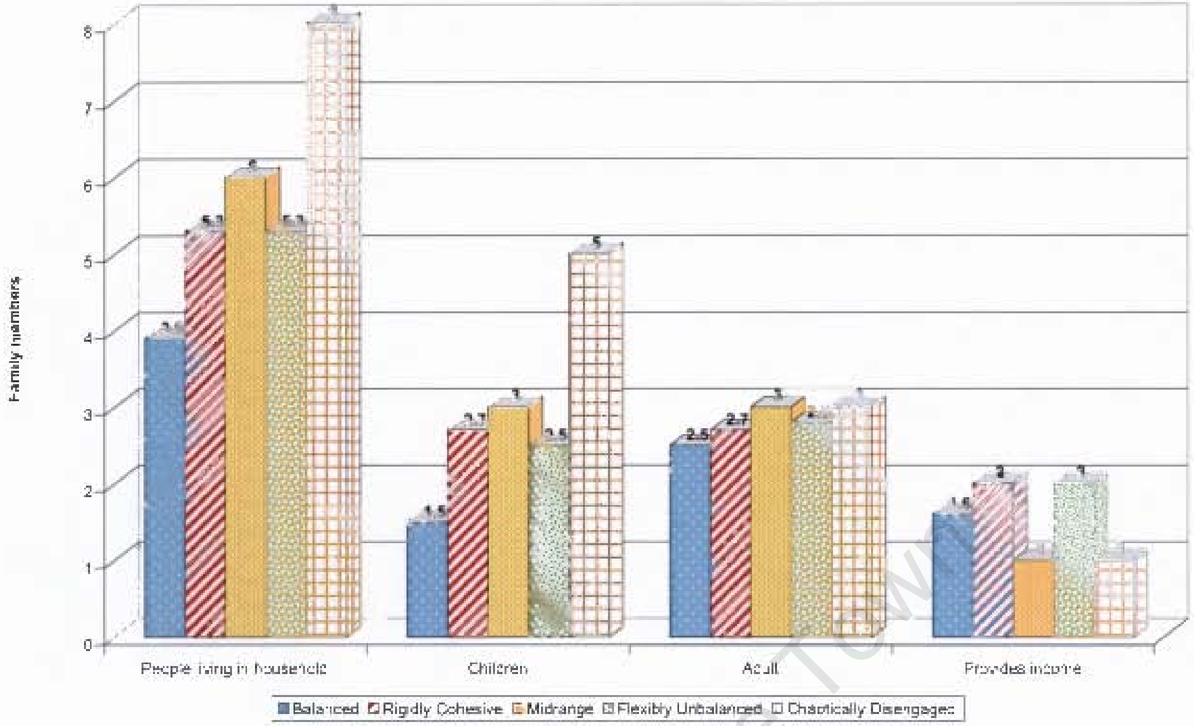

Figure 14. ***Average family members per household in relation to Family Types***

The Interview and the Background information

Interviews conducted at Red Cross Hospital were mostly with adolescents, and interviews conducted at Groote Schuur Hospital were with adults. In the discussion, two different perspectives were brought forward: that of participants from the adolescent age group, and that of participants from the adult age group. Because of the difference between groups, answers were reported separately in some of the questions.

This interview consisted of 14 structured questions (Appendix E). These questions were attached to the questionnaires so that all 25 participants were able to answer them, even participants that could only be contacted through the postal service.

In the beginning of Chapter Three, behavioural data regarding appointments made and appointments attended were collected, but it was determined that data from the records were insufficient and therefore not trustworthy. When commenting on the trustworthiness of the replies to these questions, the present study could only refer to the comments of previous studies on the transplant population group (Meyers et al., 1996; Moshokoa et al., 2000).

Question 1: Missing clinic appointments

Most of the participants (n=17) indicated that they had never missed a clinic appointment. The rest of the respondents indicated that one missed one clinic appointment, three missed two clinic appointments, one missed three clinic appointments, two missed more than five clinic appointments and one only visits Groote Schuur once a year, because he resides in another province.

Of the younger respondents ten participants indicated that they had never missed a clinic appointment, three missed clinic appointments twice and two missed more than five appointments. The older respondents indicated that seven participants had never missed a clinic appointment, one missed one appointment, one missed three appointments and one only visits Groote Schuur once a year.

Most researchers agree that some degree of non-compliance is very common and that reported non-compliance is usually underestimated (Shemesh, 2004; O'Carroll et al., 2006). South African studies also confirmed this statement (Meyers et al., 1996; Moshokoa et al., 2000). Of the whole group, a high percentage (68%) of respondents reported that they had never missed an appointment.

Question 2: Daily medicine regimen

The respondents reported that: four had never forgotten to take their medicine; seven forgot to take their medicine once a year; four forgot to take their medicine once a month; one forgot to take their medicine once a week and nine specified other habits. Other habits specified the following details regarding their medicine habits: "I have missed my medicine maybe once"; "I rarely miss my medicine doses, just now and then"; "I have only missed my medicine doses six times in five years"; "I seldom forget to take my medicine"; "During the previous month I have missed my medicine doses more than two times" and "I have not missed my medicine for more than two continuous days".

Of the younger respondents, two had never forgotten to take their medicine, five forgot to take their medicine once a year, three forgot to take their medicine once a month, one forgot to take their medicine once a week and four chose "other". The respondents who chose "other" specified the following details regarding their medicine habits: two respondents indicated that they had forgotten their medicine twice in the last month and the other two respondents did not give details. Of the older respondents, two had never forgotten to take their medicine, two forgot to take their medicine once a year, one forgot to take their medicine once a month, and five chose other.

Older respondents reported less forgetfulness regarding their medicine regimen. From the information given, we can deduce that the older respondents are more adamant and sure about their compliant behaviour.

Question 3: Forgetting medicine

The respondents indicated that twenty would take their medicine later in the day, two would skip doses and continue with regimen the next day, and three indicated that this question did not apply to them. When regarding age as a variable, the younger respondents fifteen agreed that they would take their medicine dose later in the day if they had missed their usual dosage times.

The older recipients did not agree to this extent, although five participants also indicated that they would take their medicine later in the day. Two indicated that they would skip the dose they missed and just continue with their normal medicine regimen the next day. Three participants indicated that this question is not applicable to them, because they have never forgotten to take their medicine.

An overwhelming 80% of respondents agreed that they would take their medicine later in the day if they had forgotten. This indicated that the majority of respondents have a clear understanding of the importance of a regular medicine regimen. Respondents also reveal that after making a mistake with their medicine regimen, most are very eager to correct this mistake as soon as possible.

Question 4: Medicine regimen of the past week

Twenty respondents indicated that they had "never missed" any medicine doses in the previous week, one missed one dose, one missed two doses, and two indicated that this question was not applicable to them.

Of the younger respondents, two indicated that they had missed a medicine dose once or twice in the past week, eleven missed none, and two indicated that this question was not applicable to them. The older respondents indicated that they had not missed any medicine doses in the past week.

It is alarming that of this small sample 20% indicated that they had missed medicine doses in the past week. This confirms the impression that the group with the biggest medicine compliance problem is younger people.

Question 5 Relaxing your medicine regimen after experiencing no negative effects

The majority of the respondents (n=23) reported that after missing one or more doses of their medicine and experiencing no negative effects, this encouraged them to relax their medicine regimen. The two respondents agreed that missing medicine doses without experiencing negative effects made them relaxed about their medicine regimen. Respondents gave the following explanations; "*When I miss my medicine I don't feel anything that changes in my body*" and "*I have missed some of my medicine because it got lost and I had no other choice*".

The four respondents disagreed with the statement that missing medicine without experiencing negative effects made respondents relaxed about their medicine regimen. Respondents gave the following explanations: "*I know that anything can happen at any time and therefore am very cautious*"; "*I have been instructed by my parents that if I miss my medicine I would face big trouble*" and "*I feel very guilty when I miss my medicine* ".

It seems that there is little difference for younger and adult respondents, because both groups had only one respondent that agreed with this statement and answered "yes". The majority of respondents were informed (by the transplant team, their doctor and caregivers) that just because you don't feel different when missing medicine doesn't mean that it will not have a detrimental effect on your health further down the road.

Question 6 Extra-care before clinic visits

The respondents indicated that they took extra care of their medicine regimen nine a month, three a week, eight a day before they attended the clinic, four did not think that this question applied to them because they always took care of their medicine regimen, and one did not answer the question.

Of the younger respondents, six ticked month, one ticked week, six ticked day, one indicated that this question was not applicable and another one did not answer the question. Of the older respondents, three ticked month, two ticked week, two ticked day, three indicated that this question was not applicable. There is no real difference between older and younger respondents in this question.

Question 7: Regular blood test

The respondents indicated that eighteen had their blood tests done once a month, two had their blood tests done every 2nd month, five indicated "other" and specified that three had their blood test done every 3rd month and two had their blood test done every 4th month.

Of the younger respondents, twelfth indicated that they had their blood tested every month, two had it tested every 3rd month and one had it tested every 4th month. Of the adult respondents, six indicated that they have their blood tested every month, two had it done every 2nd month, one every 3rd month and one every 4th month.

All respondents reported that they had their blood tested every 1 to 4 months. This routine is acceptable, depending on the individual health of each of the respondents.

Question 8: Blood test as an incentive for a regular medicine regimen

Nineteen respondents believed that blood tests are a good incentive, two did not agree, and four indicated “not really”.

All but two of the younger respondents agreed that regular blood tests are a good incentive to keep to a regular medicine regimen. The older respondents agreed less readily with this statement: two said “no”, two “not really”, and six agreed with this statement.

The majority of the respondents (76%) believed that regular blood tests are a good incentive for compliance. In reality, blood tests are not a good measure of compliance behaviour, but if this can be used to encourage compliance in recipients, this should not be overlooked.

Question 9: Methods to remember medicine regimen

The respondents indicated the following: ten remember through routine, eight were reminded by their parents, two were reminded by siblings, two used cell phones, one used an alarm clock, one did not fill in this question and one indicated that no method is used.

The younger respondents mostly relied on their parents (n=9). Older respondents mostly relied on routine (n=7) to help them remember their medicine.

If young people rely too much on their parents, the risk is that they do not gradually take sole responsibility for remembering their medicine.

Question 10: Organ rejection

Nineteen respondents had never gone into organ rejection, but eight had. Two of those indicated that it happened straight after the transplant. Five of the eight who had gone into organ rejection were in the older group.

Question 11: Reason for acute rejection

There were eight respondents that answered "yes" to question 10. The following are verbatim quotes from these eight respondents. The younger respondents gave these quotes: "going into organ rejection *was partly my fault because of my behaviour*", "*I am unsure about the reasons why I went into organ rejection*", "*I was in hospital during my recovery period when I went into organ rejection, but this is considered to be normal in the first few months after a transplant*" and "I deliberately did not take my medicine, because of domestic problems at my parents' home".

The older respondents gave these three quotes: "*I went into organ rejection because I became dehydrated due to another medical condition and this led to my second liver transplantation*", "*I did not take my medicine properly and I regularly skipped days when I did not take my medicine*" and "*I had to change my medication and had a lot of infection in my liver before the transplant*"

From the answers given in question 11, it can be deduced that two of the younger respondents and one adult respondent admitted that non-compliance with medicine led to a rejection episode.

Question 12: Organ rejection: what has been learned

Respondents were asked if they learned something from the experience of going into organ rejection. If "yes", they were asked to please explain.

There were eight respondents that answered "yes" to the question. The following are verbatim quotes from these eight respondents. The younger age group gave these quotes: "*Life is very unpredictable and going into organ rejection can happen very fast*", "*I learnt to appreciate my new life in general and to accept my new responsibilities*", "*I am lucky to have a second chance after my organ rejection and I don't want to blow it*", "*I have learned how to take care of myself after my organ rejection episode*", "*I nearly died and this frightened me*" and "*The experience of almost losing my life was a mind-altering experience to learn from*".

The older respondents gave these three quotes: *"I felt very sick and don't want to feel that pain again*", "*Life is too short and can end at any time therefore I have learned to take better care of myself" and "Death can happen in the blink of an eye and so I have learned to pay more attention to taking my medicine regularly*".

The answers given by both the younger age group and the adults can be described as socially desirable answers. These respondents are well aware of the consequences of irresponsible behaviour due to personal experiences or, because they witnessed other patients' experiences and learned from their mistakes (education).

Question 13: Strict policy surrounding medicine regimen

There were nineteen respondents who answered that they follow their medicine regimen strictly, three ticked "no" and three did not answer the question. The following are verbatim quotes from these nineteen respondents. The younger respondents gave these quotes: "*If I don't have an regular medicine regimen anything can go wrong*", "*my medicine is pre-packed by my mother for the whole week*", *"if I don't keep my regular medicine regimen it will affect my health and I have come such a long way to get here*", "*I need my medicine to stay healthy*" and "*I have been told to take my medicine and am responsible for myself*", *"I don't want to get sick, I want to feel positive and active every day so that I can tell others about my experiences in the near future*", " *I want to stay alive and well*", "*If I don't have a regular medicine regimen I will die*", "*having a regular schedule is very important*", "*my medicine is necessary*" and "*I am scared of going into organ rejection again and I am also scared of ending up in hospital again*".

The older respondents gave these three quotes: *"I have faith in what the doctors that saved my life tell me to do*", " *I have a regular medicine regimen because I know how important it is", "I had a new chance on life and do not tamper with that just because of negligence*", "*regular medicine regimen helps keep me alive and I don't mess around with routine*", "*my regular medicine regimen ensures my longevity and live a healthy, happy life*", "*I have increased my focus on a regular medicine regimen since I experienced late acute rejection", "I keep a regular medicine regimen because I don't ever want to go through what I did in 2003", "I know that my medicine is what keeps me healthy, and stops rejection occurring".*

The quotes from the nineteen respondents echo the fact that most patients completely understand the importance of a regular medicine regimen. Many of the respondents refer back to when they were very ill and use those emotions and memories to encourage their regular routine.

Question 14: Cosmetic side-effects of medication

The majority of the respondents twenty-two ticked “no”, two ticked “yes” and one “sometimes”. There was little difference between age groups. The younger respondents had one that answered “yes” and another that answered “sometimes”. The adult respondents had only one respondent that answered “yes”.

CHAPTER FOUR
DISCUSSION AND RECOMMENDATIONS

Discussion

Non-compliance is not uncommon and to some degree is seen as normal human behaviour and have also been well documented for various diseases (Wainwright et al., 1997; Frolkis, Zyzanski, Schwartz & Suhan, 1998; DiMatteo, Lepper & Croghan, 2000; O' Carroll et al., 2006). There is a difference between a patient being non-compliant with their birth control medicine compared to a transplant patient being non-compliant with their immunosuppressive medication (Aubeny, Buhler, Colau, Vicaut, Zadikian & Childs, 2002). The effect of a disruption in immunosuppression therapy will immediately start a reaction and could lead to the rejection of the transplanted graft. This not only has a severe impact on patients but, also on medical professionals. Laedrach-Hofmann et al. (2000) acknowledged the frustration of medical professionals. The frustration mentioned originates from the lack of understanding of the exact origin of non-compliant behaviour. Having to remedy the progressive slip into non-compliant behaviour by some transplant patients (after various obstacles have been overcome on a medical front) can be very disappointing to both the family and the doctors. With most patients, the reasons for non-compliance cannot be identified. This is a powerful statement that contradicts a great deal of research (Thomson, 1997a; Wainwright et al., 1997; Moshokoa et al., 2000). Thomson (1997a), Wainwright et al. (1997) and Moshokoa et al. (2000) identified education as one of the important factors that will improve compliance levels. Laedrach-Hofmann et al. (2000), however, stated the following "Education alone is not a sufficient factor to ensure compliance".

In a review of literature, Wainwright et al. (1997) concluded their study with this statement: "there should be an urgent need for research that examines patients' beliefs and perceptions in relation to their condition and treatment". It is important to observe all factors in context. By doing this we can acknowledge the accumulation of various factors, including education, family dynamics, beliefs, perceptions and SES. The need for education is well established, but in order for education to be effective, it must coincide with a stable psychological condition for both recipient and caregivers, and a willingness to accept and understand their condition and its obstacles.

Information was gathered by means of: beliefs about medication questionnaire; illness perception questionnaire; transplant effects questionnaire and FACES-IV. The analysis of this information indicated the relationships towards compliance which will be discussed in the following paragraphs. The present study chose to use multiple methods to evaluate compliance behaviour of liver transplant recipients: behavioural; self-report; qualitative. Behavioural analysis will not be discussed, as explained in Chapter Three. Self-report data was used in correlation analysis between sub-scales of all questionnaires and the primary compliance scale.

The present study predicted that recipients' beliefs about their illness would be related to compliance, but due to a lack of significant correlation between scales of the IPQ and complianceTxEQ, the hypothesis could not be supported. Both Horne et al. (1999a) and Wainwright et al. (1997) agreed that in order to effectively understand transplant patients and develop effective intervention plans, we must strive to understand the context and frame of reference of every recipient.

Butler et al. (2004b) reported that the greater the emotional impact of the transplant, the higher the compliance levels of recipients. O'Carroll et al. (2006) contradicted Butler et al.'s (2004b) findings and reported that the greater the consequences and emotional impact of the transplantation on the recipient's life, the poorer the compliance. This replicated data that was found among patients with diabetes (Barnes, Moss-Morris & Kaufusi, 2004).

The present study also predicted that recipients' beliefs about their medication would relate to their compliance level, and the results supported this hypothesis. Data indicated that the more concerns patients have regarding the adverse consequences of their prescribed medication, the poorer their compliance. No significant correlations between the remaining factors of the BMQ and compliance was observed.

The lack of association between need for medication and compliance is not consistent with previous studies in a variety of other medical conditions. This is something to be concerned about, since it indicated that many recipients do not feel the necessity to take their medicine, and this is important in order to be compliant. Concerns about medication are strongly associated with compliance. This seems to be in line with the recognised concerns patients have about the side-effects of immunosuppressive medication (Butler et al., 2004b). O'Carroll et al. (2006) also reported that the greater concerns patients have about their medicine, the poorer their compliance. The strong feelings of concern may be associated with the recognised side-effects of immunosuppressive medication.

The present study predicted that recipients' feelings of guilt regarding the donor will be related to compliance, but due to a lack of significant correlation between scales of the TxEQ and complianceTxEQ, the hypothesis could not be supported.

Fukunishi, Sugawara and Takayama (2001) and Teneze-Guinard, Bouyer, Mattei, Villemot and Laxenaire (1994) observed feelings of guilt relating to compliance in their research, although further research found no relationship between these two variables. Few patients in this sample and in the sample researched by Achillea, Ouellettea, Fourniera, Vachona & He´bertb (2006), Griva et al. (2002) and O'Carroll et al. (2006) reported a relationship between feelings of guilt towards donors and compliance. Goetzmann, Sarac, Ambühl, Boehler, Irani, Muellhaupt, Noll, Schleuniger, Schwegler, Buddeberg and Klaghofer (2008) administered the TxEQ to their sample, which included heart, lung, liver and kidney transplant patients. In the total group, researchers found that the group experienced little guilt regarding the donor.

The predominance of feelings of guilt towards the donor was more common among recipients of living related donations (LRD), whereas cadaveric (CAD) recipients reported much fewer feelings of guilt (Achillea et al., 2006; Griva et al., 2002). Griva et al. (2002) explored the different emotional responses of LRD and CAD donors by controlling for sub-variables. Feelings of guilt were found to be more prominent in LRD recipients. The relationship between LRD and feelings of guilt is understandable and can be explained by the different relationship between the transplant recipient, donor and their family and the recognition of the sacrifice made by the donor.

In this study, all of the LRD recipients were relatives, but it is common that LRD kidney recipients continue to have a relationship with donors. Donors made an enormous physical sacrifice for recipients and exposed themselves to a new risk of only having one kidney. This led to an enormous sense of indebtedness towards donors. CAD recipients did not share the same strong relationship with guilt towards donors and the reason for this is the lack of a relationship between donor and recipient. Liver transplant recipients in this study's sample also received organs from CAD donors. This can serve as a reason why there is no strong relationship between guilt towards donors and compliance. There is rarely a relationship between recipients of CAD organs and the donor's family. Recipients are prohibited from knowing the identity of their donor.

It was also predicted that patients' feelings of responsibility towards the transplant team and donor's family are related to their compliance. The hypothesis is supported by the results. Data indicated that the more responsibility patients feel towards the medical team and the donors, the more compliant their behaviour is. No other significant correlations between other components of the TxEQ was observed.

O'Carroll et al. (2006) tried to relate feelings of responsibility to compliance in their liver transplant population, but no relationship was found. Siegal, Hanson, Viswanathan, Margolis and Butt (1989) examined the health beliefs of transplant patients and the results showed that patients who felt a sense of responsibility for their transplant, worried more about the side-effects of their medication. Goetzmann et al. (2008) administered the TxEQ to their sample, which included heart, lung, liver and kidney transplant patients. In the total group, recipients also found that the group feel responsible towards family members, friends, their treatment team and/or the donor of the transplanted organ. Of the whole group, 72% stated that they would feel responsible towards their family, friends and treatment team, but also towards the donor, as regards the functioning of their transplanted organ.

Goetzmann et al. (2008) did a comparison study with heart, lung, liver and kidney transplant recipients by comparing the variables of the TxEQ. The results indicated that heart and lung transplant patients worry significantly less about the transplanted organ than liver or kidney transplant patients. This is surprising since the risk of medical complications for lung transplant recipients is very high. Possible explanations include: heart and lung recipients perceive themselves as more at risk for medical complications than other organ groups; therefore fails to report on worries because of risk denial and [8]affect isolation; to counteract

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[8] Affect isolation - **Is** a defence mechanism in which emotion is detached from an idea and rendered unconscious, leaving the idea bland and emotionally flat. Through this defense mechanism one may attempt to resolve an emotional conflict by separating ideas from associated feelings.

these emotional effects heart and lung transplant recipients receive intensive medical psychosocial treatment, which counteracts worries. Heart and lung transplant patients themselves also disclosed that a follow-up treatment that is arranged with groups of other recipients creates a feeling of security. The remaining variables showed no differences between organ groups. For the future, encouraging recognition of the generosity involved in donating an organ can lead to patients' recognition of donors by complying optimally with the doctor's instruction. If liver and kidney recipients worry more than heart and lung recipients, this illustrates that more responsibility towards transplant team, family and donor's family is felt by both liver and kidney recipients.

The South African study shared one significant correlation with the Scottish study between specific concerns about medication and compliance. The South African study, however, confirmed a hypothesis that a relationship exists between compliance and responsibility felt towards transplant doctors, family and donor's family. This hypothesis could not be proven by the Scottish study.

Finally, the study predicted that family functioning will have an effect on compliance, and balanced family functioning will be associated with higher levels of compliance. From the sample population we identified: 12 balanced; 6 rigidly cohesive; 1 mid-range; 4 flexibly unbalanced and 2 chaotically disengaged family types. These family types are divided into two broad categories, balanced (balanced, rigidly cohesive, mid-range family type) and unbalanced (flexibly unbalanced, chaotically disengaged). Each of these family types represents families with different functioning techniques. Compliance decreased from balanced to unbalanced family types. The relationship between balanced families and higher compliance levels have been illustrated by both relationships between cohesion and complianceTxEQ, and theoretically cohesion scores are higher for the three balanced family types (balanced, rigidly cohesive and mid-range) and low for the unbalanced families (chaotically disengaged and flexibly unbalanced) (Olson et al., 2006a).

Cohesion scores increase in balanced families from (mid-range, rigidly cohesive to balanced) and decrease in unbalanced families from (flexibly unbalanced to chaotically disengaged). Cohesion shares a positive significant relationship with compliance and indicates that balanced families are more compliant. The chaotic sub-scale increases from balanced to balanced families are more compliant. The chaotic sub-scale increases from balanced to unbalanced families. Compliance shares a negative significant relationship with chaotic and indicated that unbalanced families are more likely to be non-compliant.

Foulkes et al. (1993) established that a healthy relationship between fathers and transplant recipients was indicative of a decline in non-compliance. Younger children who experienced stressors were less compliant. This established that a healthy supportive family are more inclined to support a decline in non-compliance compared to families that are not supportive. Lunsford et al. (2007) used FACES to assess the perceptions of the family structure and tried to identify a relationship between FACES variables and willingness to ask a family member for a living donation, but no relationship was identified. Soriano-Pacheco et al.'s (1999) FACES data suggested that families of CAD organ donors going through bereavement scored high on cohesion and low on adaptability. Barrera et al. (2000) researched adjustment after bone marrow transplant. There was a significant reduction in adaptability and this indicated a decrease in flexibility of post-transplant families. Foulkes et al.'s (1993) is the only study that resembles the present study, measuring the compliance of kidney transplant patients and relating this to family functioning. When families undergo a stressful life-changing event such as transplant or donating the organs of a family member, certain changes take place. The above-mentioned families reported high to mid-range cohesion and flexibility measures. These measures related to an increased closeness and decreased flexibility of the family because of the traumatic event the family underwent.

The structured interview delivered the following information. Respondents gave background information about their family structure, education level, compliance patterns and discussed various emotions surrounding the transplant experience.

Self-reported background information of the sample population revealed the following. Respondents or parents of respondents of balanced families have achieved a higher level of education compared to other family types. Balanced families are also more likely to consist of a two-parent household from a first marriage. The relationship between family members and income providers per household was explored. Balanced families have the least amount of occupants per household, and occupants per household increased from balanced family type to chaotically disengaged family type. The income providers per household do not increase with the occupants per household. The chaotically disengaged family type has the highest amount of occupants, but the least amount of income providers. This information serves to prove that there are many transplant recipients that live and function in diverse circumstances.

This information relates to compliance, SES and family structures. Both South African (Moshokoa et al., 2000 & Thomson, 1997a) and international (Berquist et al., 2006) research indicated that low SES had a negative influence on compliance. Family functioning structure is not rigid and is influenced by the surrounding stressors, as discussed above. Families with fewer stressors were more likely to fall into the balanced family group. Families exposed to stressors such as: one-parent families; low education; many occupants and dependants in their house and low household income were more likely to fall into the unbalanced family group.

Findings from the short structured interview revealed the following. Most recipients revealed as little information as possible, seventeen recipients revealed that they have never missed a clinic appointment. Asking recipients about how many times they have missed their medicine or clinic appointment revealed nothing significant. However, enquiring about their behaviour when they missed their appointment revealed more detail. When respondents forgot to take their medicine, twenty indicated that they would take their dosage later in the day. Missing one of the medicine dosages did not encourage a more relaxed attitude towards the medicine regimen; this statement was supported by twenty-three respondents. Recipients twenty-one revealed that they do take extra care of their medicine regimen before they visit the clinic. Nineteen respondents believed that regular blood tests are a good incentive to take their immunosuppressive on a regular basis. Further questions reveal that most of the adult respondents rely on daily routine to remember their medicine. Younger recipients have various methods including alarm clocks and cell phones, but most still rely on their parents. Most respondents who have gone through a rejection episode are very aware of the consequences and are motivated to stay healthy and out of the hospital. For the last questions, three respondents admitted that they had previously stopped taking their medicine, because of the effects it had on their physical appearance.

The information gathered through the structured interview gave a more detailed view of recipients' compliance behaviour and how they would handle certain compliance obstacles. From these questions, we also had a view of how similar or different the views of the young and adult recipients were. When questions were asked about medicine compliance, patients were very hesitant to include any wrongdoing in the questionnaire.

In the medical field, transplant intervention methods have developed fairly quickly and left psychological intervention lagging. International literature confirmed this statement (Engle, 2001; Rodrigue, Greene & Boggs, 1994). Only one research study from South Africa was found to discuss liver transplantation and mentioned non-compliance as a problem. The international studies gave a more developed perspective into non-compliant behaviour, but South Africa is a complex country and has many different contexts.

For more than 20 years, liver transplantations has been conducted in South Africa. The problem of non-compliance in the transplant population has been highlighted for years by international and local research studies, but no South African study specifically focusing on liver transplant patients have been published on this subject. Red Cross Hospital is a special institution. It's team pioneered the first Paediatric Liver Transplant Unit in Africa. For many years, South Africa was at the forefront of paediatric liver transplantation in particular, but because of an increase in the scarcity of donors, the hospital no longer takes in foreign patients for liver transplantations. This is illustrated by a steady decline in liver transplantations from 1991–2007 (Figure 4).

In conclusion, when we explored poor compliance further by means of psychological assessments, it emerged that our core finding was that poor compliance can be explained by medication beliefs, transplant effects and family structure/functioning, but not by illness perceptions. A positive finding retrieved from this sample population is the fact that responsibility towards the transplant team and donor's family indicates a higher level of compliance. The results suggest that there exist a real and major need within the post-transplant community for support and education of recipients. This is not to say that the hospital and transplant team does not give efficient support. The patients and parents merely expressed the need for more support and this is understandable since many of these families function in a low SES household and community. Now that the conclusion has been reached that most of the poor compliance is explained by the recipients' health condition, medication beliefs and family functioning, this information can be utilised for the future design of a interactive pre-and post-transplant intervention programme that will help to educate and prepare awaiting transplant patients and transplant recipient for the challenges and changes that they will encounter.

Recommendations

1. Following the progress of this population will be interesting in a 5- or 10-year follow-up study to compare new and old compliance data.
2. To enable comparisons between future studies and this study we would encourage the use of the same measures.
3. In the field of medicine compliance the use of electronic measuring can be trusted as a more reliable source of data compared to a self-report questionnaire. Therefore we would encourage the inclusion of the electronic measure in future compliance research on the liver transplant population.

Limitation of the study

Of the forty-nine (Thirty-seven from Red Cross and twelfth from Groote Schuur) recipients that were available, only 25 participants were recruited. Fifty-one percent of the total population are represented in the present study. Data from the present study would therefore unfortunately not be generalizable to the population. It is also possible that respondents included in this sample are more compliant because they took the time to participate, and the 49% that could not be reached might include the more non-compliant recipients.

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APPENDICES

Appendix A

RECRUITING LETTER TO ALL POSSIBLE PARTICPIANTS

Dear (Participant name)

LETTER TO PARTICIPANTS AND GUARDIANS

In the present study I would like to study the experiences adolescents have with the transplant they received. I am interested in the concerns people have about the transplant and the donated organ, how they deal with the challenges of complying with the medication they have to take, consequences of the transplant, and views on treatment.

I would like to gather this information from young people between the ages of 12 and 21 years and adults 22 years and older who have had a liver transplant. This research will be used to write my thesis for my Master's degree. Information from participants will be gathered via a brief set of self-report questionnaires and a short interview including 14 short questions. The whole process would not take more than 30-45 minutes to complete.

Participation in the study is completely voluntary, but I would like to urge you to participate, as this information will be very valuable to the transplant community which includes transplant recipients. Data from the research will be used in the followings ways. Presenting new transplant patients and their families with information about the obstacles a transplant patient could experience in the form of a booklet or information session could have a profound effect on how they view compliance and their compliant behaviour in the future. All information will be treated with complete confidentiality and no form of identification will link you to the questionnaire you have completed.

Your efforts in helping us to know more about what it is like taking your medicines will be greatly appreciated and your anonymity will be is held in great regard. Please answer as honestly as you can - you answers will be kept confidential – no one, including the doctors, will be able to link you to your answers.

If you are interested in the outcome of the research and wish to be informed of the end results please send me an e-mail or a postal address and I can forward an abstract of the study when the research has been concluded.

The present study has been approved by the Research Ethics committee of the Faculty of Health Sciences. If you have any questions about your rights as a research participant you can contact Prof. Marc Blockman Chair person of the Ethics committee (021-406 6496)

Thank you very much for your participation in this research project.

Dominique Brand (084 206 3949)

dominique.brand@gmail.com

Supervisor: Prof. J.Louw

Psychology Department

Appendix B

ETHICAL DOCUMENTATION

UNIVERSITY OF CAPE TOWN

Department of Psychology

University of Cape Town · Rondebosch 7701 · South Africa
Telephone: (021) 650 9111
Fax No: (021) 650-4104

15 May 2007

Dominique Brand's (BRNDOM003) proposal on patterns of non-adherence to immunosuppressive medication for an M Soc Sc degree has been accepted by the Department of Psychology. It also has received ethics approval from a sub-committee of the Faculty of Humanities. As far as the Department and the Faculty of Humanities are concerned, she therefore has approval to commence the study. I am happy to provide more detail if required.

Yours sincerely,

Johann Louw
Professor
Supervisor

OUR MISSION is to be an outstanding teaching and research university, educating for life and addressing the challenges facing our society.

UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
e-mail: Lamees.Emjedi@uct.ac.za

26 July 2007

REC REF: 327/2007

Ms Dominique Brand
Green Oaks C 6
St Quinton's Road
Oranjezicht 8001

Dear Ms Brand

WITH GREAT POWER COMES GREAT RESPONSIBILITY: PATTERNS OF ADOLESCENT NON-ADHERENCE TO IMMUNOSUPPRESSIVE MEDICATION

Thank you for submitting your study to the Research Ethics Committee for review.

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

Before you begin, please will you obtain permission from the medical superintendents to undertake your research in Red Cross War Memorial Children's Hospital and Groote Schuur Hospital.

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

Please quote the REC. REF in all your correspondence.

Yours sincerely

[redacted]

A/PROF. M. BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

lbenley

Departement van Gesondheid

Department of Health

iSebe lezewMpilo

Verwysing: Reference: Isalathiso	RESEARCH	Telefoon. Telephone: Ifowuni.	(021) 658 5383
Navrae Enquiries:	Dr. T. Blake	Fax:	(021) 658 5166
Datum: Date:	8 August 2007		

Dominique Brand
Green Oaks
St Quintons Rd
Oranjezicht
8001

Dear Ms. Brand

Research Study (REC REF): 327/2007: Patterns of Adolescent non-adherence to Immunosuppressive medication

Thank you for the submission of your documentation.

Approval is granted for you to conduct the above mentioned study at Red Cross War Memorial Children's Hospital

Yours faithfully,

Dr. T. Blake
Senior Medical Superintendent

Red Cross War Memorial Children's Hospital Rooikruis Oorlogsgedenk Kinderhospitaal
Klipfontein Road / Private Bag Klipfonteinweg / Privaatsak
RONDEBOSCH RONDEBOSCH
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Dr Bhavna Patel
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Management Suite
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Telephone: (021) 404-4459
Pager: (021) 404-3333 (1846)
Fax: (021) 404-4304
E-mail bpatel@pawc.wcape.gov.za

Date 06 August 2007

Dear Ms Brand

Re: Permission to conduct research

With reference to your request, permission is hereby granted for you to conduct your research in the Liver unit, Department of Medicine of the hospital

Please note:

- Your research may not interfere with patient care
- Please present this letter to the person in charge when you arrive at the unit
- No hospital consumables may be used for your research.
- No staff may be asked to assist with the research.

We wish you success with your project.

Your sincerely

Dr Bhavna Patel

Appendix C

ASSENT TO PARTICIPATION IN RESEARCH

ASSENT TO PARTICIPATION IN RESEARCH

I, the undersigned____(patients name) Hereby grant permission to researcher, Dominique Brand, to use information disclosed by me on the terms discussed and for the purpose explained above, provided that this information remains confidential. I understand that the data and information gathered by questionnaires or an interview will be used in the present study, but that no personal details will be disclosed in the study. I am assured of anonymity and confidentiality. I declare that I understand the nature and purpose of my participation in this research and consent to such participation. If you have given permission to the researcher to use your folder number this folder number will be used to obtain computerized data such as attendance records. No access will be granted to researcher to gain access to personal information from the participant's medical folder.

Signature: ____

Place: ____

Date: ____

Appendix D

CONSENT TO PARTICIPATION IN RESEARCH

CONSENT TO PARTICIPATION IN RESEARCH

I, the undersigned____ (Full name)

Mother/father/guardian of________________________________ (patients name)

Hereby grant permission to researcher, Dominique Brand, to use the information disclosed by my child on the terms discussed and for the purpose explained above, provided that this information remains confidential. I understand that the data and information gathered by questionnaires or an interview will be used in the present study, but that no personal details will be disclosed in the study. I am assured of anonymity and confidentiality. I declare that I understand the nature and purpose of my participation in this research and consent to such participation. If you have given permission to the researcher to use your folder number this folder number will be used to obtain computerized data such as attendance records. No access will be granted to researcher to gain access to personal information from the participant's medical folder.

Signature: ______________________________________

Place: ____

Date: ____

Appendix E

14 QUESTIONS FOR STRUCTURED INTERVIEW

1.1 Have you ever missed a clinic appointment? If yes how many times?

Never	
Twice	
More than 5 times	
Other…	

1.2 Do you ever forget to take your medicine? If yes how often does this happen?

Once a year	
Once a month	
In the last month more 2 times	
Once a week	
Other…	

1.3 If there have been days that you just completely forgot to take your medicine.

Do you take your medicine later in the day	
Would you just skip that dose and continue with the normal medicine regimen the next day when you have to take your next dose	

1.4 Have you missed a dose of your medicine in the past week?

How many times…………………………

1.5 After missing one or more doses of your medicine and experiencing no negative effects do you think this made you more easy-going towards your medicine regimen. If yes please explain?

yes	no

1.6 Do you take extra care to take your medicine the

month	week	or day

before your appointment to go to the clinic or see your doctor?

1.7 How often do you have your blood tests done?

Once a month

Every 2nd month

Once every 4th month

Once every 6th month

Once a year

Other

1.8 Are regular blood tests a good incentive for you to help you to stay in the habit of taking your immunosuppressant on a regular basis?

yes	
no	
not really	

1.9 Are there any other methods you use to help you remember to take your medicine?

alarm clock	
cell phone	
parents	
siblings	
routine	
Other…….	

1.10 Have you ever gone into organ rejection?

yes	no

1.11 Only answer this question if you answered yes for question 1.10. What do you think was the reason for your liver to go into acute rejection?

1.12 Did you learn something from this experience? If yes please explain?

1.13 Do you follow your medicine regimen strictly? If yes please explain why?

1.14 Have you ever stopped taking your medicine for a day or more because of the effects it had on your body?

Yes	
No	
Sometimes	

Appendix F

QUESTIONNAIRES: ILLNESS PERCEPTION QUESTIONNAIRE

YOURVIEWS ABOUT YOUR ILLNESS

Moss-Morris et al., (2002)

We are interested in your own personal views of how you now see your current condition by ticking the appropriate box.

Please fill in all the statements

	VIEWS ABOUT YOUR CONDITION	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
IPI1	My illness will last a short time					
IPI2	My illness is likely to be permanent rather than temporary					
IPI3	My illness will last for a long while					
IPI4	This illness will pass quickly					
IPI5	I expect to have this illness for the rest of my life					
IPI6	My illness is a serious condition					
IPI7	My illness has major consequences on my life					
IPI8	My illness does not have much effect on my life					
IPI9	My illness strongly affects the way other see me					
IPI10	My illness has serious financial consequences					
IPI11	My illness causes difficulties for those who are close to me					
IPI12	There is a lot I can do to control my symptoms					
IPI13	What I do can determine whether I get better or worse					
IPI14	The course of my illness depends on me					
IPI15	Nothing I do will affect my condition					
IPI16	I have the power to influence my condition					
IPI17	My actions will have no effect on the outcome of my illness					
IPI18	My illness will improve in time					
IPI19	There is very little that can be done to improve my illness					
IPI20	My treatment will be effective in curing my illness					
IPI21	The negative effects of my illness can be prevented (avoided) by my treatment					
IPI22	My treatment can control my condition					
IPI23	There is nothing which can help my condition					
IPI24	The symptoms of my condition are puzzling to me					
IPI25	My illness is a misery to me					

IPI26	I don't understand my illness					
IPI27	My illness doesn't make any sense to me					
IPI28	I have a clear picture or understanding of my condition					
IPI29	The symptoms of my illness change a great deal from day to day					
IPI30	My symptoms come and go in cycles					
IPI31	My condition is very unpredictable					
IPI32	I go through cycles in which my condition gets better and worse					
IPI33	I get depressed when I think about my illness					
IPI34	When I think about my illness I get upset					
IPI35	My illness makes me feel angry					
IPI36	My illness does not worry me					
IPI37	Having this illness makes me feel anxious					
IPI38	My illness makes me feel afraid					

Appendix G

BALANCED AND UNBALANCED SCALES: PERCENTILE SCORES & LEVELS

Balanced Scales: Percentile Scores & Levels

Cohesion Raw Score	Cohesion Percentile Score	Balanced Scale: Cohesion Level	Flexibility Raw Score	Flexibility Percentile Score	Balanced Scale: Flexibility Level
7	10	Somewhat Connected	7	10	Somewhat Flexible
8	10	Somewhat Connected	8	10	Somewhat Flexible
9	10	Somewhat Connected	9	10	Somewhat Flexible
10	10	Somewhat Connected	10	10	Somewhat Flexible
11	10	Somewhat Connected	11	10	Somewhat Flexible
12	10	Somewhat Connected	12	10	Somewhat Flexible
13	10	Somewhat Connected	13	10	Somewhat Flexible
14	10	Somewhat Connected	14	10	Somewhat Flexible
15	10	Somewhat Connected	15	15	Somewhat Flexible
16	10	Somewhat Connected	16	15	Somewhat Flexible
17	10	Somewhat Connected	17	20	Somewhat Flexible
18	12	Somewhat Connected	18	25	Flexible
19	13	Somewhat Connected	19	30	Flexible
20	14	Somewhat Connected	20	35	Flexible
21	15	Somewhat Connected	21	40	Flexible
22	20	Somewhat Connected	22	45	Flexible
23	25	Somewhat Connected	23	50	Flexible
24	30	Somewhat Connected	24	55	Flexible
25	35	Connected	25	60	Flexible
26	40	Connected	26	65	Very Flexible
27	50	Connected	27	70	Very Flexible
28	60	Connected	28	75	Very Flexible
29	69	Very Connected	29	83	Very Flexible
30	76	Very Connected	30	88	Very Flexible
31	81	Very Connected	31	93	Very Flexible
32	86	Very Connected	32	96	Very Flexible
33	90	Very Connected	33	98	Very Flexible
34	95	Very Connected	34	99	Very Flexible
35	99	Very Connected	35	99	Very Flexible

Unbalanced Scales: Percentile Scores and Levels

Unbalanced Raw Scores	Disengaged Percentile Score	Enmeshed Percentile Score	Rigid Percentile Score	Chaotic Percentile Score	Unbalanced Scales Levels
7	10	10	10	10	Very Low
8	12	12	12	12	Very Low
9	13	13	13	13	Very Low
10	14	14	14	14	Very Low
11	15	15	15	15	Very Low
12	16	16	16	16	Very Low
13	18	18	18	18	Very Low
14	20	20	20	20	Very Low
15	24	24	24	24	Very Low
16	26	26	26	26	Very Low
17	30	30	30	30	Low
18	32	32	32	32	Low
19	34	34	34	34	Low
20	36	36	36	36	Low
21	40	40	40	40	Low
22	45	45	45	45	Moderate
23	50	50	50	50	Moderate
24	55	55	55	55	Moderate
25	60	60	60	60	Moderate
26	64	64	64	64	High
27	68	68	68	68	High
28	70	70	70	70	High
29	75	75	75	75	High
30	80	80	80	80	Very High
31	85	85	85	85	Very High
32	90	90	90	90	Very High
33	95	95	95	95	Very High
34	98	98	98	98	Very High
35	99	99	99	99	Very High

Appendix H

COMMUNICATION AND SATISFACTION SCALES: PERCENTILE SCORES & LEVELS

Percentage and Levels	Family Communication	Family Communication	
		Raw	Percent
Very High 86-99%	Family members feel very positive about the quality and quantity of their family communication.	50	99
		49	97
		48	96
		47	94
		46	90
		45	88
		44	86
High 61-85%	Family members feel good about their family communication and have few concerns.	43	83
		42	80
		41	74
		40	70
		39	65
		38	62
Moderate 36-60%	Family members feel generally good about their family communication, but have some concerns.	37	58
		36	50
		35	44
		34	40
		33	36
Low 21-35%	Family members have several concerns about the quality of their family communication.	32	32
		31	28
		30	24
		29	21
Very Low 10-20%	Family members have many concerns about the quality of their family communication.	28	18
		27	15
		26	14
		25	13
		24	12
		10-23	10

Percentage and Levels	Family Satisfaction	Family Satisfaction	
		Raw	Percent
Very High 86-99%	Family members are very satisfied and really enjoy most aspects of their family.	50	99
		49	98
		48	97
		47	94
		46	92
		45	87
High 61-85%	Family members are satisfied with most aspects of their family.	44	84
		43	79
		42	75
		41	71
		40	66
Moderate 36-60%	Family members are somewhat satisfied and enjoy some aspects of their family.	39	58
		38	51
		37	45
		36	40
Low 21-35%	Family members are somewhat dissatisfied and have some concerns about their family.	35	35
		34	30
		33	28
		32	25
		31	23
		30	21
Very Low 10-20%	Family members are very dissatisfied and are concerned about their family.	29	18
		28	15
		27	13
		26	12
		10-25	10