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# Adaptation to renal transplantation: an exploratory qualitative study

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**ADAPTATION TO RENAL TRANSPLANTATION:**

**An Exploratory Qualitative Study**

**by**

**Edwin Maurice Bouvet, Dip App Sc (Nurs), BHSc (Nurs),  
MPH, RN.**

**A thesis submitted in fulfilment of the requirements for  
The award of the degree Master Nursing (Honours)**

**From the University of Wollongong, Department of Nursing**

**2003**

## **Abstract**

Knowledge of individual client's emotional and psychological reactions to renal transplantation is essential for the effective delivery of pre-operative and post-operative nursing care. In this study six recipients of donor kidneys were each interviewed over a period of six months at two monthly intervals

The interviews were unstructured, almost conversational, and the qualitative data collected was analysed based on the principles of phenomenology and organized into eight basic themes. After close examination of the material collected, significant issues of concern were identified and these became the focus of further and more intense study. This culminated in chapter six with three distinctive areas of concern being noted.

Nurses who deal with clients who are preparing to undertake a transplant or who have received a donor kidney are confronted with the challenge of managing a range of human emotions, which are the product of very personal perceptions of life, beliefs, and reactions to physical trauma. This study will provide the individual nurse with invaluable awareness of how best to respond to these demands.

**Declaration**

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university, and that to the best of my knowledge and belief it does not contain any material previously published or written by another person where due reference is not made in the text.

Signed: .....

## **Acknowledgements**

I would like to express my thanks and gratitude to Professor Patrick Crookes and Doctor Roselyn Melville for the help and guidance that they extended to me in undertaking this project. Also to Wollongong University, who gave me the facility needed to complete this study.

Most importantly, there are the participants, who accepted the invitation to be apart of this study.

However a very special thanks goes to my parents, who gave me encouragement, and assisted me in every way possible.

All this would not be possible without the help of God, to which I am grateful.

## **Overview of Contents**

Chapter one establishes the environment to which the study was conducted. It details the rationale behind the study and explains the process used to formulate the objectives, constructing the key research question, and selecting suitable participants.

Chapter two presents the scope of the literature search and highlights the inadequacy of existing material on which to base and test this study. The chapter consists of parts A and B. The first deals with the actual search for relevant material. The second section contains a detailed review of the literature appropriate to the research, and the third discusses the implications that are the product of the analysis of findings.

Chapter three outlines the methodological framework of the entire study, together with its application. A profile of each participant is provided, and the process of recruitment of participants is also discussed. Data collection and a detailed analysis of data concludes the chapter.

Chapter four is devoted to the study's finding, and the identification of themes. They are; relief, acceptance, trust, apprehension and mood changes, sleep and bladder habits physical appearance, diet, and

obligation. These themes are described and examined in detail.

References are made to the interview transcripts of the participants.

Chapter five sees a review of the study with the themes restated and discussed in-depth.

Chapter six is the conclusion of the study. In this chapter are the implications for nursing, with three areas of concern noted. These being; Knowledge Deficit, Communication, and Social Interaction.

In addition, the study's objectives and key research questions are addressed. This is followed by an examination of the credibility and limitations of the study.



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## **Chapter one**

### **Introduction**

#### **Background to the Investigation**

As a registered nurse my primary concern has always been directed towards the client's reactions to their illness. To me, the role of the doctor, nurse, and significant others to the client, have all been secondary. I have always been interested in how clients perceive their illness, the treatment, and outcomes.

Having experienced nursing in emergency units, I became somewhat inquisitive about finding an area that equally involved all the areas of nursing and rolled them into one specialty.

It became apparent to me that nephrology nursing encompassed all facets of nursing. Nephrology nursing is an example of complete nursing. It is a specialty that is complete and one that fully encompasses all nursing skills. A nephrology nurse can be directed toward home nursing, for

clients who prefer home dialysis, in the community, and in the hospital. The nephrology nurse is an educator, teaching both clients and their families about dialysis, particularly haemodialysis. Expertise in needling techniques, together with the operation of haemodialysis machines are a necessity. With the possibility of suicide occurring among haemodialysis clients, skills in psychology and psychiatry are paramount. Finally, the technology and intensive care treatment needed for the renal transplant recipient are a necessity to be grasped by the nephrology nurse.

It has been in the area of renal transplantation that I have become especially interested. Perhaps, it is the notion of somebody having a foreign organ inserted into them that has captured my imagination and interest.

What concerns me most, is the very little or no research that has been undertaken in this area. The reason is not known, and one can only speculate on an answer. Equally concerning is that, the available research is insufficient and lacks substance, as it does not discuss anything about the renal transplant recipient's lived experience. One reason for this is that researchers have preferred to adopt a quantitative approach, and it does not allow for any expressions of thought from the recipient to be given. This is a concern that will be discussed in further chapters. However,

what caused me greatest concern is that nobody has asked the transplant recipients, about what adaptation strategies they have employed, concerning coping and living with a donor kidney. Of equal concern is, are they aware of any such strategies, or are there indeed any?

As a result of my concerns, my attention was drawn especially to those clients on hospital transplant registries, and how they intend to adapt to living with a donor kidney. As each client is an individual one would expect their respective adaptation to the role of transplant recipient would differ, but similarly one would also expect commonalities among them to occur. The answer to those questions is unknown, which is of concern to me, bearing in mind the significance that renal transplantation has for each individual recipient.

With respect to the number of renal transplants now taking place, its significance can readily be seen in the context of the End Stage Renal Disease (ESRD) client and their families. The following statistics were evident of this. Disney (1994), stated that renal transplantation was performed in 8 % of hospitals nation wide and with the Australian Kidney Foundation indicating that in 1994 there was a first year graft survival rate of between 80 % to 85%.

In real terms (figures supplied by The Australian Co-ordinating Committee on Organ Registries and Donation, 1998), there were 849 renal transplants performed in 1997, nation wide, with 357 being taken from cadaveric donors, 367 being from living donors, and 125 being from non-living related donors. For New South Wales the figures were, 131 being taken from cadaveric donors, 40 being from living related donors, and 3 being from non-living related donors. This gave New South Wales, 125 renal transplants performed in 1997. By 1999, there was only a marginal increase on these figures, with living related donors rising by 4 to 44.

Even though these figures might only be of significance to the ESRD population, it is surprising that very little substantial research has been undertaken in this area. Literature searches have only found snippets of information on the topic in the form of an obscure section of an article, or well contained in material hidden inside somebody's thesis. This was demonstrated by a thorough search of the literature using well thought out strategies explained in the literature review. What this highlights is an area of nursing where research is sadly amiss, and in many cases what little research exists is of poor quality.



The area of Nephrology that focuses specifically on the client's individual perspective and their lived experience appears to have been overlooked. By this I mean that other areas of nursing have attracted more interest for researchers. This does not imply that any one area of nursing is more or less deserving of attention. What it does imply is that the area of Nephrology Nursing does need more research in all its aspects, so as not to be left behind by other areas of nursing.

What has been identified so far, is a description of what has been happening in the area of Nephrology Nursing, particularly with regards to research. The criticisms of Nephrology Nursing are that research is needed, and the research must be meaningful. The first step in doing this is quite simply to ask, the renal transplant recipient about their personal journey from End Stage Renal Disease to renal transplant recipient, and beyond. This is precisely what the study endeavours to do.

My intention was to initiate a study that would provide an impetus to answer some of the questions and fill in some of the gaps, where possible.

## **Formulating the Objectives**

In order to answer the key research question the following objectives were formulated

This involved;

(1) Obtaining access to a hospital's transplant registry, and become acquainted with the staff and prospective participants.

It was necessary to become associated with a hospital that had a well-established renal unit, which participated in kidney transplant procedures.

This was obvious, when you consider that the study required renal transplant recipients, who were be its focus.

(11) Developing a rapport with the clients.

It was necessary to gain the trust and respect of the clients, so that they felt at ease in my presence and had a trust in me, that I would not abuse the privilege of working with them.

It would be from these clients, that participants for the study would be obtained. A rapport with the End Stage Renal Disease clients, and indeed the hospital staff was paramount.

(111) Using the most appropriate methodological approach for the study.

The study is an exploratory in nature, in light of the fact that there is very little existing literature. This study is an essential step in both designing and conducting larger studies.

It would be obvious that this study would require a qualitative approach, because there has been little research on the topic, and the renal transplant recipient has never been asked to comment on his/her lived experienced. Therefore, a questionnaire could not be formulated, because one would not know what questions to ask. What was needed was a methodology that was rigorous, and would allow one to develop a theory, which would not only describe but also provides some tentative exploration of the renal transplant recipients' adaptation to living with a donor kidney.

It was expected that this study would benefit the individual contemplating or just having received a renal transplantation, and similarly be of benefit

to nurses and others involved in the delivery of care to clients with End Stage Renal Disease and caring for the renal transplant recipient. To accomplish this a combination of phenomenology and grounded theory was deemed appropriate, by the researcher.

## **Objectives**

The objectives were;

(1) To provide renal transplant recipients with the opportunity to discuss their personal experiences.

(11) To observe any commonalities between the responses of each participant.

(111) To observe any commonalities or disparities of the participants between each interview, over a period of six months.

(1V) To provide the opportunity for the development and facilitation of coping mechanisms by health care professionals for the renal transplant recipients.

(V) To make aware the special needs of the renal transplant recipient.

## **Key Research Question**

The study focused on four areas of concern. These were;

- The End Stage Renal Disease client
- The Renal Transplant Recipient
- The Renal Transplant Recipients' perception of their

transplantation

- The Renal Transplant Recipients' adaptation to the donor

kidney

The culmination of these "areas of concern" identified the key research question under investigation for the study. The key research question set out to examine and ask;

"How does the renal transplant recipient adapt to living with a donor kidney?"

## **Location of the Study**

Being part of the Southern Eastern Sydney Area Health Service (SESAHS), St. George Hospital lies within the Suburb of Kogarah. The

Real Estate Institute of New South Wales (1998), states that the area bordered by the Southern Eastern Sydney Area Health Service has a slightly higher percentage of elderly adults to younger adults from a largely Anglo / European background, as well as an increasing percentage of Middle - Eastern groups.

According to Kogarah Municipal Council (1998), the region has a predominantly medium to high socio - economic status.

## **Ward**

In the renal unit of St. George Hospital, provisions are made for treatment of those clients with renal disease or renal complications, peritoneal dialysis, haemodialysis, together with renal assessment and client training for home dialysis.

The unit comprises, three rooms each with four beds, one room containing six haemodialysis machines, one "quiet" room, one room used for Continuous Ambulatory Peritoneal Dialysis (CAPD), and two isolation rooms are set aside for transplant client's. Between January 1997 and June 1998, there were twenty-seven ESRD clients on the St, George Hospital Transplant waiting list. During the study, the hospital performed

eight renal transplants. Seven transplants were taken from cadaver donors and one transplant was from a living related donor. The graft survival has been successful in all but one transplant. That particular graft failed at two months post - transplant.

## **Participants**

The age of participants ranged from early thirties to early sixties with a two female to four male ratio. Ethnicity of the recipients included, East European, Middle Eastern, Asian, and Anglo- Australian.

## **Chapter two**

### **Literature Review**

This chapter is divided into;

#### **Part One**

- \*Preliminary Literature Search
- \* Preliminary Literature Preview

#### **Part Two**

- \* Literature Search
- \*Reviewing The Literature
- \* Implications of the Literature



## Part One

### **Preliminary Literature Search**

Prior to the commencement of the study a preliminary literature search was undertaken by the author, using Cinahl and Medline databases. Its purpose was to preview the available literature, as this would help to create a feeling as to what direction the study could take.

However, what was found was a collection of articles focussed on stressors and anxiety of people undertaking a renal transplant. This focus was either directed to the recipient or the recipient's family. One can appreciate the concerns of stress and anxiety, but at first glance, there seemed to be a disproportionate number of articles directed to stress and anxiety, to the exclusion of anything else, which did very little to create a feeling as to the study's direction. The general trend was for articles to use the "Kidney Transplant. Recipient Stressor Scale," (KTRSS) that was developed by Hayward et al (1989). Other authors were found to make variations of this scale, to suit their own particular requirements.

This is what made these articles disappointing because, the authors chose the answers that they wanted. The participants had to decide their responses by ticking a box from the authors' selection of answers.

### **Preliminary Literature Review**

It soon became apparent that the KTRSS would be a significant part of the articles. Only two articles did not base their study on the KTRSS, but they were also quantitative in design. Their appropriateness to this qualitative study is in itself questionable.

Frey (1990) identified stressors that renal transplant recipients report experiencing six weeks post transplantation and compared them with the stressors reported by Hayward et al (1990). Of the forty-eight transplant recipients who participated in the study, it was found that stressors concerning, side effects of medications and changes in body appearance, rated five and six respectively. This compared to five and ten respectively in the Hayward study. Both studies used the Kidney Transplant Recipient Stress Scale (KTRSS) that compared forty-four items in order of importance. From these two studies it can be assumed that side effects of medications and changes in body appearance rate as high stressors among transplant recipients.

White et al (1990) conducted a study to identify specific stressors and coping strategies by adult kidney transplant recipients in their first six months after transplantation. Of the fifty-five transplant recipients in the study, the specific stressor that received the highest score behind concerns for organ rejection was, worries about changes in physical appearance (61.9%). For coping strategies, 83.6% of recipients stated, “I isolate myself”.

Voepel – Lewis et al (1990) explored specific stressors and identified coping strategies used by family members of kidney transplant recipients in the first six months following transplantation. Of fifty family members, the specific stress item that received the greatest score was “concern about side – effects of anti – rejection medicines” (76 %). Specific coping items reported to be of great use to the family members were, “remain realistic” (98 %), and, “carry on as I normally would” (94 %).

Similarly, Wilson (1988) looked at the evaluation of renal transplant recipients and family support that identified a concern of medication side effects as being the most significant stressor. The study, comprising of sixty families also used a questionnaire that was based on the, Kidney Transplant Recipient Stress Scale. (KTRSS).

A review of articles by Sutton et al (1989) that focussed on stressors and coping patterns of renal transplant recipients also used a KTRSS as did, Weems et al (1989) in examining stages of anxiety for renal transplant recipients. Each study used a sample of fifty subjects and once again concern for medication side – effects was identified as the most significant stressor.

For my study, which is looking at adapting to life with a donor kidney, those articles were only partially helpful. They did not allow for the transplant recipient to express their own thoughts or give an opinion. Selecting answers from a questionnaire was not the best way to gain this sort of information.

An article by Ohkubo (1995) also used a questionnaire directed at dialysis clients, organ donors and transplant recipients. The study indicated that out of 675 renal transplants, the results were successful in 40.1 % of them. The study found that fear of rejection was the most significant stressor.

Juneau (1995) wrote a paper where she claimed that renal transplant recipients sometimes would become depressed over missing the dialysis machine that has become a significant part of life for many years prior to

transplantation. Although not supplying any data, Juneau comments were thought provoking, and offered an opinion that you would not expect.

The significance of Ohkubo's (1995) study and Juneau's (1995) to my study will be further discussed in the forth-coming chapters.

In summary, the Preliminary Literature Review tells us that the identification of stressors among renal transplant recipients was of significance. Most studies were quantitative in design, and either used a KTSS or variations of it.

Therefore, it was decided by the author to further investigate the literature to determine if any qualitative research had been undertaken, and to what extent.

The Preliminary Literature Review, gave an insight into the fact that more research was needed, but using a different approach, and preferably a qualitative design. Another, more in depth literature review would either confirm or deny this.

## Part Two

### **Literature Search**

Further searches were undertaken, with the search strategies being developed.

These searches found forty-nine articles that could be considered to be remotely applicable to the research statement under investigation for this study. Two articles were subsequently discounted as they were focusing purely on dialysis clients, with no reference to transplantation.

With the author's study focus being on adaptation to a renal transplant the process for gathering literature, used the following search topics:

Topics deemed appropriate were; body image, quality of life, renal transplant, coping, adaptation, lived experience, psychological, self care, stress, adapting psychologically, kidney transplantation

These search topics were fed into Australia Medical Index, 1966 – 2001 Psyc Info, (1986 – 2001), Medline (1975 – 2001), and Cinahl (1982 – 2001) databases.

There were 1318 citations under Kidney; 2797 under Renal; Then combined Transplant and Kidney, 406 citations; Then Transplant and Renal, 301 citations. This was narrowed down to 49 citations when looking at the lived experiences of renal transplant recipients.

It came as a surprise, that only a small amount of literature was obtained. Keeping in mind the thoroughness of the investigation and the focus of the study, one would expect more literature to be available.

### **Reviewing The Literature**

Unfortunately most of the literature was of minimal use for the study, but at the time of this study no other literature was available.

By this I mean that when narrowing down the literature to finding its suitability for the study, the result was a small cluster of articles that were quantitative in design with a focus on stressors to which a Kidney Transplant stress scale (KTSS) was utilized to obtain answers.

This pattern became so distinctive that the literature was readily able to be divided into three obvious categories. These were;

- (i) Family Support
- (ii) Stress Factors of Renal Transplant Recipients
- (iii) Miscellaneous

The first category (family support) was seen to focus on questionnaires that identified stressors of the renal transplant recipients' families.

The second category (stress factors of Renal Transplant Recipients) was seen to be the same as the category of "family support", but the individual transplant recipient answered the questionnaire.

The third category (miscellaneous) offered some variation with one article focusing on the role of the nurse and another examining spirituality as a coping mechanism.

It was noted that only two articles were qualitative in design.

Finding literature that co-related with the study was difficult. In most cases the scope of the articles were very narrow and their findings were limited.

A description of the literature is given, as follows;

#### (i) Family Support

With regards to the available literature, support offered to the renal transplant recipient by family and significant others was evident.

Starzomski and Hilton (2000) in their study examined how family members assisted the renal transplant recipient into adjusting to life with



a donor kidney. Here the focus was more on the effect of having a transplant after a long period of dialysis as opposed to having a transplant without even commencing dialysis, more than anything else. The study was directed towards the family of the recipient, rather than the individual recipient. A questionnaire was given to twenty family members of renal transplant recipients. They were asked to indicate by numbers the areas in which their loved ones had to make adjustments to their lives. Results of the questionnaire revealed that in terms of family adjustments it did not really matter when their loved one underwent the transplant. In a study by Funkunishi and Honda (1995) the recipients were children and not adults. Sample size and the questionnaire were the same in each study. For both studies, medication side effects and fear of rejection were most significant in dealing with family adjustments.

Moran, Christensen, Ehlers, and Bertolatus (1999) in their study focused on the family of the end stage renal disease client who was awaiting a renal transplant. They looked at the family environment, whereas Coolican, Politoski and Casey (1997), focused on the family of the donor organs, and the impact of the family. In each study thirty participants were asked to rate the benefits of organ transplantation. It was found that the families could only see the benefits of heart, lung and renal donation. These studies had a strong emphasis on the family of the client, and used

questionnaires to obtain their data. No body was able to express their individual concerns, but could only select answers from the questionnaire. Notably the client was not given the opportunity to participate in these studies. Similarly, Frazier, Davis-Ali, and Dahl (1994), showed a strong emphasis in family support in helping the renal transplant from becoming non compliant with treatment. However ,they also asked family members to rate what was of greatest concern. From the questionnaire all of the twenty participants ticked the box labelled, “fear of organ rejection”, to be of greatest concern. Brownbridge and Fielding (1992), and Bremer et al (1995) examined the parent adjusting to acceptance of their children undertaking dialysis and subsequent renal transplantation. The study asked thirty parents respectively, to rate the greatest area of concern. A fear of organ rejection of their children was unanimous. Reynolds, Garralda, Postlethwaite, and Goh (1991), took this one step further by asking parents how they would rate their children’s health when moving from dialysis to renal transplantation. The response from the sixty parents in the study was, ”a significant improvement”, but the parents also expressed, “ a fear of organ rejection”. The focus was on the family and these studies relied on questionnaires and close-ended questions to obtain their results.

This was also apparent in studies by; Fedewa, and Oberst (1996), Frauman, Gilman, and Carlson (1996), and Davis, Tucker, and Fennell (1996),- which all made extensive use of questionnaires, in order to access the level of burden placed upon parents of renal transplant recipient children, and to access the family child interaction. With participant samples of thirty, fifty and sixty respectively, it was revealed that each study identified, fear of organ rejection to be most prominent.

The stress of spouses of renal transplant recipients was examined by Frazier, Davis-Ali, and Dahl (1995), that found with the use of KTRSS from its sample of sixty ,that a fear of organ rejection was the greatest stressor. While a case study on family support for the renal transplant recipient was examined from a personal perspective. The case study by Gartland (1987), looked at the parents concern over the rejection of their child's donor kidney, which was very similar to a case study by Abram and Buchanan (1978), on family support for the renal transplant recipient. Both studies focused on the respective parents and how the parents would cope with their child following a renal transplant.

However, Gartland (1978), were asked to select a response from a questionnaire, to which they expressed denial and disbelief of the outcome. Arbram and Buchanan (1978) drew up a questionnaire bases on

the KTRSS, to which it was indicated that a fear of organ rejection was the principle stressor. Concerns about the stress of families with children receiving a renal transplant were stated in the respective quantitative studies by Poznanski, Miller, Salquero, and Kelsh (1978), and Bouras, Silvestre, Broyer, and Raimbault (1976). In these articles eight and ten parents discussed the concerns that they had for their children. A concern of possible organ rejection was most commonly expressed.

It was now apparent that with all of the articles the most significant stressors were, organ rejection followed by medication side effects. However, as these tended to be collected from mostly closed-question surveys, little was made known about the qualitative elements of such fears and stressors.

## (ii) Stress Factors of Renal Transplant Recipients

The literature also put a strong emphasis on the stress factors influencing the renal transplant recipient. The articles focused primarily on anxiety, to the exclusion of almost any thing else. Fallon, Gould, and Wainwright (1997), explored what the recipient of a renal transplant perceived stress to be, and in their study Keogh, and Feehally (1999), surveyed how the renal transplant recipient accepts the stress associated with a transplant.

It found that although recipients expected some initial side - effects to medication, they believed that the renal transplant would provide a “cure” to their illness. Like Levenson, and Olbrisch (1993), Kong, and Molassiotis (1999), focussed on the renal transplant recipients’ acceptance of stress, but additionally the research set out to identify what stresses there are. To accomplish this, a questionnaire was used and the stress factors were listed, with the recipient identifying his / her perception of stress. It found that the principle cause of stress was fear of organ rejection and medication side effects. An article by Douglass, Hulson, and Trompeter (1998), focussed on a list of stressors that were reported to be affecting the behaviour of children who had received a kidney transplant. Once again the principal concern of these articles were anxiety. Additionally, concerns about organ rejection and medication side effects are highlighted again.

A study by Ahmed and Ahmed (1991), looked at comparing the anxiety of haemodialysis clients to renal transplant recipients, and found that for the haemodialysis clients the anxiety was hoping that when they received a transplant it would not reject, and the transplant clients were anxious about losing their donor kidney. While Haq, Zainulabdin, Naqvi, Rizvi, and Ahmed (1991), went a step further and established a questionnaire to determine how the renal transplant recipient would cope with any

anxiety. Their questionnaire was based on the KTRSS, and they found the results to be identical the Ahmed and Ahmed (1991) study. Frazier, Davis-Ali, and Dahl (1995), asked questions about the anxiety levels of the spouses of renal transplant recipients, and found with that the spouses anxiety levels were highest within the first month of transplantation and correlated to a fear of organ rejection. Studies by Fukunishi (1992) and Frieson and Frieson (1997), set out to measure the level of depression among transplant recipients, reaching the same conclusion as Frazier et al (1995), when questioning anxiety among spouse of transplant recipients.

As with the other studies depression and anxiety levels were measured by the amount of concern that the recipient had regarding the possibility of organ rejection. This highlights a major flaw in all of the preceding studies, in that they initially form the assumption that anxiety and depression is solely based on organ rejection, to the exclusion of all other possibilities. These possibilities have obviously been overlooked for it appears that almost all research has presumed that organ rejection is the beginning and ending of anxiety in renal transplantation clients.

Stress levels among renal transplant recipients were also of concern to Bugel (1990), who claimed that in relation to organ rejection stress levels declined over time. However, in relation to medication side effects, stress

levels remained constant, even with the transplant recipients' medication decreasing over a six-month period.

For Hudson and Hiott (1986), their study was primarily concerned with the stressors associated with a return to dialysis following a kidney rejection, while an article by Sensky (1989), centred on rating these stressors. These studies indicated that the fear of further organ rejection was now of greater concern to renal transplant recipients for they feared another transplant also rejecting.

The need for some kind of psychological intervention in the form of counselling, for the renal transplant recipient particularly after a graft rejection was noted in studies undertaken by Streltzer, Moe, Yanagida, and Siemsen (1983), and Chambers (1982), who listed stages of anxiety of the renal transplant participant, and the medical intervention needed for each level. It was Jacobs and Viederman (1982), who prepared a discussion paper on adaptation to kidney transplantation. In it they stated that, possible organ rejection and medication side effects were the main areas for psychological intervention. However, no answers were given as to how to accomplish this.

In the study by Van Gurp (1984), questions about the stressors of the renal transplant recipient are asked, and an almost identical study by Vruk, Mau, Taut, Khudemann, and Ernst (1985), added additional questions that were a virtual duplication, but compared non- transplant recipients with transplant recipients. One again, fear of organ rejection was stated as being the most nominated stressor from the list given on each of the two studys' questionnaires.

This was also noted in studies by O'Rourke (1981), and Rabinowitz and Van der Spuy (1980). In their respective studies, questionnaires for twenty and subjects respectively found that a fear of organ rejection contributed greatly to a fear of anxiety among renal transplant recipients. A case study, Tisza, Dorsett, and Morse (1976), questioned a renal transplant recipient on stress and anxiety. It can be considered unreasonable that the basis of a case study has its entire focus on one issue, that being stress and anxiety. It was concluded that fear of anxiety, and medication side effects contributed significantly to the stress felt by the renal transplant recipient.

These articles identified organ rejection and medication side – effects as being the most significant stressors. Like the previous section, data was collected from mostly closed question surveys, with little known about



the qualitative elements of such fears and stressors. However, the focus of these articles was on the renal transplant recipients and not their families.

### (iii) Miscellaneous

In addition to articles concerning, “family support” and “stressors,” of the renal transplant recipient, the literature search found an article by Buck (1998), that dealt with dialysis versus renal transplantation. It was commented that dialysis means a twelve-hour commitment each week, the possibility of needle sticks, the need for delicate care of the fistula (if receiving haemodialysis), and a careful watch on fluid intake. For transplant clients, flu and infections are a constant threat as is weight gain, bone disease and the lifetime cost and dependency on immunosuppressive medications. This gave an insight into the two treatment modalities.

Lau, Vathsala, Kong, and Li Mk (1999), compared the living related donor recipient, to the cadaver donor recipient in determining success rates and medication side effects. It was concluded that from ten recipients who had received kidneys from living related donors, had significantly less medication side – effects than from ten recipients who

had received kidneys from cadaveric donors. The basis for this was that a better matched Kidney requires less medical intervention. Ahmet (1993), discussed the need for an evaluation of all transplant recipients (not just renal), and focused especially on cardiac transplantation. Concern was expressed that organ recipients were not prepared psychologically to accept an organ from a deceased donor. Consequently, it was claimed that recipients were experiencing feelings of guilt and obligation to the families of the donor. It was stated that clients should undergo a detailed psychological assessment on how they would cope with this situation.

The role of the nurse with children undertaking renal transplantation was discussed by Cole (1991), in an attempt to create better interaction between the two, and Nadel, and Clark (1986) and Crittenden et al (1997), reviewed case studies on a child's graft rejection. In previously discussed studies, parents were asked to rate their children's stress, but in these studies, nurses were asked to rate their clients (children) stress and anxiety. This was accomplished by using a questionnaire. It is noted that both studies rated physical appearance to be of significant concern. Even after kidney rejection, the nurses believed the children were more concerned with physical appearance than any thing else. Perhaps they could not fully comprehend the implications of organ rejection. Reasons

for the responses made by the children were not discussed, and one can only speculate on what they might be.

Sharp, Caputo and Price (1991) conducted a case study of a person who donated one of his kidneys, then ironically developed end stage renal disease and subsequently undertook a renal transplantation. It was tragic to see this person becoming afflicted with End Stage Renal Disease (ESRD), only months after willingly donating a healthy kidney. This raises the concern about the health and wellbeing of the donor. It was an aspect that was overlooked in this article.

An article with a focus on spirituality was written by Tix and Frazier (1998) that examined the role of religious belief in coping with a renal transplant. In the study it was concluded that the transplant recipient with a religious foundation was able to cope with the traumas of living with a donor kidney significantly better than compared to those without any religious beliefs. It was found that the person who had a strong belief system was able to cope better than compared to those without. A course of interviews with ten transplant recipients revealed that a religious belief was like a crutch for the person to lean on. Whereas non-religious recipients relied upon psychologists, which they claimed were totally ineffective in helping them cope with their special needs.

These articles tended to focus on issues other than stress and anxiety. They concentrated on treatment modalities and specific ways for improving the care of the individual. Subsequently, these articles could not be grouped as readily as those in sections (.i) and (ii)

### **Implications of the literature**

The vast majority of the articles reflected research undertaken in a quantitative manner with a very small number being case studies. One small variation was that some articles dealt with children and not adults. It was found that these articles could be categorised into three broad themes;

Firstly, into the category of “Family Support.” That dealt with issues involving the spouses and family members of the renal transplant recipient. There were sixteen articles in this category.

Secondly, into the category of “Stressors” that dealt primarily with issues involving the stress and anxiety of the renal transplant recipient. There were twenty-three articles in this category.

Thirdly, a group of eight articles which topics varied from, comparing cadaver grafts to living related grafts, religion a coping mechanism for transplant recipient, and the need for evaluating clients pre - transplant.

It was alarming, that when narrowed down, there was only a small amount of research available from the literature search citations that would enable comparisons and disparities to be drawn between it, and the author's study. However, at the time of the study this was the only available literature.

This would indicate that, the author's intended line of research is something that has never been undertaken, or only slightly been touched upon before by other researchers. What can be stated, if this literature is any indication, is that the amount of qualitative research undertaken in relation to renal transplant clients is minimal.

This concern alone, did give support for the author's choice to use a qualitative approach to this study. With almost all of the studies requiring a completion of preformatted questions and answers, many might not have explored all things concerning renal transplant recipients.

Other studies did not allow data to come from clients; hence a qualitative approach is wanted to explore this issue holistically.

The need to do this prompted the author to undertake this study.

## **Chapter three**

### **Methodology**

The methodological approach for this study was loosely based on Phenomenology.

Although not adhering rigidly to Phenomenology, the study has the principles of Phenomenology as its foundation. These principles of Phenomenology and its relationship to this study can be seen in the Methodological Framework section (p.35) of this chapter, with particular reference to; Crotty (1996), Patton (1990), Merleau-Ponty (1962), Streubert and Carpenter (1995), and Spiegelberg (1975).

## **Potential Source of Participants**

To be included in the sample and therefore take part in the study, each participant had to be undertaking a renal transplant, and subsequently be on the St. George Hospital Transplant Registry.

During the study, there were twenty-seven end stage renal disease clients who received treatment from St. George Hospital, awaiting a donor kidney. They comprised a mixture of people from Anglo / European to Middle - Eastern and Asian backgrounds.

A blend of cultures and ethnicity was expected among the participants, especially when this typified the population mixture of those awaiting a donor kidney on the transplant registry at St. George Hospital. The hospital's location was in an area that was indicative of many cultures and ethnicities, a fact supported by demographic studies of, Kogarah Municipal Council (1998), and The Real Estate Institute of New South Wales (1998).

Of the clients awaiting a donor kidney, their ages ranged from twenty - five years to sixty years of age, which is precisely the age grouping that was deemed appropriate for this study. It was intended to consider



participants who are at least twenty - two years of age at the time of transplant. This eliminated any issues pertaining to adolescent growth and development as the participant has already attained adult hood, which Gould (1975), regards the period of mid - twenties age grouping onwards as pertaining to seek mastery of the real world. For the recipient this is an important point because there is a need to have the maturity to deal with the reality and commitment of a "new life" with a donor kidney. Parallels can be drawn between Gould (1975), and Erikson (1963), who saw this period and onwards as exemplifying the need for intimacy and the striving for accomplishment. The accomplishment for the transplant recipient is the triumph over illness and dialysis to the moment of transplantation and beyond.

Permission to conduct the study was granted by the Ethics Committee at St George Hospital in November 1996. A copy of the letter of approval is included in Appendix One. Following the hospitals approval the first participant of the study received a donor kidney in January 1997. Subsequently, six transplant recipients were interviewed, five recipients three times and one recipient twice. By September 1998 all interviews had been complete.

## **Recruitment of Transplant Recipients**

Access to renal clients was provided by the Renal Department at St. George Hospital where, notification of transplants, facilities to conduct interviews, and access to the Renal Transplant Registry was readily made available.

Every body who was on the Renal Transplant Registry was sent a letter inviting them to become a participant in the study, including a consent form. If they wanted to be in the study, they returned the consent form signed, in the stamped addressed envelope provided.

When a donor Kidney was made available, the researcher was notified by the hospital. The author would then meet the recipient prior to him/her undertaking the transplant, If the recipient still wished to participate in the study he/she would sign the consent form a second time, and then be included in the study.

All efforts were made to ensure that people voluntarily participated in the study. Participants merely had to say that they did not want to be part of the study, if they so wished. All participants were made aware of the study's contents and purposes. Safeguards for anonymity and confidentiality were assured because participants' names and addresses

were only known by the researcher and transplant coordinator. Any suggestion that clients felt compelled to participate in the study can quickly be dispelled because of the procedures used to elicit their voluntary involvement in the study. One transplant recipient did refuse to take part in the study, and one client on the hospital's transplant registry indicated a disinterest in participating in the study should they receive a transplant. Also one transplant recipient preferred to be interviewed only twice and declined to be interviewed a third time. This shows respect and understanding on the part of the researcher toward the clients.

All confidential material obtained during the course of the study was stored in a locked filing cabinet at the home of the author as stipulated by the ethics committee of St. George Hospital. Following a five-year period after the completion of the study all confidential material will be destroyed.

If they so desired, participants could have a copy of the study's findings forwarded to them.

## **Brief Profile of the Participants**

It was deemed appropriate to present an image of the participants, so as to create a mental picture of them as people. The author felt it necessary for the participant to be seen, and this was only possible (Berger, 1972), through the first impression. This is when a brief sketch of each participant can be drawn in one's mind. From this 'mental' sketch of each participant, the reader is able to identify any similarities or differences between them. It helps to create a visual image and as Berger (1972) would comment, "It is a way of seeing".

The study consisted of the following six participants;

Maria was of medium stature. She was of good disposition and took pride in her dress. She had puffiness around the cheeks, and her complexion was showing signs of colour. Slight discoloration of her teeth was evident and she expressed excitement about participating in the interview.

Although being of an East European background, there was no difficulty for her to convey her thoughts and expressions, despite a not so good command of English, grammar and phrasing.

She was sixty- one years of age and lived in a room at the home of her daughter and son –in law Maria was receiving a widows pension.

Gary was of small stature. His face had signs of slight puffiness around the cheeks and under his eyes. His complexion was showing signs of colour and his scalp was balding. His speech was polite and quietly spoken. He was eager to be interviewed but cautious before he spoke, and sometimes was hesitant in his approach.

Gary was Australian born, and held a position of assistant manager in a local recreational club. He lived alone, since his divorce, in his own house.

Karl was of large stature. His complexion was sallow but showing signs of colour. His face showed signs of puffiness with slight swelling under his eyes and on the cheeks. There was evidence of weight gain. His speech was clear and precise. He was more than happy to be interviewed and was direct in his approach.

Karl was Australian born. He lived in his parents' home with his widowed mother. He was receiving a pension from the government.

Eric was of a medium to heavy stature. He had slight darkish discoloration around the face and his eyes appeared to be showing signs of slight puffiness. Although of a Mid Eastern background, he spoke quite good English that was easily understandable. He tended to use a lot

of hand movements and facial gestures and at times become quite excitable. He was more than anxious to participate in the study and constantly expressed his appreciation to those who had helped him. Eric lived with his wife and two small children in the modern house. He was employed as a teachers aid in a nearly high school.

Anna was tiny and rather plumpish in appearance with long ash blond hair and large brown eyes. She showed signs of puffiness around the face and particularly the eyes. She spoke very articulated but at times her grammar was incorrect. She exhibited a casual unworried attitude, which she claimed was uncharacteristic of somebody from her Mid Eastern background. However this casual attitude sometimes was seen to be a façade.

Anna lived alone in a housing commission house, and she was in receipt of a government pension and assistance.

Daryl, was of a slight stature. Signs of slight hair growth was noticeable and a slight discolouration of the face was present. Although able to convey his thoughts adequately, his command of the English language was at times poor. This can be attributed to his Asian background, characterized by a strong spoken accent. He was very enthusiastic about participating in the study.

Daryl lived with his wife in a small home unit that they were buying. He was employed as an electrical technician.

### **Methodological Framework- A Qualitative Approach**

The study was an exploratory qualitative one.

As stated previously the study focused on four areas of concern (Introduction Chapter; p. 9) that culminated in the identification of the key research question under investigation.

That was, "How does the renal transplant recipient adapt to living with a donor kidney."

In order to undertake a study of this kind it seemed appropriate to adopt a qualitative approach that was based on a phenomenological perspective. Although not sticking rigidly to the guidelines of phenomenology the basic structure was utilised. This was deemed appropriate because the purpose of phenomenology is to describe particular phenomena (Crotty, 1996) or the appearance of things as a lived experience. This implied viewing the phenomena under investigation with an open mind, trying to preclude any preconceived notions. The study's purpose was to examine

the renal transplant recipient's adaptation to living with a donor kidney. This, being the lived experience of the recipient over a six-month period, post transplant.

The appropriateness of phenomenology with the study can initially be seen with regards to Patton (1990) who viewed it as a focus of what people experience and how they interpret the world. This sentiment was also expressed by Merleau-Ponty (1962).

Merleau-Ponty (1962:8) described phenomenology as the study of essences; and according to it, *"all problems amount to finding definitions of essences; the essence of perception or the essences of consciousness."* According to Streubert and Carpenter (1995), essence are the common understanding to the phenomenon under investigation. It is how you perceive the phenomenon to be unfolding and the part that it plays in the whole picture. Essences represent the basic unit of common understanding of any phenomenon. Understanding the phenomena under investigation requires that the researcher imaginatively vary the data until a common understanding of the phenomena emerges. In phenomenology it is important that the researcher remains neutral with respect to belief or dis-belief in the existence of the phenomena. For, according to Merleau-



Ponty (1956: 24), *"the only way to really see the world clearly is to remain as free as possible from preconceived ideas or notions."*

A holistic perspective (Spiegelberg 1975), and the study of experience lived; serve as foundation for phenomenological inquiry. Spiegelberg (1975) identified a core of steps or elements that are central to phenomenological investigation. These being; descriptive phenomenology, phenomenology of essence, and reductive phenomenology. These core steps were central to the phenomenological investigation of the renal transplant recipients' adaptation to a donor kidney.

The method choice was guided by the appropriateness of it to the study. All of these steps, as stated by Spiegelberg (1975) were utilised in this study, as follows;

- In descriptive phenomenology, the researcher probed and searched for common themes, and the data was reviewed. The essence of the phenomena was identified and common themes began to merge. For the study, all the interviews were examined by the author. As an understanding of the data developed, themes were able to be developed.

-The phenomenology of essence showed the researcher probing and searching for common themes, as the data was reviewed. For the study, the interviews were constantly reviewed. The themes are further examined by the author for more detail.

- With an understanding of the essence of the phenomena, the significance of the common themes to this study became apparent. For the study, an understanding of the data from the interviews has been established, and the themes are clearly defined.

- Reductive phenomenology, addressed any concerns of personal assumption, which was necessary in order to obtain the purist description of the data. For the study, the author put aside his experience and knowledge of nephrology nursing. This enabled a non - bias approach to conducting the interview with no personal assumptions influencing the content of the interviews.

- Why was this methodological framework applicable?

When undertaking a study on the recipients' adaptation to a renal transplant, it is essential to find an approach that will provide the richest and most descriptive data. This is particularly true when a review of the

literature reveals that there is very little published on renal transplantation, let alone the recipients' adaptation to renal transplantation. Also what little is published needs to be in greater depth, because most articles are in a quantitative format, and the focus is not directly on the transplant recipient. In many ways a true account of the transplant experience for the individual recipient is lost primarily because the recipient is not given the opportunity to ventilate his or her feelings, as would be possible with a qualitative research design that asks the transplant recipient to discuss his or her experiences. Therefore, it would be appropriate that a phenomenological approach is best suited for the study. This is because the study is looking at the lived experiences of the kidney recipients.

The appropriateness of a phenomenological approach is further supported by Spiegelberg (1965) who stated that the essential truths about reality are grounded in the lived experience and what is important is the experience as it is presented and not what anybody says or thinks about it. For the study, the kidney recipient's experience will be transformed into language during the interview. According to Reinharz (1983), the verbal interaction between the participant and the interviewer will create the opportunity for the lived experience to be shared. Additionally, it can be noted that the lived experience of transplant recipients within the study

will differ from each other. Therefore the lived experience of the individual can be compared and contrasted with others in the study.

Reinharz (1983), goes on to say that what is understood about the phenomenon is transformed by the researcher into categories that are the essences of the original experience. Thereby the classification of the data, allows the essences to be documented. The documentation in turn captures the researchers thoughts about the experience and reflects the participant's descriptions and actions. The written documentation is transformed into an understanding by the researcher that can function to clarify all preceding steps.

The written documentation, revealed the richness of the experience identified from the very beginning of the investigation, as perceived by recipients of renal transplantation

The use of the in-depth interview according to Wilson (1989), can provide background accounts of the participant. The strength of the in-depth interview method is in its adaptability and flexibility when used as a research tool.

Interviews were conducted on a one to one basis in an area where there was no disturbance or interference from any thing or any one. Each participant was sent a reminder notice prior to each interview, allowing them to verify the time and location of the interview. For as suggested by Egan (1986), the major role of the interviewer was to develop a rapport with the participant, that relaxed the participant and provided an atmosphere that was conducive to allow the participant to fully express himself / herself.

At each interview, the participant and interviewer would firstly engage in an informal conversation. When the participant felt comfortable and relaxed and was ready he / she would indicate, and the tape would be turned on. Then the participant was asked to discuss their renal transplant experience. Thereby commencing the interview.

Location of the interviews was primarily determined by the participant. Whether the participant choose to be interviewed at their home or at the hospital was quite acceptable as long as it was conducive to the purpose of the interviews. The participants were given the option to decide where they would be interviewed. Some chose private rooms at the hospital, whereas other participants chose to be interviewed in an uninterrupted quiet area of their home, usually the study.

This reasoning is supported by Fenichel (1945), who indicated that the location of any interview did not matter, and he insisted that the best location is the most appropriately suited location for each individual client. For Fenichel (1945), the interview is a tool to accomplish an analytical task.

### **Data Collection**

With regards to this study, the process of data collection began after ethics approval was granted by the hospital. Obtaining participants for the study was always going to be a problem, there was no way of predicting when a donor kidney would be made available, and because of organ rejection and organ compatibility issues, there was no way to nominate a recipient prior to a kidney being made available.

Twenty-seven End Stage Renal Disease clients were invited to participate in the study, this being the total number of End Stage Renal Disease clients on the transplant registry. Only two End Stage Renal Disease clients refused to participate, should a donor kidney be made available to them.

Those transplant recipients who participated in the study were sent a reminder letter prior to each interview and were given a choice as to the time and location of their interview.

The interviews were no more than two hours in duration, and adopted the principles established by Egan (1986). His model which prompts the interviewer to; hear the story, focus on specific areas of interest, and then present it (i.e. transcribe from tape to written paper). This approach was adopted and used in the study because of its suitability.

The interviews; one two months post - transplant, one four months post - transplant and one six months post - transplant, allowed verbal interaction between the participant and the interviewer that created the opportunity for the participant's lived experience to be shared.

## **Analysis of the Data**

\*Each interview was taped

\*Within an hour following the interview, the author listened to the tape recording at least three times.

\*The tape recording of the interview was then transcribed onto paper.

\*The transcribed interview was then typed into a computer in a separate file designated for interviews only.

\*During this procedure, the interview transcripts were repeatedly read.

\*Further reading of the transcripts were undertaken until an understanding of the data was complete.

\*From the interviews, the participant's spoken word, was clustered into themes by the author.

\*The above steps were applied to every interview.

\*The identified themes of the interview, were then compared with the other interviews of that participant.

\*The purpose was to determine, if the themes varied in importance over a six months period. Additionally, it was to be noted if any new themes



were introduced over the period or were there any variations to the themes for that participant.

\*This procedure was used for all the participants.

\*Similarly, the themes of each participant were compared and contrasted to the identified themes from all the other participants. Commonalities and disparities were to be noted.

## **Chapter four**

### **The Study's Findings**

Following the interviews with the participants and having subsequently reviewed all the transcripts, it became apparent that substantive themes began to emerge. These themes were quite consistent throughout all the interviews and varied with intensity and duration from participant to participant.

The order in which these eight identified themes are detailed is solely based on the authors perception of how he would imagine issues surrounding post transplantation would unfold. They are not placed in alphabetical order, or in any specific order as might be stated by a participant. The themes presented themselves throughout the interviews in no set sequence, but were derived from statements made with the clients that were taken during the course of conversation.

The significance of the identified themes can be now detailed;

## **RELIEF**

The theme of relief showed the participants in a situation where the traumas of dialysis and the wait for a donor kidney is over. They have a feeling of relief, knowing that they have a new kidney.

This theme was strongly expressed throughout the interviews of five of the participants. Only Anna did not consider relief to be any significance. Quite possibly this could be due to the fact that Anna received a living related donor (LRD) kidney from her sister. Consequently, her waiting period for a new kidney and her time spent on dialysis was not as great as the other participants within the study. Of more significant concern to Anna was the health of her sister and the obligation extended towards her.

One would tend to expect relief to be natural among renal transplant recipients. Gone is the "old life" of literally being chained to dialysis, with its many array of restraints that it imposes on the life of an end stage renal disease (ESRD) client. For those formerly on Continuous Ambitory Peritoneal Dialysis (CAPD) there is no more four hour bag changes, distended stomachs and the forever risk of peritonitis. For those formerly on haemodialysis, no more horrendous long needles inserted for six hours, three times per week. No more disequilibrium syndrome and a

relaxation on diet restrictions. Additionally, transplant recipients usually find more free time on their hands. This was a fact echoed by, Gary, Karl, and Daryl.

The relief that, Maria, Gary, Eric, Karl and Daryl had regarding their transplants was based on the desire to be free from the strict treatment regime that dialysis had imposed on them, for periods ranging from three to seven years. Undoubtedly, Karl was by far the most relieved participant to be free from dialysis. He would constantly remark that any problems arising with the donor kidney was better than the alternative of dialysis. To a lesser degree Gary and then the other participants would agree. However, they were not as direct as were Karl's remarks, and tended to be a bit more polite in their assertions. A relief from the perception of other people not regarding the participants as being sick was a common thread throughout all the interviews. This was especially noticeable with Eric who was the only participant concerned about projecting a "good health image," to his family. Maria claimed that she is not sick any more because she has a transplant now. Both Maria and Gary regarded "normal," as being a person who was free from dialysis. A concept shared by all of the participants.

What relief means to the participants is able to be seen with reference to their interviews, and subsequent transcripts.

At first, Maria could not explain how she felt. She remarked, *"I feel different. How do you explain it? I feel happy not to go for dialysis. My body feels different."*

However, Maria expressed some concern about social isolation. She stated, *"... I miss my company."* Maria continued by saying, *"I like hospital and Dr. Brown from hospital, I have two houses. One house that's my dialysis. Over there (dialysis unit) patients and sisters have freedom, everyone like one family."*

Despite that, Maria commented once again about the benefits of her kidney, and said, *"I feel all the time stronger and younger, do you believe me. I'm a old woman 61."*

Maria insisted that the transplant has made her healthy, and she felt stronger than others. Maria remarked, *"... I am very very strong healthy lady."*

During the final interview Maria strongly expressed her relief in having a transplant. She stated, *"Yes. I am very happy that I had a transplant."*

Gary indicated that, *"There's a lot of time up my sleeve at the moment I don't know what to do with. I'm still wrapped up in a lot of cotton wool looking after the new kidney and I find I only need about 4 hours sleep at the most and there's so much time. To do nothing at the moment. To heal I suppose but I just don't feel like sleeping anymore which is a great change."*

The relief that Gary felt about his new kidney was obvious, when he reflected upon how he felt about accepting a donor kidney. He spoke, *"How did I feel about accepting a new kidney? Well I really was looking forward to it. I didn't like the outlook of living the rest of my life on dialysis, a chance to possibly get a new kidney."*

*To be on a transplant list was a little ray of sunshine a bit of hope at the end of the rainbow or so a pot of gold. It really gives you something much more to live for and it's a chance I may not have to be on dialysis for the rest of my life. I had my opinion of things could only get worse in the long run I don't know how many years that would take being on dialysis. I considered it a great importance, especially at my age (41) that I had a rainbow maybe to look at and maybe through the new kidney my life could go back to a normal life where I'd feel good and not being sick as normal. Just the whole look of life and maybe there are a whole lot of restrictions when you are on dialysis no matter how good dialysis is going. There are a lot of restrictions. Those restrictions for the new kidney give you a much better chance of having a better quality of life."*

Gary went on to comment about the importance of being able to return to work. He replied, *"... I was really impatient to get back to work so back to work I went, maybe too early actually. I've been back at work a week now they realise yes I can do the job fully capable again. I think it's good for you because life starts for me with work and if I can get that system back first of all, I can start looking at other sides of my life that have got potential with a very new kidney."*

For Gary being normal was being free from dialysis, and being able to experience a social life. Gary stated, *"... I've never thought about having a relationship since I've been on dialysis. Just before dialysis I had a big marriage break up. It was partly caused because of it. It was just not the right woman to deal with dialysis. I've never really thought of it, never even attempted a relationship while I was on dialysis I thought it was too much complication for the other person concerned. Maybe I was wrong that way but it was just my opinion, people sort of throw you off when you've got two tubes sticking out of you. It's a very hard thing to understand if your not into it or married into it. It's a big ask. Maybe things might work out with the transplant and everything. It's sort of a free life again. And just with social life, there has been no social life since dialysis cause there has been no room for it. When I tried to have a social life I seemed to get very ill in the stomach after an hour or so and you just can't do things like normal healthy people do."*

It was quite obvious that Gary was becoming quite attached to his donor kidney. He explained, "... I've actually got a name for it, Myrtle. People ask me why I'm cross-dressing. Actually the first one I give them all names the first one was Holmes-a-Court because Holmes-a-Court died on the day I got the kidney so I picked the biggest man to die on that day."

During his second interview Gary commented about the benefit of having a transplant and the relief that a life on dialysis is over Gary remarked, "... I know that I'm virtually free to do as much without restriction as possible. Sort of same as a normal person. I don't have to think as hard about, I can't do this or I can't do that. Or, I can do this for a couple of hours and that's about it. That's the way it was on dialysis. You sort of got trained for it. You get use to that sort of thing. I find I got a lot of time on my hands now. Besides, work takes a lot of time, so I might do eleven hours, twelve hours a day. So, at home I've got a lot more time, it doesn't take an hour and a half, two hours to get to work because I've got to do dialysis, and waking up in the middle of the night to do it again. So, all those spare forty, forty minutes at a time, four times a day, they're vacant now. It's pretty good, I'm not complaining about that. It's really good.

*Interviewer*

Since the last time I saw you, "Has it improved?" You have been able to manage your time better?

*Client*

Oh yeah. Well I got time on my hands now. That's good, I suppose I can relax, and not as much on me in the head to what I use to have. Like rules and all you have to obey, and, what time is it now? I got another half hour to do dialysis and what ever. The time table is a lot better now."

It was during his final interview that Gary truly summed up his transplant experience and the relief he felt. He remarked, "... It's been a blessing."

Karl was very happy to be free from dialysis. This was apparent throughout his interviews. Karl was talking about the physical side effects of his transplant when he remarked, "Well, I mean you've got to look at the

*alternatives. If Its only a fat face compared to five and a half hours on the machine, three days a week; I'd live with it."*

During his second interview Karl was discussing the advantages about having a transplant. He was asked, *"What is the biggest advantage that the transplant has done for you? At the present moment?"*

*Client*

*Just getting rid of the machine.*

*Interviewer*

*Do you ever miss it?*

*Client*

*Why would I miss the thing?*

*Interviewer*

*Some people form an attachment with the machine.*

*Client*

*I wouldn't say I missed it. I noticed that it's gone, because I've just got a lot of free time on my hands. Basically you could write off three days a week, you couldn't do anything I'll even notice it more when I go back to TAFE because there will be the three days that I use to come home, have to race around and get on the machine and be up until all hours of the night doing the machine whereas now I'll just come home and I'll have nothing to do except what ever I want."*

Karl stated during his third interview that he had resumed his TAFE studies. Karl's eagerness to promote transplantation and discuss his experience was exemplified. He commented, *"Ah, everybody does. I told them. They've curious and want to know all about it. The teachers knew from last semester because I was actually doing the course, and I had to give the course away because I had the transplant, so they knew anyway, and I explained it all to the other people in the class and I handed out some things about, "Light Up Australia Day." I gave them a reminder notice to put the outside lights on. Then a picture will be taken and the public can buy a poster. All money raised goes towards the transplant games and awareness."*



When discussing how he felt about his new kidney, Karl was direct. He stated, "

*Oh good. It's better than the alternative.*

*Interviewer*

*Do you feel any different?*

*Client*

*Yeah. When I look back and think how tired and sick I was on the machine (haemodialysis). I think I could be a lot fitter and a lot more energetic, but that's just up to me to get out and exercise. I started cricket training and I'm fit today because I had my first go out in the nets. I started last week actually, but it was fairly light yesterday I had a bat and a bowl, today I'm just stiff all over. Dr. Trew is on my back, he wants me to lose weight. He says that I should be going to the Gym and all that sort of stuff. I am trying, I'm walking every day and even running a bit. So I've started running and I've tried one of those treadmills that I borrowed off my sister. I get bored with it, and they are hard to walk on. I'd rather get out and go around the block because at least it's something to look at. When you start out you think, "well I've got to get home so I've got to keep walking." If it's a treadmill you just get off and watch some television. We've just started training with Bowral Cricket Club. I was fairly ordinary, well I haven't played in seven years. I use to bowl more than bat although yesterday I wasn't doing much of anything I had a go running around and had a bit of fielding practice. I just even noticed from the first week to this week how much better I was fitness wise. I didn't get as puffed quickly and dry in the month. So it should improve if I keep going every week, and running and walking during the week. I'm watching my diet fairly carefully now. In the morning I just have a couple of pieces of toast. A sandwich at lunch time and then at ten, I'll either have, steak, chicken or fish."*

He went on to comment on how he saw himself. Karl spoke, "... I know I'm, different now, because I saw a photograph of myself when I was on the machine, I was thin and pale. My face was really hollow, and I just looked sick. Where as, now I don't. A teacher actually commented to me, that he saw me at the beginning of last semester, and then saw me for the first time to day since then. He commented how much he did not recognize me and how much different I looked."

Eric was quick to say that being free from dialysis was a relief. He explained,

*"Before the transplant I was on the machine (haemodialysis) five hours, three times a week. The machine hurts, and it is not easy. Anybody who can sit on the machine*

*three times a week, all the time like me for five years would like a good kidney as soon as possible. To replace all the needles that hurts the body, everyone hopes for a new kidney. For me, I've gotten a good kidney, thanks to my God. Today, eight weeks after the transplant and the kidney is very good. I'm very happy because the machine is gone now and I have a different life. Before, if I walk a very short distance, I have to sit down, and I can't walk with my children. To day, I feel stronger. I feel a different person."*

He further spoke about his wife's thoughts. Eric said, "*My wife is very happy, but still eight weeks she still hopes that I get well like before I was on the machine. This is my first transplant, and I hope it's the last one to. No more, just this one working good."*

For Eric other people's opinions about his transplant were important. He spoke,

*"Other people think I am very good. I, myself was very irritable and restless when on the machine. Now, I am more quiet and patient. My blood had to much urea, to much waste products, it made my mind uncomfortable. This time my blood is alright, my mind is at ease. I still sometimes get anxious and depressed. Sometimes I have mood swings, perhaps like everyone else, but not like I was before the transplant. Before, I liked to go home quickly after work to do the machine. There was to much to worry about with my family. I'd like to take my children to soccer. but I couldn't. I had to ring somebody to pick up my son because I am sick. Now it is different."*

During the next interview Eric spoke about his family's attitude towards his transplant. Eric said, "*... My family is happy for me now that I am off the machine. They feel that I can do anything now, and they like the extra time that I have now, without having to be on the machine. They say I now can go anywhere. I'm happy not to be on the machine anymore."*

Concern about other people's opinions were stated during Eric's final interview. He remarked, "*Shopping makes me nervous I feel that people are watching me. and I wonder how I look I sometimes think that the transplant is a dream and I have to go back on dialysis. It can be a nightmare. I thank my God its just a bad dream."*

A sigh of relief was expressed by Daryl as he spoke about his renal transplant. He remarked, *"About my health, I am feeling quite well I can do more than when I was on dialysis. When I was on dialysis. I would go to work and feel very tired. I would sleep all the time. So with sleeping, working, and dialysis there was not much time left for me to do other things because I have to dialyse three times a week."*

Daryl went on to further state, *"I feel much more happy. More contented because my health is better. People say that I'm not so tired as before. I've got more energy because I've got more time to sleep. When I was doing haemodialysis three times per week. Besides doing it, I had to do a lot of preparations. Preparing the machines, the needles. It took me quite a lot of time before I begin haemodialysis. I was doing home dialysis. At that time, when I stood in the sun after five minutes I felt itchy all over I had to find a shady area. Now I am alright in the sun, but I still have to apply sun screen and where a hat. The doctors said that sometimes happens to you when on dialysis. But, I have a transplant now. That's good."*

During his next interview Daryl was asked if he misses being on haemodialysis. He replied, *"No not at all. I'm glad to see them take it away I hope I don't have to go back on it. I don't think any one would want to. (be on dialysis). But, I still think I have to go on it. Just force of habit, I guess. Old habits die hard."*

One concern seemed to trouble Daryl about his transplant, which was probably due to his sister's reaction. Daryl explained, *"Can I say that, "around where my kidney is, it is going lumpy." When I do exercise it shows more. If I go swimming others will see, and might laugh. The doctor told me not to worry, and it might not be so noticeable in two months."*

*Interviewer*

*Has that become worse since last time I saw you?*

*Client*

*I don't know. Just more noticeable since I've become more active. I think my sister was shocked when she seen it."*

By his final interview Daryl's concern about his lumpiness, "had eased and he felt more comfortable. Daryl spoke, *"The first time when I saw you I was feeling uncomfortable and nervous. I felt soreness and uneasiness. I was bothered by the lumps in my side (wound site) and couldn't walk fast. You helped me cope and you understand. Now I am not nervous, I still feel like a lump in my side. But, I can now exercise properly, and walk fast I feel much better. Each interview I felt an improvement in my health."*

From the study issues pertaining  
to relief saw:

Maria was extremely pleased to be off dialysis. For her, normal referred to anybody not receiving dialysis. It was, "like having a new life," that was a typical comment expressed by her, about the exhilaration of being free from the restraints of dialysis. However there was one downside that was indicated by her. This was, her missing the social interaction with the friends that she made among haemodialysis clients and staff at the clinic where she attended for many years, and spent long periods of time with them during her haemodialysis treatments. Gary, was also happy to be somebody without a disability. He considered his body to be whole and complete, with the new kidney. Giving his kidney a pet name, the participant indicated his belief that this transplant would not fail, like a previous transplant. The relief that was felt was one of now being "free,"

and having no longer to set aside time to undertake dialysis, resulting in spare time which he never had before.. Perhaps, the greatest relief expressed by Gary was to be settled back at work, and not to be sick anymore. For him not being sick was being free from dialysis and this was normal. Gary summed his enthusiasm up by commenting, "its been a blessing." Karl, like Maria and Gary, was overjoyed with his new kidney, and experiencing the freedom of life without needing dialysis. This is despite the fact that Karl was perhaps the sickest of all participants interviewed. The donor kidney was not an ideal match, but it was the best match of any kidney that was previously offered to him. There was always going to be significant medical problems with Karl's health, and any donor kidney on offer. This was due to his rare tissue type. heavy physique, and high Creatinine levels. Despite this, Karl clearly stated that any thing, even medication side effects was better than dialysis. A desire to complete his TAFE studies, and willingness to discuss his illness with anyone who asked, showed his zest for life. Karl's wanting to associate with other people was exemplified by his strong advocacy in promoting the Transplant Olympic Games.

Daryl, was extremely happy to be free of dialysis. He stated that he was happier with his donor kidney compared to being on dialysis. More than any of the other participants, he showed a concern for his physical appearance of "lumpiness" around the wound site. Despite a re-assurance from his doctor, the thought of other people laughing at him appeared to be of significance. Of the five participants who felt relieved to have a donor kidney, Daryl was the only one to exhibit anxiety about people seeing his wound site, and his perception of their laughter. Being more emotional than Daryl, Eric strongly stated that life was extremely difficult for him when on dialysis, and to be free from it was a relief. Eric also stated that his wife was pleased, and she hoped that life would return to how it was like before he became ill, with End Stage Renal Disease. The opinions of other people appeared to be of significance to Eric, perhaps more so than with any of the other participants. Eric was relieved to hear the doctors comment that his donor kidney was, "a good match."

### Adapting to feelings of relief:

Perhaps the main area of concern in feeling relief, would be one of complacency. That is to say, the participant might become overwhelmed with the exhilaration of acquiring a donor kidney to the extent of unconsciously neglecting their health. It must be remembered, that having a donor kidney does impose a responsibility on the part of the recipient to care properly for it. This includes watching ones diet, and adhering to the medication regime.

The participant should relax and enjoy the benefits of life with a new kidney while relishing the relief of no longer requiring dialysis and all the restrictions that it imposed. There can be no doubt that everything including renal transplantation does have its drawbacks. For Maria the social aspect of missing her friends who are still undertaking haemodialysis, and the "lumpiness" around the wound site that troubles Daryl are an example. However, for Gary and especially Karl, the benefits of a transplant far outweigh the alternative of a life on dialysis.

### In Summary:

The study was able to identify that, one of the main components of relief for the participants was to be free from dialysis. With the long wait for a transplant now over, the beginning of a "new life" is at hand. Being free from dialysis implied that you were "normal." This was expressed by all the participants, but notably by Gary and Maria. Consequently, no longer can they be regarded as sick for they are normal with their new kidneys.

The feeling of relief and subsequent acceptance of the donor kidney was repeatedly and openly expressed by Karl. He stated that any problems arising from the donor kidney was better to face than the alternative, that is a life on dialysis. This was a common sentiment of all the participants without exception, with Karl being the most outspoken. Karl's persistence could be due to his poor medical condition, and the additional problems in finding him a suitable kidney compared to the others.

Whatever, the feeling of relief was clearly noticeable by him, and the other participants.



## ACCEPTANCE.

It is fair to assume that nobody wishes to be isolated from others or feel different. The feeling to belong and conform with others is in us all.

Whether you release it or not, everybody inherently tries to conform to one idea or life style, an issue that Sampson and Marthas (1981), touch upon.

Indeed, this could be very indicative of Maria, Eric, and Karl who strove for "perfection" in order to obtain acceptance and dispel any social isolation. This was also apparent with Daryl and Gary who emphasized the need for a return to work and acceptance from colleagues to overcome any feeling of non acceptance. These participants did bring to the fore, the correlation between the desire for social interaction and the perception of social isolation. Undoubtedly, these perceptions, had their impetus when these participants first developed renal disease, who subsequently becoming end stage renal disease clients and now transplant recipients. The reality of being different from other people, as Karl felt when his friends saw him on haemodialysis was undoubtedly entrenched in their minds. This in turn would foster a deep desire to be liked by others, which was strongly felt by the participants. This is readily seen when viewing their respective interview transcripts.

Maria's desire to find acceptance stemmed from her time on dialysis,

when she would try to hide the truth from her children. She remembered, "...I never say when I come from dialysis, you believe me. In my mind I will be at work tomorrow.

... I never in my mind say to the children when I'm come from dialysis I'm tired. I'll go to work tomorrow I'm fine....I'm go to work. I no go to dialysis. You believe it?"

Throughout the interviews with Maria, she gave the impression that she was constantly striving for their acceptance and approval. Maria said, "... Professor Brown mind me 4 years he tell me at last year Christmas time, "I'm happy with you, I'm glad with you, you the best my patient"

Maria compared herself with a friend saying she was not like her. Maria remarked, "I don't understand why sick people don't look after themselves. I don't understand my many diabetic friend." Maria further indicated that her friend was, "a stupid woman."

During her second interview Maria was discussing what people thought about her since the transplant. Maria commented about the responses made by her friends in the dialysis unit and the staff. Maria spoke, "... Especially people on dialysis, they and the sister tell me I look ten years younger."

Throughout the interview Maria would remark about her friends comments. She stated that her friends would recognize her because she is healthy. Maria stated, "Talking people and telling, "You looking fantastic." "You looking nice." "You look alright."

The correlation between Maria's, "good health and acceptance from her friends was, apparent when Maria compared herself to other people Maria said, "... I am very very strong healthy lady. Some ladies have ankle pains, some have leg pains, some have hands, some arms. For me, I'm so luck they can't understand. I have no headache, sore back shoulders nothing. I said to them, "I'm a healthy lady."

In her final interview Maria was still insisting that she was healthy and feared non acceptance if she was sick Maria commented, "... don't want people to see me walk like a cripple. I have no trouble with my back. I can bend. My back never sore. Arms, shoulders never sore."

Maria concern about increased clothing size led to a conversation where she sought acceptance from the doctor and compared herself once again, to somebody else. She said, "... I tell you, last time when I went for blood test the doctor said you are so lucky being not fat. Others tested were big and plumpish. One man I know put on nearly fifteen kilo and he is still young. That is to fat."

Gary never really found any problems of being accepted by other people. Even from time spent on dialysis, Gary stated, "It was no problem. Dialysis 4 times a day. I'd always do about 1 or 2 exchanges at work cause I'd work about 12 hours a day sometimes. The staff got were very use to it because I'd go down the microwave and heat up the dialysis bag. They'd think it was food and wonder why I wouldn't share it. There was one girl there and I told her it was mainly glucose so she wanted to take some home to drink it. She kept on trying to con me into taking some bags in for her so she could go home and drink. While I was on dialysis, the staff got so use to it I'd just walk into the office and just talk to me and tell me on the telephone, it never quite disturbed them. They were quite good."

*Interviewer*

*And what about now?*

*Client*

*Their wondering why I'm not doing dialysis.*

*Interviewer*

*And what do you say to them?*

*Client*

*Well before they use to benefit from that because I use to go up to my office, lock myself up for 1/2 hour to 45 minutes and do dialysis. Now I don't have to do that and they're saying what are you doing now? and I say well I can't do this dialysis anymore so I can't lock myself up anymore so I've decided to come and annoy you. That really impressed them.*

*Interviewer*

*Do you miss not having dialysis CAPD? Not having CAPD?*

*Client*

*Not at all. I reminisce about it at times. It's hard to get it out of your system. You could never miss it."*

For Gary, returning to work was a sign that he had gained acceptance. A valued acceptance from his work colleagues. Gary remarked, *"They are all quite good about it actually. I was really impatient to get back to work so back to work I went, maybe too early actually. I've been back at work a week now they realize yes I can do the job fully capable again. I think it's good for you because life starts for me with work and if I can get that system back first of all, I can start looking at other sides of my life that have got potential with a very new kidney."*

He indicated, that very close friends have suddenly become shy. Gary explained, *"... very close friends see virtually what I do. They're actually a little bit shy of it at the moment. I tell them I intend to change my life in small ways. They've still adapting that I've got a new kidney. They've always known me on dialysis and there are some special people I work with who have pampered me all the time making sure I was OK now. They've sort of stunned at the moment."*

Gary went on to speak about being pampered, *"He said, "... actually they do only because I've only just come back to work and they think they have to look after me because I've got a new kidney. It's mainly the females that I work with. They have all tried to be old Mother Hubbard."*

*Interviewer*

*And how you find that?*

*Client*

*I find I'm a little bit stunned cause I don't really know what to do at the moment because not many people know how to deal with a transplant patient really and they're all a little bit shy at the moment to ask things.*

*Interviewer*

*They still want to wrap you up in cotton wool?*

*Client*

*At the moment yes but as I said I've only been back at work for 5 or 6 days and they will get very use to me and treat me like anyone else."*

In his second interview it became clear that Gary had developed a type of rapport and acceptance with people that transcended age and whether or

not he was on dialysis, or with a transplant. This was particularly due to his employment and was more significant with elderly people. Gary spoke about people being aware of his end stage renal disease. He said,

*"...It never did annoy me when I was on dialysis. Half of them didn't even know, I had a tube or that but didn't annoy me then because it was something that had to be. Doesn't really annoy me now because people who know that I had a transplant know that I'm much better. I've noticed many of the patrons, mainly older people ask me how is it going, and all. I don't know why it's older people maybe because they're frightened they might get kidney disease. Or I might have astounded them because no one realized in the patrons that I was on dialysis. It's quite intriguing how much older people ask me how the kidney is going, they're really happy when I say, no worries. It's amazing how much some of the older people know, they ask me what drugs I am on. They know all the drugs, Maybe they're been available to them at one stage or another, or their friends.*

*Interviewer*

*Do you find that's been of help to you a lot, being in the hospitality industry? Being able to converse with people, and take your mind off things?*

*Client*

*Yeah, I've always liked being in the hospitality industry cause of that. I like people. I found that even on dialysis conversing with people all the time was the greatest therapy of the lot. I never really told many people that I was on dialysis among the patrons, just conversing with them. Sometimes getting involved with the kidney, with the dialysis centre and all; understanding the older people a little bit more."*

Gary mentioned his sister who has always accepted him. He comments, "Ah, she's always asking me, "How it's going?" Always mothering me. She is quite use to me there, being back to virtually normal now."

It was in his final interview that Gary spoke of his special fondness towards one of his sisters. He commented about the help she was affording him. Gary spoke, "Still doing the washing, not doing the ironing. They've been good. They know that I'm quite independent I always have been. They know I'm independent and lead my own life. I pop over there once a week and say hello, and give her my present of a weeks washing. She gets upset if she doesn't see me and she always asks for a report. She is my closest family member. There is six in the family. I have a brother in Vietnam. I don't know how he is going now, with

*Cambodia going. He's got a swimming pool business over there. For all the hotels. I suppose there's money in everything.*

*Interviewer*

*What is his response to your transplant?*

*Client*

*Well, I haven't seen him. I don't really know why I mentioned him. I've got six brothers and sisters, there're all around this area, but I don't see them that much. They've all got their own lives. My elder sister is very close, and the others are just really there. Families are like that when they get older.*

*Interviewer*

*What about friends in general?*

*Client*

*I've got a close friend sort of grown up together from school years. I might see him about once a week, and special friends at work.*

*Interviewer*

*What are their responses to your transplant now?*

*Client*

*Really good, quite good."*

Gary went on to say that work colleagues don't look upon him as a "transplant person," anymore. He spoke, "... Couple of the office girls are still keeping an eye on me. I just mention it a couple of times in conversation myself, it's hard to get out of, and they still realise that I'm still a fairly new transplant person. They can't do anything, but I've noticed they try to make sure that I don't overdo things.

*Interviewer*

*How about the patrons at the club?*

*Client*

*A couple of older ones keep asking, how is it going? I know exactly what they are talking about. I just say it's great, been no hiccups."*

Karl commented on how his family teased him about medication side-effects as being a sign of acceptance towards him. Karl spoke, "My sisters and brother rag me a bit. I don't mind that Its just how a family works."

Karl had a desire to find acceptance from the family of his donor kidney but he expressed some indecision. Karl explained, *"I just feel sorry for his family, what they were going through to say yes. From what I can understand, he was only a young fellow who died in a car or motorbike accident. As far as my faith goes I say a pray for that family, when I say one; the family and the young bloke. I believe you can write to them through the red- cross."*

*Interviewer*

*Will you do that?*

*Client*

*I'm still thinking about it; I don't know. You would have to know them, whether they wanted to be reminded or not.*

*Interviewer*

*It's a bit dicey, isn't?*

*Client*

*Yeah, do you send them a letter, and they are happy to get it. Or, are they trying to get over it, then all of a sudden this letter arrives in the mail and reminds them of it all again. See, I've seen people have bad experiences especially with donating organs. There was one woman down home; she started an organization called, "The Lonely Hearts" or "The Black Hearts, but she never really got over the fact she donated her sons organs who was only five. She couldn't get over the fact that he looked like he was alive on the life support. He was actually brain dead but he looked that he was still alive. She was under the impression that he was being brought to Sydney to be saved. But, it was actually to harvest the organs. So if you sent a woman like that a letter you could actually cause more trouble. That's my experience of it. On the other hand my friend writes to his (donor) family every year, on the anniversary that he got the kidney and thanks them every year for it."*

He went on to say that he does feel accepted by those close to him. Karl remarked, *"Everybody was just so happy that I got it. because those close to me know that I have been waiting six and a half years. If they have known me for that period of time, they are just so happy that I've got it."*

Karl further commented about people reacting differently to him since the transplant He stated, *"I don't think so I think people are pretty good these days. I mean they understand I haven't changed. Basically I have got this organ in me that's not mine. I mean, I don't think they would see it as, unless they're opposed to the*

*whole idea of transplants. I mean I don't see why they should perceive me to be any different to what I was before."*

He attempted to interact more with other people, through his sporting interests Karl said. *"...I want to play sport. Because before I got sick I use to like to play cricket, mainly it's my main sport. I want to get back into that so to do that you have to achieve a certain level of fitness."*

In Karl's following interviews he made mention of how his friends found it difficult to accept seeing him on dialysis, and then with a transplant Karl spoke, *"A couple of friends saw me on it. All of my family saw me on it. Don't know whether it meant anything to them."*

*Interviewer*

*What did that mean to you? did it bother you?*

*Client*

*Didn't bother me. them looking at me. I'd rather them look at me and ask questions and understand it. A lot of them shied away and couldn't stand to look at me on it. That bothered me, and bothered my cousin (recent transplant recipient) too."*

*Interviewer*

*Do those people come and see you now, that you have had the transplant?*

*Client*

*No, they don't. One was my old uncle, he's seventy odd, and he's just no good with health. He just said he couldn't stand to look at me on it. So that's fair enough. A lot of people couldn't handle it. Mainly old people. My Brother was never much good even when I had the transplant. He'd come in, he couldn't even stand to look at my catheter bag. He said can't you cover that up."*

Eric was somewhat quick to state that other people accepted him. Eric spoke, *"Other people think I am very good. I, myself was very irritable and restless when on the machine. Now, I am more quiet and patient."* He continued to say that all people have accepted him. Eric said, *" They are all very good. All of them have helped me. People whom I don't know have helped me, more than my brother has. I'm pleased to be home, and my family is very pleased. You are most welcome to see me anytime at all."*

During his following interviews Eric was continually looking for acceptance. He would repeatedly say, *".... My family is happy for me now that I*



*am off the machine. They feel that I can do anything now, and they like the extra time that I have now, without having to be on the machine. They say I now can go anywhere. I'm happy not to be on the machine anymore."*

Eric's wanting to be accepted by his family was further exemplified by wanting to participate in the Transplant Olympic Games. He remarked. *"...At the school where I work, the sports teacher trains athletes for the Transplant Olympic Games. I said that I would like to compete in either cycling or volley ball, if possible. Where would I apply?"*

Eric continued, *"Maybe we can go to Holland, and win some medals too."*

Eric tried to hide any weaknesses from his son for fear of non-acceptance. Eric said, *"....In my country I played soccer a lot I teach my son how to play soccer. However, after the operation, he keeps asking me to play with him. Yesterday, I played soccer with him. It was the first time since my transplant."*

*Interviewer*

*What effect did that have on you?*

*Client*

*It made me very tired, but I did not tell him. Perhaps later, I will be able to play longer with him."*

Eric was constantly seeking praise and acceptance throughout the interviews. He was upset about his wife seeing physical changes in him, and the possibility of her not being able to accept the situation.

Daryl stated that he was welcomed back to work, which he regarded as a sign of acceptance. He spoke, *"... They welcomed me back and seemed pleased to see me. I told my supervisor that I can't lift the heavy things for a few weeks, and he gave me some small equipment that was easy to handle because my main job is repairing and I can't repair the heavy equipment just yet. I worked a full five day week."*

During his following interviews Daryl had found much acceptance from other people since his transplant. He remarked, "*.... People say I look better since I had the transplant. They say my face doesn't look boney. They say I've got a healthy colour in my face. My face is darker now, and people say that I have the healthy Chinese colour now. I've got more brightness.*"

Daryl regards teasing from his family as being their way of showing acceptance. He comments, "*... My friends and relatives are saying my face looks much brighter than it's ever looked. They can't get over it. They call me fat face. It is much better than before when I was on dialysis. I'm still very happy and I feel normal now, without the (haemodialysis) machine.*"

From the study issues pertaining to  
acceptance saw:

Maria, expressed a strong need to be accepted by other people. Maria would constantly seek approval from other people forever waiting for their comments of approval to which she equated with social acceptance. Maria had the belief that if she was not healthier than other people. it would result in a lack of acceptance from her friends. She was deeply concerned about increased clothing size and weight gain, because or how people might perceive it. Her need for acceptance was stated early in the interviews, with Maria wanting to hide needing dialysis from her children, fearing they would not accept her. Acceptance by her family was evident, with Maria residing with the family. Eric conveyed an urgency in desiring to be accepted by other people. Similar to Maria, but much more intense, Eric was constantly seeking acceptance, praise, and

encouragement throughout the course of the interviews. He tended to have the perception that his wife and children expected more from him. He constantly worried about his wife and friends noticing physical changes in him. Eric stated, he would hide any sign of tiredness after playing with his son, fearing non-acceptance. More so than Maria or Eric, Karl had extended his desire to be accepted by other people, to wanting contact with the family of his kidney donor. However, this was unattainable. He regarded teasing from family members about medication side - effects, as being an indication of acceptance by them. Primarily through sporting interests, Karl was able to social interact with people and find acceptance. Being ignored by people on the basis of his medical condition bothered Karl.

Daryl, was welcomed back at work, which made him feel accepted by being, "part of the team." Receiving friendly teasing regarding medication side effects, from family and friends was welcomed by him. Daryl remarked that this created a feeling of acceptance for him. However Gary, did not highlight acceptance from other people as being a significant issue. Instead, he tended to regard this as a natural occurrence in the course of life and did not give it much thought. He was grateful for the acceptance he received from an old school friend, and Gary regarded

extra responsibilities at work as being an indication of staff and managerial acceptance. However some disappointment was expressed about minimal contact with siblings, apart from one special sister.

### Adapting to a feeling of acceptance:

For each participant, actually getting used to people accepting them can be somewhat traumatic. As previous stated the most significant concern would be the fear of social isolation. Overcoming this fear of social isolation and striving for acceptance would first of all require the individual to have a belief in oneself. The perception that the participant has of himself / herself, will undoubtedly be projected to other people. Should this projection be one of negativity (Berger, 1972), uncertainty or even shyness, then most probably other people will be repelled. Thereby social interaction will be negative or non-existent. You must have a positive image of yourself to portray and project a positive image.

If there is any basis behind this analogy, and realistically it is quite logical, then the participants should be made aware, and encourage to believe in themselves, As Schilder (1935), would comment on conveying the right perception, it is how you perceive yourself and how others

perceive you that is important. Positive perception hopefully will prevent any social isolation, and promote acceptance with other people, which would be a preferred feeling to the alternative.

#### In Summary:

The study identified that being accepted by other people was of significance. The desire to conform with others and not show any signs of ill health was particularly strong with Maria, and a little less significant with Eric and Karl likewise Daryl and Gary conveyed the desire to be accepted, to which they focused on the need for acceptance among work colleagues.

A need for social interaction was evident throughout the interviews amongst all the participants. It was also obvious that a desire to be liked by people was paramount to their perceptions that they had of themselves.

## TRUST

The concept of trust or faith can have religious or philosophical connotations. This is quite true probably because trust and faith are hard to define in a physical sense.

Based on the interpretation of the referenced material, and on an understanding that each participant viewed trust and faith to mean the same while not differentiating between each; both faith and trust will have (for the benefit of this study) the same meaning.

The significance of a trust or faith in some kind of belief system be it spiritual, in oneself, or in others, was discussed in frequent writings by Durkheim (1915), and was considered to be the framework of society and paramount to mankind. Indeed, trust was significant to all the participants in the study and they identified trust as being; in oneself, in the doctors, and in God

### (a) In Oneself

The notion of having trust in oneself was seen in Gary. His trust was in his own judgements, and because this was his second renal transplant,

Gary was more aware (than the other participants) as what to expect. His attitude to the transplant experience was somewhat philosophical. This is particularly evident with his remarks about waiting for a donor kidney.

*Gary spoke ".... I just had a strong faith that it would come. It depressed you. Sometimes you'd think when is it going to come but I was never greedy about it because I realized it was only a short period I knew a lot of people from the clinic and the haemodialysis, they have been waiting 8 to 10 years. I knew that 3 years was nothing. I always call a transplant when people talked about it, a sort of Russian roulette game. I accepted that death may come along. It didn't frighten me.*

*Interviewer*

*Why do you have a strong spiritual faith?*

*Client*

*I've got small spiritual faith.*

*Interviewer*

*Do you think that helped you at all?*

*Client*

*No not really."*

Gary's faith and trust in his own judgments, is further exemplified as he comments "*.... I'm not even worried about the kidney now I know to make sure that I look after it, as much as I possibly can. Really the doctors do that for me, well I've still got my own obligations, I don't know how you would look after a kidney really. I've never been much of a drinker and I'm making sure that I don't drink very much alcohol. I don't really know if that will effect the kidney. No one's never lectured me over that. Maybe because I have not been a very big drinker. Maybe some of my friends at work say don't drink at all. Mostly the women because they think I'll do damage, but they still don't understand. That's about the only way I know how to look after the kidney. I don't indulge in alcohol too much and I don't be stupid. That's about all, make sure you drink plenty of water.*"

Gary further remarked about his skepticism concerning the survival of his donor kidney. ....

*I was a bit skeptical, whether it would work or not. Whether it would work or not, or whether I would go through rejection. Actually I've been trained from the last time to expect rejection. People who have transplants know that rejection comes up, but it never came, which I am quite amazed about. I don't think it will come now.*

*Interviewer*

*You said that last time too.*

*Client*

*I was really expecting a little bit last time, but it never came - Because, last time it came out of nowhere. I know that with rejection we normally get it very soon after transplant. I'd say a week after transplant. But nothing came and I was waiting and waiting. It won't come now, I don't think.*

*Interviewer*

*So you are quite confident?*

*Client*

*I'm very confident. Somehow I know the kidney is really good and the doctors are really pleased with it. Apparently bloods are as normal as they can be. They reckon the haemoglobin and Creatinine levels are really good.*

He discussed perceived problems in the future;

*Interviewer*

*You cannot see any problems in the future?*

*Client*

*No. If there's a problem you take them as they come. Same as any thing else in life, but its not something that I lay in my mind. I'm very confident about it. If something happens it happens because I've personally been on dialysis two times now, probably six or seven years on dialysis at one stage. I'll take this kidney the best I can. I'm sure it's going to work. If anything happens, well that's the way it goes. It's been a blessing, but it won't happen any way. It wouldn't upset me that much.*



From the study issues pertaining to  
trust in one self saw:

The issue of trust in oneself was only significant for Gary. You cannot help to wonder what influence this transplant being Gary's second, had on his attitude. Gary experienced skepticism almost immediately from the prospects of obtaining a donor kidney. Once receiving a donor kidney, his attitude revealed somebody who was well aware of what to expect, particularly in terms of potential problems that could arise.

Adapting to attitudes of trust in oneself:

This would be an extremely difficult task if not impossible for the renal transplant recipient to do. Apart from a trust in his / her own judgment, the renal transplant recipient must also put trust into the hands of others if the transplant is to be a success.

Perhaps the closest person that a kidney recipient will be associated with is the doctor. If the recipient does not have a trust and faith in the doctors judgments and decisions, the probability of a graft surviving is minimal.

In addition to the doctor, there are other health care professionals who are of significant importance. Once again, the recipient must inevitably have trust in these people, if the recipient is to receive the best possible care.

When waiting for the arrival of a donor kidney, the recipient (and virtually everybody) can give no guarantee of when this will occur.

What the recipient needs to consider is that a trust or faith in your own judgments will not alone, insure the arrival of a donor kidney and its survival.

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#### (b) In the doctors

Interviews with Daryl revealed both, a trust in God and the doctors. He regarded the doctors as an instrument of God, and he declared his faith in both.

Daryl states, "*...I always do what the kidney doctors say, and put my trust in God, always.*

*Interviewer*  
*You still go to church?*

*Client*  
*Yes. Every Sunday."*

He further indicates his trust in his renal surgeon by saying, "*...The doctor is a bit strict but he is very good.*"

Karl was also quick to give his support for the renal doctors and declare his faith in them. This is revealed when Karl discusses the survival rate of his donor kidney. He says, "*I've never really thought about it, because they've (the doctors) all said the chances are it's going to last you a long time, so I try not to think about it. I understand that one day it's going to fail.*"

However, Karl showed an annoyance directed towards his General Practitioner, to which he expressed a lack of trust. He stated, "*He doesn't listen to me. He just sits there and talks. He's annoying. I only go to see him for coughs, colds and prescriptions. That's all he's good for. He is a good-hearted old bloke but he's too busy wanting to know what members of my family are doing. He talks about everybody except me when I go in. See, I go to Dr. Trew, once a month and if I had any big health problems I would see him.*"

Similarly during the interviews, Gary who had contracted influenza spoke about his visit to his General Practitioner. What he revealed was an absolute distrust and lack of faith in his General Practitioner.

*Interviewer*

*You have seen your doctor about the flu?*

*Client*

*Yes, I seen my G. P. He didn't want to put me on antibiotics in case it counteracted with my drugs. He hasn't got too much idea about renal. I saw Dr. Trew (renal specialist) last Thursday. He whacked me on antibiotics. He knew how serious it was because he's run into a lot of people with it. I've had more than a week of work. They didn't want me at work to spread the germs around. Luckily my boss has already had it and he was off work for about a week, so he understood.*

*Interviewer*

*Is Dr. Trew worried about your kidney, in terms of this?*

*Client*

*No, he just said stay in bed. Actually he said that I could go back to work on Friday. I had the flu from Monday onwards and he told me to go back to work on Friday, but I was still down. I was ready to go back to work but they didn't want me back anyway.*

*Interviewer*

*Do you think this will affect your kidney?*

*Client*

*I don't think so. Dr. Trew would have told me if so. He just whacked me on antibiotics for three weeks, that's it. I see him every three weeks now I've got a lot of time for him. But, you can tell that the G. P. knows nothing about renal at all. He never even looked at my pelvic catheter, the G. P. I kept on trying to take it off, and he didn't want to see it. It must have frightened him. Renal is a specialist area anyway I've been around renal doctors for that long now, I know that they are a special sort of doctor. So I couldn't really knock a G.P. for not knowing what's going on. However the G. P. should know the basics."*

From the study issues pertaining to

trust in the doctors saw:

Daryl expressed a complete faith and trust in the doctors. He likened the doctors to be an instrument of God, an extension of God's arm. In respect, Daryl saw his trust in God and the doctors to be interwoven. Distinction between the two could not be separated, regarding his treatment.

Similarly, Karl and Gary had complete faith and trust in their renal doctors. However, what was disturbing was their complete lack of faith and trust in their General Practitioners. The remark was even made by Gary that, "the General Practitioner should know the basics." Karl expressed an annoyance towards his General Practitioner.

### Adapting to attitudes of trust in doctors:

Every recipient should be encouraged to develop a rapport with the doctor of their choice, in order to promote optimal treatment.

What is distressing is the apparent lack of understanding of renal disease and treatments that General Practitioners have, according to Karl and Gary.

Suggestions to improve this dilemma could include, the establishment of training programmes to make General Practitioners aware of the special needs of transplant recipients. Additionally regular updating of material concerning renal transplantation could be made readily available to General Practitioners.

Perhaps if a type of register of General Practitioners, with an interest in renal transplantation could be made available to organizations like the Kidney Foundation, then end stage renal disease clients would know the General Practitioners that are sympathetic to their needs. Another suggestion could be to establish a telephone information line. Here contact could be made to people specialized in the field of nephrology.

## (c) In God

In a study conducted by Tix and Frazier (1998), they found that after renal transplant at three and twelve months, the use of religious coping was generally associated with better adjustment both concurrently and over time in both clients and their significant others. They stated that religious coping was more effective in promoting adjustment for Protestants than for Catholics.

It was Maria and Daryl who expressed a strong faith in God, with Maria stating that she prays twice a day. She commented that she followed the teaching of the Orthodox religion.

However, it is Daryl who quite openly displays his faith and trust in God by directly applying his belief to his transplant experience. He speaks, *"...During the transplant and now there were times when God gave me the power to continue on. To continue to live. See nobody can help you. They just try to help you. See I know that people can only do limited things. We don't know the future, even doctors can't help you there. Only God can. I and my wife are confident that God can help me. Maybe if it is God's will, God will direct it to what he thinks is suitable for me. At the end we will lose our lives but we trust God that my wife and I will go to heaven."*

Probably more than any participant in the study, Anna openly and continuously declares her faith and trust, in her God.

She speaks, *"I am Muslim. I'm not a religious person, but inside my heart I feel that my religion is a good religion. I don't live the life style of a Muslim. But, I feel that my religion gives you faith and relaxes you if you read the Koran or pray."*

*Anna believed that it was her God's will that she should be sick, Anna commented, "I believe that my God wants me like this. I don't know why God wants you to be rich, or poor or to be a sick person. Nobody knows why God wants you to be rich, or poor to be a sick person. Nobody knows why God wants that from us. To find your faith in this life, is how you accept this illness and whether or not you accept it. If you accept it you have good faith in your heart so that you believe in God. For me, I find that hard to accept that I am sick. But, I'm not sick now and I hope I won't be sick any more."*

Anna continued to state that through her trust and faith in her God, she has been blessed. She continues and elaborates, "... I read the Koran nearly every night. But, I should read it more. When I read it, I feel calm, I try to understand what god wants from us, It is peaceful. It stops me from being scared of this life. I know that something will happen after this life. I believe in a heaven. I don't feel as if I am doing what god wants from us. I have been bad.

*Interviewer*  
*In what way?*

*Client*  
*I have not been fasting or praying properly. There is a set order for prayer, and I haven't followed it lately.*

*Interviewer*  
*Anything else?*

*Client*  
*I'm not lucky in this life. I feel inside my heart that luck is born with the person. You are either born with luck, or not. Maybe I don't feel lucky because I have kidney illness. But on the other side I guess I am lucky because I have this kidney."*

Eric put significant importance on his faith and trust in God, and the importance that church made in his life. He commented, "...My friends, everybody at church are very happy and they pray for me. I am very religious. We are Egyptian Orthodox.

*Interviewer*  
*What effect do you think being religious had on your transplant?*

*Client*  
*It helped a lot. Couldn't cope without my religion."*

He emphasized that his faith helped him to cope, and his devotion was clearly stated. Eric further commented, "*... Now I'm eating everything. Now I am fasting and only eat fish, no meat I am Egyptian Orthodox I must fast at this time. We celebrate Christmas on the 7th January. It is very important time for me.*"

*Interviewer*

*Religious faith is very important to you?*

*Client*

*Yes. I am a devout Christian. It is a big help to me."*

Karl was quick to declare his faith in God. He remarked, "*I am a Catholic.*"

*Interviewer*

*What advantage is that to you, going through this process? Do you feel closer to God? Anything?*

*Client*

*Yes, I mean it's good because you can sort of say, "If it doesn't work out, you figure that is the way He wants it, and that's the way its going to be." There is nothing much you can do about it."*

*However, it became apparent that perhaps Karl's trust in God was a bit skeptical. He made an interesting remark concerning the intervention of God. Karl spoke, "...I suppose. I am not a great believer in God intervenes in our every day lives. My mum is that sort of way. The older generation is but not so much with me. See I had a hard time dealing with it. I never really prayed for a kidney. I could not see the justification of God killing someone to give me a kidney. They all prayed (my family) for it, but I couldn't see that sort of thing coming. If it was going to come it will come, whether God had anything to do with it; I don't know. "*

Gary's trust in God was only prominent when he felt troubled. He remarked, "*I am religious in my own way but not really too much so. Only when I'm in a really tight jam I suppose."*



From the study issues pertaining to trust in God saw:

For Maria, Daryl, and Anna, a trust and faith in God was paramount to their daily lives. These participants used their beliefs as a coping mechanism to help them through the bad times.

However for Karl, an air of skepticism bothered him. He found it difficult to believe that God would allow somebody to die, so as to give him a donor kidney. This skepticism is despite Karl's apparent trust in God.

You tend to have the impression that Gary did not have a trust in God, and he tended to reject this notion.

Adapting to attitudes of trust in God:

Any adaptation to God is a personal issue. If the person feels a need and has a belief that spirituality will be of help, then this should be pursued. Religious organizations can be of help, to any interested person. Tix and Frazier (1998), reported that for the renal transplant recipient religious affiliation promoted significant health advantages and was an effective coping strategy.

The attitude that Karl raised concerning God allowing somebody to die so that he could receive a donor kidney was significant. Consultations with religious leaders, could not give a substantial answer to the issue. The general response was that it was God's will that the donor died and the recipient received the kidney. It was suggested that the donor's time on earth had expired, and that the donor was destined to enter immortality. Unfortunately, that was the only answer given. Perhaps it is best if the recipient graciously accepts the donor kidney, as a gift to be cherished.

This is a question that science cannot answer, and never will.

#### In Summary:

From the study three kinds of trust were identified. These were;

- (a) In oneself
- (b) In the doctors
- (c) In God

One participant indicated a trust in himself to the exclusion of everything else. This notion was difficult to believe, especially when it can be said that nobody can be independent, as we are all interdependent. Everyone

needs to put their trust into something or someone other than themselves, in order to survive.

The trust that participants had with their doctors brought both a positive and negative response. It soon became apparent that the trust participants had with their renal doctors was very deep. It was said by one participant that, "I always have had one hundred percent trust in the renal doctors. They are a sort of brilliant people..." That tended to be a wide spread opinion within the study.

However, comments about General Practitioners were rather negative, to say the least. The common felt opinion was that, "General Practitioners should at least know the basics," Remarks like that only promoted a distrust and lack of faith with the General Practitioners. It did highlight any area of concern that being the inability to obtain immediate information on renal transplant issues. Perhaps organizations like Australian Medical Association and Kidney Foundation could address this need.

In terms of trust and faith in God, one issue that was raised should be considered more carefully. That is, "Why would God allow somebody to die just to give me a kidney?" This was expressed by one participant, but

with that one participant representing one sixth of the study participants, perhaps this is a common opinion felt by many other renal transplant recipients. If so it should be given more consideration and not pushed aside.

## APPREHENSION AND MOOD CHANGES

If one is to believe Juneau (1995), apprehension and mood changes co-exist and are linked together in the case of the renal transplant recipient. Juneau (1995), wrote that if a renal transplant recipient becomes dependent on dialysis, it is the impetus for non-compliant reactions for a renal transplant. This shows a desire for the recipient to want to return to dialysis. She writes that the recipient "develops a sense of dependence on the dialysis machine and staff because without the machine and staff the patient would not survive. Some patients enjoy this sense of dependence... (p.63)" Juneau continues to say that, "individuals who have the propensity for dependence may transfer their dependent focus to some member of the transplant team. It is conceivable that extreme dependence on dialysis may precipitate or perpetuate further machine-dependent behaviour, resulting in noncompliance. The transplant patient may prefer to be dependent on the dialysis machine, become noncompliant with dietary or medication regimens, and eventually experience graft rejection, necessitating a return to dialysis... (p.63)"

Although this response can be seen with regards to Eric, Daryl and especially Maria, as a possibility, this being based on their questioning of

the benefits of their medication regime; this study did provide evidence that Maria missed the company of friends when she left dialysis. This could support the claims made by Juneau. In terms of mood changes Kaplan and Saddock (1988), comment, "Mood may be normal, elevated, or depressed. A normal individual experiences a wide range of moods and has an equally large repertoire of affective expression: he feels in control of his moods and affects (emotional state.)"

The key factor here is, "in control of his moods and effects." This might be questionable particularly regarding episodes with Eric, Karl, and even Gary. However, mood changes are normal and were frequently experienced by the participants

So, when looking at the feelings of apprehension and the mood changes that the participants were experiencing following their transplants, the basis was primarily due to their medication regime and the side effects of these medications. Secondly, but just as significant too their concerns of not really knowing how to minimize the danger of organ rejection. These were in turn linked directly to how each participant would adjust to a life with a donor kidney. Just how this was achieved can be seen in the transcripts taken directly from the participants during the course of their interviews.

Initially Maria could not fully understand why she was given a donor kidney. She said, "*...I can't still, you believe me in my mind I'm still thinking how did you get a new kidney. Everyone who are the same me all people in hospital everybody happy like me everyone.*"

There was an air of uncertainty about, whether Maria felt comfortable with accepting a donor kidney. She remarked, "*Before the 14th January, it had been a Tuesday. I'd been on dialysis in the morning, and the same night 14th January Tuesday at 11.30, Professor Brown called me. My son was on the telephone. I'm being up stairs in my room and I take the telephone. Professor Brown tells me, 'I've got news for you', I no believe it. 'I say what news. 'I have news for you.' I say I can't believe you Dr.Brown. 'Yes' he said, 'I'm telling you, 100%.'*"

*Interviewer*

*Why couldn't you believe it?*

*Client*

*I can't believe it*

*Interviewer*

*Why?*

*Client*

*You never expect it. I am all time say to people, and some people tell me I'm being more healthy than anybody. That's why I'm being all right ... Yeah, that's what they say. A patient tells me one day your healthy one day you'll get a kidney and I tell the lady one day when I'm lucky I'm not be here. All the time in my mind I no expect."*

During the following interview, Maria expressed concern about weight gain. She was becoming apprehensive about eating food because of this. Maria stated,

*"Before on dialysis I like to drink and drink in day a good 800ml, 2 full glasses say up to you drink tea and water and drink that's all very hard, but me everyone put in from Saturday afternoon to Tuesday morning six to seven kilos, do you believe that, me never put on only two kilos.*

*Interviewer*

*So you've never gained weight, excessively, over two kilos?*

*Client*

*No, I push myself, 'I'm not drink, I'm not eat."*

Her final interview saw Maria still apprehensive about her transplant, but happy.

She was asked,

*Interviewer*

*Are you happy that you had a transplant?*

*Client*

*Yes. I am very happy that I had a transplant. But, I'm still in my mind, I tell Dr. Kelly, "I miss the company, I miss all the people. Many times on Saturday morning I wake up and think I have to go on the machine." Once when I was on dialysis a man who was seventy and looked healthy told me that from sixty five years of age you could not have a transplant. I worry about that, and that's why I think I am lucky to have a transplant."*

However, Maria was becoming increasingly upset with her weight gain, and was becoming apprehensive about taking the medication. She commented, "...

*Tablets problem. I tell you, last time when I went for blood test the doctor said you are so lucky being not fat. Others tested were big and plumpish. One man I know put on nearly fifteen kilo and he is still young. That is to fat. Now I find myself fifty - six kilo is a surprise. Perhaps I am getting like him. I cried and the man said no, no you are nice, you are looking alright. I said no, no I'm looking too fat. I'm taking to much Prednisone, over one hundred milligrams.*

*Interviewer*

*Is that more than you use to take?*

*Client*

*It's now gone down just a little bit. But still, I'm not happy to be fat. I've never been in my life. Fifty-six kilos. all the time I've been forty eight kilos no more."*

Maria would comment continually throughout the interview that, "I have not been sick since the first day of my operation." She was asked, "Are you worried about being sick, yourself? Then, Maria's disposition changed to despair. She remarked, "No. I don't worry."

Gary who was apprehensive about lifting remarked "... I'm still not allowed to lift weights cause I've got a tender wound. That's only because one of my cuts from the CAPD dialysis when they took the catheter out, burst open.

*Interviewer*

*How is it now still seeping?*

*Client*

*Still seeping a tiny bit at the moment but it's nearly fully healed, so I've just been told not to lift anything heavy.*



Concerns about lifting were further stated during the next interview when Gary spoke about his work. He comments, "...they won't let me lift tables because the tables are pretty heavy and I sought of get use to that. I use to like getting in to things myself, that I am a boss, I pass the buck you see, I don't really have to because they realize and they just do it for me anyway. Like any heavy lifting or that."

Apprehension, about lifting was further stated during the final interview, "... I have still got to be a little bit careful because I still feel a bit of pressure around the kidney area. So I'm not lifting any great things or anything. I use my common sense and don't over do things".

Additionally, apprehension was expressed about the thought of undertaking exercise. Gary remarked..." At the moment I don't think I'd worry about exercise. I couldn't do a lot of exercise with the strain still around the kidney area at the moment. I don't know if I'd do it damage but I wouldn't do it any good.

*Interviewer*

*How long do you think that strain will last for?*

*Client*

*I really don't know. I'm quite aware that it's there and I've got to use a bit of common sense. You don't over do things especially when you've got a transplant in there.*

It was noted that mood swings can at times be attributed to an apprehension, the participant might have. Such was the case with Gary. He spoke "...Sometimes it's emotional when things change. Moods swings, but I don't know whether I can blame that on the pills, or I can blame it on working conditions at the moment. I've had a lot of mood swings lately. I think there's a lot of pressure at work, at the moment. Things even themselves out. I have changed a lot. I'm not mucking about as much as what I use to. Maybe, I'm matured a bit.

*Interviewer*

*Do you like that?*

*Client*

*I was thinking about that the other day. My character when I was on dialysis I use to really muck about. Maybe because I had the attitude, I don't know what's going to happen tomorrow, so I'm going to make the best of each day. Now, I seem to be back in the real world.*

*Interviewer*

*Do you like your attitude?*

*Client*

*I use to like before, actually. Like treating each day as a joke. Without being a "village clown," or anything. I really made sure I enjoyed each day, but now I'm getting on the serious business side of it again.*

*Interviewer*

*What do you mean by serious?*

*Client*

*I think the business is changing a bit, so I sort of have to change a bit too; get a bit more serious. Where going through management surveys of how to run things and all. I tend to think I really know how to run things but we've got these so called experts in, trying to change every routine. There're times efficiency people, I've talked to others in other industries and it drives everyone crazy when it comes. You tend to wonder, do they know what they are doing. They know how to upset the calm. The young up and comers, they think, they know the world. That tends to cause mood swings. Things will even themselves out when people wake up to themselves and get back it the running. The clubs are a fun game to be in.*

*Interviewer*

*Your medication? Any effect?*

*Client*

*I think it does. I've been warned that the Prednisone can cause mood swings, but you can't blame too much on that because everyone does have mood swings."*

Karl expressed a strong apprehension about the possible success of his donor kidney. He spoke "... Basically he said to me it was not a good match. I think it was something like fifty percent, and it was probably the best you are going to do, considering your rare tissue type. So he recommended that I take it. He (Dr.Kelly) said that he cleared it with Dr. Threw. Dr. Threw actually rung me last year with one but advised me not to take it, so I didn't. This kidney came up, apparently there were others that I did not know about that had been worse. So, they obviously thought that this was going to be the best one I could get. Considering, what else had come up. There had been nothing for six years, then all of a sudden these bad ones come, So maybe they thought this was the best, they were going to do. I said I'd take it, and I did. I was surprised I thought, that I'd be jumping around and carrying on but I just stood still. The doctor asked when could I get to the hospital. I said, " in about an hour." He said "take your time, don't rush." I left pretty much straight away. I got here about eight o'clock; they weren't expecting me till about ten o'clock. They didn't do me till about eight o'clock, the next morning, because they couldn't get the surgeon, or something.

*Interviewer*

*What was going through your mind at this stage?*

*Client*

*I don't know, just hoping that it would work.*

*Interviewer*

*Did you ever think that it would not?*

*Client*

*Oh yeah."*

Karl has noticed that he has been experiencing mood swings, that has caused irritability. Karl speaks, "... I mean if you look at my medications now I'm on fairly high doses cause its only two months since the transplant. Yeah, the thing that bothers me the most is the mood swings, I've been getting mood swings from it.

*Interviewer*

*In what way?*

*Client*

*I've been getting irritable, that bothers me because I was not really an irritable person before but ever since I've had the transplant, I've noticed, and other people have noticed too, that I've been a bit irritable.*

*Interviewer*

*This is just after the transplant?*

*Client*

*Yeah, I was particularly irritable in hospital, but it's been getting better lately.*

*Interviewer*

*Irritable in an aggressive state, or irritable in a non - aggressive state?*

*Client*

*Non-aggressive, just short with people. They might say something.*

*Interviewer*

*You might say something that you regret later?*

*Client*

*O' yeah, not even that so much. You might snap at somebody."*

During his next interview, Karl indicated that his mood swings were noticed by his mother. Karl remarked, *"...Mum did notice mood swings, especially in the hospital. But, I think that was a combination of being in the hospital and the drugs. I always get a bit cranky when I'm in hospital I think everybody does. I was in hospital a month straight without getting out. Then they started letting me out on weekend leave. I think even the nurses noticed me getting a bit cranky, which I normally don't do. If I do get cranky I don't take it out on other people. So if it was the drugs or me, I just don't know."*

However, by the third interview, Karl stated that he was less irritable. He said, ...

*" Less irritable, like I told you I was getting fairly irritable. But, I don't feel that way anymore. That's the biggest change; I'm not as irritable. I'm a lot happier. I'm normal."*

*Interviewer*

*What do you mean, normal?*

*Client*

*Not getting cranky, all the time."*

Karl did not wish to pursue this matter any further, and it was not pursued any further. Karl indicated a concern and apprehension about working.

He explained, *"...There's no way that I could go back to fitter and turning. I think I'd be flat doing eight hours work, any work. I had some work a couple of weeks ago looking after a furniture shop for a bloke. I only just sat there all day, if somebody asked about something, I'd tell them the price. If I had to do anything physical I wouldn't last any more than a couple of hours. Even standing up, after a while I've just got to sit down, and take it easy. Dr. Kelly said it takes about six months before you are back to feeling normal. Definitely, since the last two months, I spoke to you, there's been an improvement."*

Karl further indicated a concern about his eyesight, and was apprehensive about maintaining his vision. He said, *"...I don't know whether it's just before I got the kidney. I got some glasses because my eyesight has never been that flash. So I don't know whether it's actually from the kidney, or from the glasses, but I can't stand to be to long without my glasses now."*

*Interviewer*

*Did you tell the doctor about that?*

*Client*

*Actually, I keep forgetting... I have noticed my eyesight getting worse. I did read something about you've got to have your eyes checked regularly...I did also read in some of the literature on the drugs, that you should have your eyesight checked, fairly regularly after a transplant."*

There appeared to be an apprehension for Eric not to continue his medication. He stated, "*...I still sometimes get anxious and depressed. Sometimes I have mood swings, perhaps like everyone else, but not like I was before the transplant. Before, I liked to go home quickly after work to do the machine. There was too much to worry about with my family. I'd like to take my children to soccer, but I couldn't. I had to ring somebody to pick up my son because I am sick. Now it is different. I am still very tired. There is too much medication and too much drugs that make my body not feel well I told the doctor that I am still tired. Maybe in the future in another two months or by six months the medication will come down. I use to think that my body could not take the medication, but I guess it is."*

During the next interview Eric hinted at being apprehensive about taking his medication saying it imposed restrictions on him. He said, "*...When I was on the machine I was fit and played soccer with my son. Now I can't play with him like I did before. I feel a little weak, not strong. Maybe in the future I'll play with him like I did before, but now I can't. Before when I did the machine at night. I could play with my son in the morning. Now, the medicine makes me not strong enough to play with him."*

Eric at times became quite distressed, and would be calm and then unexpectedly become quite excitable for no apparent reason. He became obsessed with the correlation between a pet kitten and infection, to the point where his mannerism became erratic. He stated, "*We have a kitten. Could I get an infection from it?*

Anna expressed apprehension about leaving her home, even though she stated that now she has more freedom. Anna remarked, "*...I feel now especially since I saw you, that I have freedom. Freedom to go out without the fear of dialysis. But, I'm frightened sometimes. It feels different now when I go out. I'm scared I'll be sick again and put back on dialysis. My sister says it shows when I'm out."*

She stated that her life has changed for the better, but also indicated an apprehension for the future, Anna stated, *"...I'd like something to change in my life. I don't know what. In the past three days I have been feeling upset, and depressed. I get a headache, I don't know why. I try to be a happy person, but later I cry and get upset. This just started happening like this recently. Perhaps its just life. My sisters and brothers are settled with their families, but I'm not settled and they say I'm different because of my kidney problem and transplant. Anyway things will improve. My new kidney is a good friend."*

*Interviewer*

*A good friend?*

*Client*

*Yes. Because of the kidney. I can do everything now. I am lucky to have the kidney. Thanks to my God."*

Daryl was apprehensive about the effects of his medication, particularly regarding his weight increase. Daryl said, *"...Yeah, about seven or eight kilos in only a few weeks. After the operation I can't move, and also I have to eat a lot. Otherwise my stomach feels no good. It feels painful, when I eat it feels better. I do feel it is the Prednisone and I'd feel better with the dosage reduced. My dose now is 15mg before it was 25mg. My Cyclosporine is 15mg."*

He further remarked by saying, *"... I look forward to my medication being reduced. The doctors tell me it will be done gradually over six months. Sometimes I feel like a "junkie," but I must not complain. The doctors said my weight is going up. They cut the Prednisone down rather fast because of this. My stomach is getting bigger and bigger I don't like it. Like a beer gut. Anyway I have a kidney."*

However, Daryl indicated a strong dislike for his medications during his second interview, He stated, *"...The doctors said they will review my medications. I don't like taking many pills, I feel like a junkie. But, I guess it has to be done."*

In his third interview, Daryl's apprehension about his medication is somewhat eased by a slight reduction in Prednisone, but there was uncertainty about the Cyclosporine. Daryl comments, *"... Before, I felt very uncomfortable in the stomach but now its pretty good. My medication is almost the same as before, but the doctor has reduced the Prednisone to eleven milligrams and*

*the Cyclosporine is one hundred and twenty milligrams. The others are almost the same. I find when I'm concentrating, reading something for about twenty minutes I get an uneasy feeling. Sometimes, suddenly my eyes go watery.*

*Interviewer*

*You get watery eyes?*

*Client*

*I've had this for about one month. I have no vision problem but reading something they get easily tired. I heard Cyclosporine can effect eyesight."*

Apprehension about lifting objects was also expressed by Daryl, for fear of harming his donor kidney, and also for concern about peoples' opinion. Daryl stated, "...They welcomed me back and seemed pleased to see me. I told my supervisor that I can't lift the heavy things for a few weeks, and he gave me some small equipment that was easy to handle because my main job is repairing and I can't repair the heavy equipment just yet."

From the study issues pertaining to  
apprehension and mood changes saw:

Daryl was apprehensive about his medication regime and the effects it would have on his health status. Throughout the interviews apprehension about medications was of significant concern. Also, he was apprehensive about lifting objects, particularly at work, for fear of possible damage to the donor kidney. Similarly Eric questioned if his body could endure the medication, and subsequently he became apprehensive about taking it. This was of significant importance throughout the course of the interviews, particularly regarding medication dosages. Apprehension was

also noted regarding contact with pets, for fear of possible infection. He admitted to experiencing mood changes, very briefly during one of the interviews. He stated that he, and his wife attributed this to medication side - effects (particularly Prednisone). The intensity and duration of these mood changes was not known. Maria also was apprehensive about the side - effects of her medication making her sick. However, her greatest apprehension concerning medication was the possibility that she would gain weight. With the possibility of weight gain, Maria became apprehensive about consuming food. At the age of sixty - one years she stated that initially there was apprehension about undertaking a renal transplant. Maria would put on a brave appearance and insist that she had, "no worries." Despite this, she claimed that the transplant felt good, but later Maria was cautious about the future of her new kidney. At that point an element of concern and worry was evident.

Gary was apprehensive about lifting objects for fear of possible strain or damage to the donor kidney. He further stated that he was apprehensive about engaging in excessive exercise, again fearing possible damage to the donor kidney. Gary indicated a concern about mood changes. Gary was troubled as to the cause of the mood changes he was experiencing. He was uncertain if they were a result of medication side - effects (eg



Prednisone), depression, adjustment to life, or a combination of each. He gave the example of being more "easy going and casual," when on dialysis, but since the transplant he was more of the serious type." He enjoyed life more when undertaking dialysis being more of a "clown." Since the transplant life has become serious, and his mood wants to change back to the "clown," but Gary felt compelled to be "serious." For him, life had to be lived one day at a time when on dialysis, because he did not know how much longer he would live. Hence, live life for the present. However, the transplant has given Gary a hope and a future, with life being more certain than before. For Anna this hope and a future also showed signs of apprehension. Particularly, regarding social contact with people and leaving her home, fearing possible infection of the donor kidney due to contracting a virus. Anna, claims that her life had changed for the better, were somewhat overshadowed by her experiencing depression, headaches and crying. Anna indicated that her family believed her to be depressed because of an envy of her siblings who were settled with families of their own. Anna was unmarried, and this was considered unusual for someone in her culture. However, this reason for her depression was feasible but still only supposition.

Karl was extremely apprehensive about the success of his transplant. He was aware that one day his donor kidney would fail due to a poor match,

the difficulties in lowering his high Creatinine levels, and his heavy built. Karl was further apprehensive about working a full day because he could not stand for long periods, and there was concern about diminishing eyesight. Karl, had a long stay in hospital which was probably the cause of periods of irritability that he says were noticed by everybody, especially hospital staff. Towards the end of the interviews, he was notably less snappy with people than previous. These bouts of irritability caused Karl considerable concern. If any methods were adopted to help him with this problem, they were not discussed. He felt uneasy in discussing this. and subsequently this issue was not pursued.

#### Adaptation to feelings of apprehension, and experiencing mood changes:

As noted, from the recipient's responses, the greatest concern to them was the effects of their medication regime. This is followed closely by an uncertainty of knowing how to minimize the danger of organ rejection and the subsequent adjustment to a new life with a donor kidney.

The most significant concern that was expressed by all participants, but emphasized most by Maria, Eric, and Gary was medication. There can be

no doubt that medication does have its draw backs, and it is unfortunate that as to date medical science has been unable to totally eliminate their side effects. These side effects have been experienced by all the recipients and include, unwanted hair growth, weight gain, and yellowing of teeth. The only alternative would be for the recipient to cease medication, which would facilitate organ rejection with the graft dying. Consequently, this would necessitate a return to dialysis together with all its limitations and restrictions that were part of the recipient's life for many years prior to transplantation. The notion of organ rejection has been of great concern with the participants, as they would do anything to prevent this from occurring. That is why there is apprehension on their part, to undertake certain tasks. This sometimes leads to mood changes as they feel restrictions placed upon them. This is particularly evident with, Eric, Daryl, and Gary, with worries about lifting heavy objects. They all emphasize, the desire to ensure that their kidney is not damaged. With somewhat minor restrictions such as lifting causing participant's anxiety, for them having to return to dialysis would be catastrophic. Undoubtedly, this is in sharp contrast to comments made by Juneau (1995), at least on the basis of these six participants. Even Maria, who missed her friends from the dialysis unit, had no desire to return to dialysis.

In adapting to feelings of apprehension therefore result in developing a trust in the nephrology doctors. Unfortunately, it is primarily the only answer and the participant needs a total trust in the doctor, and to some extent the other health care professionals to alleviate any apprehension. The participants should be made aware that mood changes are normal phenomena and will occur from time to time. What needs to be remembered by the participant is the ultimate goal of obtaining a new life free from the rigorous restraints of dialysis. Coupled together with commonsense, and the participants are well on their way to a new and enriched life.

### In Summary

From the study it was noted that all the participants did experience an apprehension of not knowing how to minimize the danger of organ rejection, and there were potential problems with how to live with a donor kidney. It was Gary, who faced perhaps the greatest change in his mental outlook on life. As previously detailed, Gary would view himself as a "clown," when undertaking dialysis. The advent of his new donor kidney has seen a complete new and somewhat more serious outlook on life. Similarly, the adjustments to a "new life," were echoed by Karl who was apprehensive about working because he was unable to stand for long

periods and who admitted to bouts of irritability. Eric and Anna expressed an apprehension about interaction with people and pets, fearing an infection. Daryl was apprehensive about lifting, which was also expressed by Gary and Eric.

It was alarming to see that an element of apprehension about the benefits of medication to health status was being felt among the participants. This is especially true of Maria who questioned the role of her medications in causing weight gain. Excessive weight gain was becoming a significant area of concern for Maria. Similarly, claims by Eric that he felt less tired when on dialysis compared to post transplant, prompted him to openly question the benefits of his medication. Despite this, claims made by Juneau (1995), that this is indicative of a person wishing to return to dialysis, were totally unfounded with respect to this study and its participants. Everybody within the study expressed strong anxiety at the thought of ever having to return to dialysis.

Ultimately what is required, is for each participant to have a complete and absolute trust in their nephrology doctor, and the utilization of a little common sense on their behalf. Where appropriate, facilities to counsel and educate transplant recipients should be established, which in many circumstances is non-existent.

## **SLEEP AND BLADDER HABITS**

It must be remembered that the participants, prior to undertaking a renal transplant were receiving dialysis. This period of their respective dialysis treatments varied from three years to seven. What this means is that during that pre-transplant period each participant had a total kidney function of much less than fifteen percent of that of a non-renal disease person. This is quite clearly described in the terminology End Stage Renal Disease (ESRD), which literally means no kidney function. The implication being that the individual is unable to urinate, and subsequently requires either haemodialysis or Continuous Ambulatory Peritoneal Dialysis to filter and eliminate waste products from the body, because the person with ESRD has no "functioning kidney" to do this. Quite simply, it can therefore be easily understood that fluid intake restrictions, should apply for the person with ESRD, because the filtration of by products with artificial devices is not as proficient as with a normal functioning kidney.

Once a person has received a renal transplant, many of the previous fluid restrictions are not necessary. The person sometimes is encouraged to drink fluids, to help promote the proper functioning of the graft kidney.

With the person not using a toilet for many years, the dilemma of having to urinate by oneself can initially be quite a shock. Having to drink fluids, experience a full bladder and then having to visit the toilet is somewhat a new experience for them. They are faced with an uncontrollable bladder as they try to come to terms with their new kidney. Sometimes if the kidney does not filter fast enough, fluid retention can occur. This was particularly experienced by Daryl, and Karl. Gary complained of a swollen stomach which is also characteristic of fluid retention. The problem is usually solved with a course of Diuretics that in turn promote increased frequency and a greater use of the toilet. With all this increased activity embarrassment might occur, as stated by Maria and Anna. In addition to embarrassment, alterations to sleep patterns and tiredness are not uncommon, for a person tends to urinate more at night. This was true for Maria, Anna, and Karl, who found it annoying to be awoken several times at night.

It is therefore readily seen, that the changes in bladder habits and the alterations in sleeping patterns that were experienced by the participants, were based on the introduction of a donor kidney to the participant, This required the body of each participant adjusting to the donor kidney, for the donor kidney to become a "real" part of the recipient's body.

This is further explained with reference to the transcripts taken from the interviews of the participants;

Maria was looking tired, and when this was commented upon she replied, *"Maybe not sleep. I'm going to bed at 10.10 pm, wakeup at 12 pm go to the toilet, second time 3. 00 am again, all the time."*

*Interviewer*

*You go to the toilet a lot?*

*Client*

*Oh. Yeah."*

She went on to say, *"Me no mind, sometimes."*

During the course of the following interview it was becoming apparent, that Maria was becoming annoyed with disturbances to her sleep pattern, She commented, *"When I go to bed, I wake up three times and have to go to the toilet. That is a nuisance."*

Gary stated that he takes fluid overload, and fluid output very seriously and is always ready to mention it to the doctors. Gary remarks, *"Well I always mention and consider quite importantly the fluid overload. I notice when I'm working, my stomach really goes up by the end of the day."*

*Interviewer*

*What do you mean goes up?*

*Client*

*Well, Holds a lot of fluid around the scare tissue of the transplant and the legs always tell the tale where you get swollen ankles and all. They're not to bad but they're definitely a lot bigger than when I first started work."*

*Interviewer*

*So the swelling is getting worse?*

*Client*

*It hasn't changed. Put it that way."*

*Interviewer*

*Do you find yourself running back and forth to the toilet? Regarding your fluid output?*



*Client*

*Only at night really. I go quite regularly to the toilet. Mainly at night it seems to go about four or five times a night.*

*Interviewer*

*Do you think that it's pretty odd that it just waits till the night time?*

*Client*

*The kidney must have been a night owl."*

Gary expressed a concern about pressure around the stomach and commented".... *The pressure comes around the scaring tissue. No really where they inserted the kidney, where they inserted the peritoneal catheter. But, the Long scar down your stomach seems to have a bit of pressure, and a little pressure around the old kidney when I seem a bit bloated. It's not painful or anything it's just sort of pressure around it. I'm sure everything is OK, just gets so bloated that's it.*"

Although he tried to push it aside, Gary did show concern about the effects of this pressure on his bladder and his swelling feet, which Gary felt were interrelated. He said, "*... there's no pain just a little bit of swelling in the feet. The legs go up a little bit. When I go home to bed by the time I wake up it's gone.*"

During the third interview Gary spoke about feeling a strain around his "old" kidney. Gary stated, "*...I feel a bit of strain around the old kidney. I keep telling Dr. Trew that, and he seems to be happy with it. There is a lot of strain around the old kidney even during the daytime. But, I don't think there's much wrong with it. I tend to think, if there is a strain there, there must be a reason for it; being close to the bladder and everything. Sometimes at night it's sore, and it feels like a sought of a full bladder around the old transplant area. It's still kicking and it hasn't really given up the ghost or anything.*

*Interviewer*

*Speaking about a full bladder. How have you been going in toileting?*

*Client*

*Goes pretty regular. It wakes me up in the middle of the night a couple of times still. It's not as fierce, like it was at the beginning of the transplant where it was consistent on the hour. About two times a night, it can't hold as much as a normal bladder. I suppose the kidneys are fighting. The old one is still ticking and I've virtually got two new kidneys around that area. I don't think that scar tissue where he took the peritoneal catheter out will ever heal this time around. It's just been open to many*

*times. There's been a lot of pressure there. I know it's a bit weaker than any other part of my body. It's been open at least eight times, probably more. You can feel little lumps here and there. It's just something to be aware of. I know it's impossible to pop open or anything, but it's still a weak part of the body.*

*Interviewer*

*What did the doctors say about that?*

*Client*

*Ah, there're quite happy with it. I remember the surgeon checking it, when I was having trouble with it. He said, "Well it's been open that many times that you've going to have trouble with it. It's going to take a long time to repair because of that." They kept on going over the same cut over and over again. I should of had a zipper on it."*

Concern about swollen feet had diminished by the time of the third interview. Gary spoke, "*Still a little bit swollen, when I'm working. Still holds a bit of fluid but they're (the doctors) quite happy about it. They're always keeping a check on that.*"

For Karl his initial concern was regarding fluid retention. He spoke, "*Ah, he put my Lasix up today because I was retaining a bit of fluid. He thinks that's from me eating a bit to much salt.*"

A concern for irregularities in sleeping was stated by Karl. He said, "*... What happens now is I get into a bad pattern because I be in bed till about two o'clock and then I'll nod off. But the problem is I'll get up late, because I don't have to be up for anything. I'll just be in bed and sleep. So I get up late anyway. That means I don't really feel like going to bed till late again the next night. This morning I fell asleep at about two o'clock, and I was up again at six.*"

Sleeping was of further concern for Karl during the final interview. He remarked, "*I had trouble when I was on the machine, being sleepy. It seems to be a little bit more consistent now that I can't sleep. So, generally the next day I'll be tired to get up and go to TAFE, but that's getting better since I've started exercising. Trying to lose some of the weight, so that might be contributing to the tiredness a bit.*"

Problems arising from the bladder were now being of a more significant concern for Karl. However, he was quick to indicate that there has been an improvement. Karl commented, "*Getting better since I've been exercising, and drinking the water. Increased output, going to the toilet more often. I still get the*

*odd pain, not when I'm going to the toilet but its like twitches around where the scar is I don't think it is actually in the kidney, it's just in the scar.*

*Interviewer*

*Have you been noticing that the new kidney is there?*

*Client*

*Yeah. It is still a bit lumpy. Still a bit of a lump there.*

*Interviewer*

*What was the response from the doctors about that?*

*Client*

*They said that it usually takes about six months to go away. So it's coming up to that time. It's better and what's probably more pronounced to is the weight. But, it's getting better."*

Anna experienced problems with her bladder. Anna claimed this resulted in sleepless nights, and acted as an inducement to consume foods. She explained, *"The toilet. I'm going to much I wake up at night lots of times. I wake up at 6.30 - 7.00 every day. Even during the night. I want to sleep, but it won't let me. When I can't sleep, I just lay there and soon my body wants some food I want to eat."*

During her final interview Anna indicated that two months earlier she was embarrassed about needing to use the toilet. She commented that now she was not embarrassed, and attributed this to a reduction in medication. She stated, *"Not embarrassing. It's much better now. Before I go to the toilet at night too much. I think it's because of the medicine."*

Anna revealed that her sleeping pattern was irregular. She stated that she felt tired and wanted to sleep, then at times she was unable to sleep. Anna said, *"I do feel more energetic. I can go out in the morning but sometimes I feel tired. When I'm doing some work or just standing, I sometimes do have enough energy. I have to sit or lay down. See at Easter I went to my sister's house, and stayed there. She is always very active. I had to do everything with her. After one day I feel very tired and I wanted to go home just to relax. I didn't want to , and couldn't do anything. I needed to relax. I slept and slept."*

*Interviewer*

*Do you sleep easily?*

*Client*

*Sometimes. Sometimes I'm tired, can't sleep and then drink coffee. Probably this keeps me awake. I don't know."*

**Daryl expressed concern about fluid retention. He remarked, "I have a little fluid retention, after I go to work because I sit a lot. I come home and by morning it's gone. But, the doctor said it's OK. I was concerned because with only one kidney, and not two, my kidney has twice as much work to do."**

**During the next interview Daryl was feeling uncomfortable around the stomach. He stated, "I'm so uncomfortable around the stomach as it was before. But, if I do exercise I feel uncomfortable. A little is alright. I have an uneasy feeling around my stomach. It sought of makes me feel bloated. When I drink water, I have to go to the toilet almost straight away. It feels very uncomfortable, a lot of pressure and uneasy."**

*Interviewer*

*Do you go to the toilet a lot more times, than you did before?*

*Client*

*Yeah, I hope so. It depends on how much I drink because in the morning before ten o'clock I drink about one litre of water. I have a meal in the morning and mostly drink water. I like to eat mostly fruit. I use to only eat one piece of fruit per day. Now I'm eating about four or five pieces of fruit per day."*

**Daryl continued to comment, "... The transplant is good, but it makes my stomach feel bloated. I'm not use to having to go to the toilet all the time. Sometimes I'll go once or twice each hour. Sometimes in the afternoon between three o'clock and five o'clock I go four or five times. I don't like that much, people see me running to the toilet all the time."**

**He concluded by saying, "... At least I can drink more water. On dialysis I could not drink much. Now post-transplant I can drink much water. I'm not use to drinking much water because on dialysis I had fluid restriction."**

In the final interview Daryl indicated that his stomach was feeling better. He stated that, "*... Before, I felt very uncomfortable in the stomach but now its pretty good.*"

From the study issues pertaining to sleep and bladder habits saw:

Maria indicated that there was an increase in fluid output and frequency, particularly at night. This was an embarrassment for her, for she did not want people to notice her going back and forth to the toilet. Maria further stated that she was always tired, and endeavoured to hide it from other people. She claimed to be awoken at least three times at night, due to a need to use the toilet. Maria did not want anybody to see her tired, perceiving that this would show weakness.

Like Maria, Anna was initially embarrassed about urinating at night, and difficulty in sleeping because of this. Anna blamed her embarrassment on her medications, and by the time of the final interview frequency and output of urine had decreased significantly. She also expressed concern about irregularities in her sleeping pattern.

Gary also, felt embarrassed about passing excessive amounts of urine. He complained about feeling pressure around the wound site as well as swollen legs and a swollen stomach. During the final interview Gary stated that, his output was down from twice hourly-to-hourly. However Karl, was initially inconsistent and irregular. Fluid retention was of concern and Diuretics were administered. Karl's fluid output did increase, according to him as he had stated, during the final interview. Additionally Karl, indicated difficulty in sleeping, and a lack of strength and energy during the day. This was despite him keeping his mind and body active, by exercising and attending TAFE classes. Similarly Daryl, claimed that he had experienced fluid retention while sitting at work. By night time he would be up urinating. Daryl stated, that he felt uncomfortable around the stomach, felt uneasy and bloated, and was embarrassed. He added that. after drinking water he felt an urgency to use the toilet.

#### Adapting to changes in bladder habits and sleeping patterns:

Unfortunately, there is nothing that can be done except to let nature take its course. If the donor kidney is functioning properly and showing no signs of rejection, both bladder habits and sleeping patterns should be "normalized," and the participant will become more comfortable. It was noted that around six months post-transplant, that the participants had

developed greater control of their bladders, and their sleeping patterns were beginning to be less disturbed, particularly at night.

#### In Summary:

It was noted from the study, that irregular bladder habits and altered sleep patterns were normal for the participant who underwent a renal transplant to experience. At times the participant might experience some fluid retention, as did Daryl and Karl. Similarly, embarrassment of having to use the toilet at regular intervals is possible, as stated by Maria and Anna. However, around six months post-transplant the donor kidney "becomes" a part of the recipient's body. Subsequently, both bladder habits and sleep patterns become "normalized."

## PHYSICAL APPEARANCE

It is noted that all the participants expressed concern about their physical appearance. In order to validate the significance of this theme, it will require further discussion and the breaking down of the Theme into Sub - Themes. Only by doing this can the richness of the data become visible to the point where saturation is attained, as each minute detail is examined.

The Theme has been broken down into the following Sub - Themes;

- (a) Complexion.
- (b) Weight Gain.
- (c) Hair Growth.
- (d) Swelling.
- (e) Teeth Yellowing.

(a) Complexion:

The significance of complexion is that it is determined by skin pigmentation. The skin of a client with chronic renal failure (CRF) has a pale gray or yellow brown appearance, depending on the premorbid pigmentation, as stated by Daugirdas and Todd (1988). They continue to say that darkening of the skin can be observed in dark skinned clients,



whereas in some fair skinned clients, tinting of the skin might conceal anaemic pallor. The uraemic pigmentation is attributed to retention of urochrome pigments and increased melanin production. Neither Haemodialysis or CAPD is effective in correcting the altered skin colour.

Additionally, haemosideroses can lead to darkening and brownish coloration of the skin. This is seen in clients who have received numerous blood transfusions with resultant iron overload.

Correcting of this altered skin coloration in CRF clients is usually possible following a kidney transplant. This change is expected, and usually all recipients will experience some type of colour change.

Maria, Gary, Karl, and Anna, were most prominent within the study about their experiences regarding complexion.

Maria, who was sixty-one years of age, and who gave the impression of someone who took extra pride in her appearance, was overjoyed with the new skin pigmentation that the transplant had given her.

Maria, developed a mild suntan complexion that was present during her first interview, darkened slightly in colour, during her second interview,

and her new colouring was unchanged at the time of her third interview.

Regarding her new complexion, Maria was delighted, ".... it makes me look younger." and she would comment on her complexion, "making me healthier."

In many respects, Maria is what you would expect all recipients to be like. That is, having a mild suntan complexion and looking younger. In fact you could even remark that Maria is representative of all the recipients. However, this image painted by Maria, could hardly be appropriate to Karl and Anna. Even Gary did not entirely fit into the picture painted by Maria.

With Maria being overjoyed, Gary was somewhat cautious about his new complexion. Like Maria, Gary within two months post transplant developed a mild suntan complexion. However, by the time of his third interview Gary experienced a redness in the face that was present around eight o'clock at night and would disappear within a couple of hours.

*Interviewer*

*Comments about your skin colour?*

*Client*

*Always get comments about that. They say that you have a nice colour. People see it better more than what you do. When you're pale they don't tell you. When your colour comes back to normal they tell you. Sometimes they tell me later that I use to look half dead. They mention how red I am and how much colour I've got now. I sometimes go really red about eight o'clock every night. The Prednisone works and I go really red in the face when I'm working.*

*Interviewer*

*How long does that last for?*

*Client*

*About an hour. I take the Prednisine in the morning. It seems strange about eight o'clock at night I just say to people that its one of the drugs again.*

*Interviewer*

*Comments from the doctors?*

*Client*

*No. They just give a little laugh.*

*Interviewer*

*Is it getting worse or better?*

*Client*

*About the same. It gives me colour. No redder than some of the people there who drink a lot. I happen to look in the mirror and it happens every night at about eight o'clock I could be more agitated then because it's the peak hour, and maybe a little bit tired. There's nothing I can do about it anyway.*

This phenomenon was unique to Gary, and not experienced by any of the other participants. Whether, it was due to this being Gary's second transplant was unknown, but that explanation would give an understanding as to why Gary was the only participant in the study to have this experience. Gary believed it could be due to his Prednisone, but this was not substantiated. Reviewing articles, and consulting a Nephrology Specialist were unable to give a substantial answer to Gary's plight. Although, he later laughed at the experience, it was becoming apparent that Gary felt a strong embarrassment, and disappointment from being unable to find a satisfactory explanation to his plight.

In many respects Karl was different to the other participants within the study. Karl's mild suntan faded dramatically just after two months post transplant. This is extremely uncharacteristic both in comparison with other participants and also with regards to kidney recipients in general.

It is appropriate to understand a little about Karl's situation regarding his transplant as it might provide a background in explaining why Karl was so different to the other participants. The following extract might shed some light on this;

*Interviewer*

*Did he give you a rating; for your kidney? Do you understand the "rating" system?*

*Client*

*No, I don't really understand the rating. Basically he said to me it was not a good match. I think it was something like fifty percent, and it was probably the best you are going to do, considering your rare tissue type. So he recommended that I take it. He (Dr. Kelly) said that he cleared it with Dr. Threw. Dr. Threw actually rung me last year with one but advised me not to take it, so I didn't. This kidney came up, apparently there were others that I did not know about that had been worse. So, they obviously thought that this was going to be the best one I could get. Considering, what else had come up. There had been nothing for six years, then all of a sudden these bad ones come, So maybe they thought this was the best, they were going to do. I said I'd take it, and I did.*

It was revealed that Karl had a poor donor kidney rating. The circumstances stated above, coupled with Karl's heavy build, would tend to indicate that he was on a more intense medication regime compared to the other participants. Karl was also fair skinned. To what extent these

factors attributed to Karl's somewhat dramatic fading complexion was uncertain. An explanation was unknown.

Anna only experienced a very slight mild suntan complexion that was barely noticeable, but remained consistent. She had the opinion that she could be spared some of the side effects experienced by the other participants. Regarding complexion this seemed true. She made a general comment;

*"After the transplant I feel different I'm laughing all the time. My sisters and friends are surprised that after the transplant, I am looking so good. Laughing and talking, not like before. Now, I try to make everyone happy."*

There was a less dramatic change in her complexion, compared to the other participants. Being the only participant to receive a Living Related Donor (LRD) kidney could account for this. It might also be indicative of all LRD recipients, in comparison to cadaveric donor recipients, but this is only supposition.

From the study issues pertaining to complexion saw:

Maria being more than overjoyed about her mild suntan complexion. There is no doubt that this gave her a feeling of contentment and well being. Whether or not this was a placebo effect that it made her feel

healthier or even younger can be taken on face value. What it has done is give Maria added confidence in her day to day life, and her new complexion is a much welcomed change from the uraemic pallor of her skin during the past years when she was on dialysis. In much the same way. Although not expressed so flamboyant as Maria, Eric and Daryl were also equally as pleased with their respective complexions. This is precisely how you would expect all kidney recipients to be.

However, it was revealed that Gary began experiencing his mysterious redness in the face each evening. This posed the question that perhaps it was attributed to being his second transplant. Despite consultations and investigations with "experts." no valid explanation was obtained.

Unfortunately, this was becoming a source of embarrassment for Gary, as other people were beginning to notice. Especially with Gary working in the hospitality industry, and being in direct contact with the public would be distressing, as would any physical alteration.

The dramatic fading of Karl's complexion over a short period of time posed the question as to why this would happen. Reasons could include; a poor kidney match (poor rating), heavy build, or fair complexion. The answer was not known but in an attempt to find one, an understanding of Karl's plight was deemed appropriate. No other participant endured as

much, nor had the physical characteristics similar to Karl. Subsequently, no other participant had their complexion fade either.

Anna felt immuned to the side effects that the other participants were experiencing. In most cases this appeared to be true. Anna's complexion was barely noticeable but remained consistent. She did not experience dramatic, or easily detectable changes, as was the expected characteristic of a transplant recipient. She would remark and comment in a general manner, sometimes appearing to be exercising an air of defiance. Anna was the only participant to receive a Living Related Donor (LRD) kidney, which would seem to account for the differences between her and the other participants. The donor kidney came from her sister, and the matching was very good. However, claiming that an LRD recipient would have differences compared to other recipients is only supposition.

#### Adaptation to changes in complexion:

There can be no doubt that Maria, Eric, and Daryl were more than pleased with their change in complexion. This change was more than welcomed.

An observation of renal transplants has shown that this change in complexion is typical of recipients who had very few complications during the transplantation process. The colour change is usually permanent and will not diminish over time.

For Gary, the mysterious redness during the evening that he experiences is something that he will have to endure with the hope that it will disappear over time. Documentation pertaining to this has not been found, and further consultation with medical doctors has failed to find an answer to Gary's dilemma.

In two studies, one undertaken by Frey (1990), and the other by Hayward et al (1989), that identified and ranked stress factors effecting transplant recipients found a "change in work," rated 19/48 and 17/60 respectively among the recipients that these studies surveyed.

What these studies reinforce is that for transplant recipients a "change in work," is a real fear. No doubt, Gary is stressed about the possibility of a future change in employment due to an unexplained phenomena with his complexion each night. It is unfortunate that something at face value might seem amusing, but can cause so much embarrassment for Gary, and ultimately force him to change his employment.



The differences between Karl's complexion and Anna's complexion could not be greater. Observing Karl and consulting medical opinion tended to suggest that Karl's complexion would not darken but remain as it is. It is assumed that Karl's poor kidney match resulted in fading of his complexion, but documentation of other cases like Karl's was not found. Unfortunately it is apparent that Karl will have to live with his fading complexion. One concern expressed by the doctors was that it could be an indication that problems were arising with the possibility of kidney rejection. Only time, and further observations from medical personnel will determine if this concern is founded or not. This will place added stress on Karl, especially over the next three months.

However, for Anna, she does not have to adapt to any significant changes in her complexion. Being a recipient of a LRD kidney from her sister, has meant that the kidney match is almost perfect. Obviously with fewer complications, you would expect little or no side effects. Regarding complexion this is true, a fact that Evans et al (1985), would support, in relation to studies of LRD recipients compared to Cadaveric donor recipients. With this in mind Anna would appear to have a relatively "trouble free" future.

(b) Weight Gain:

Next to complexion, perhaps weight gain was the most significant alteration to the physical appearance of each participant. This would account for the recipient being encouraged to follow a balanced diet.

There are several reasons why it is important for the recipient to ensure that they are consuming a well-balanced diet after their kidney transplant. Anti-rejection medications can change the body's needs for certain nutrients, (O'Shaughnessy, 1991), specifically increasing the requirements for protein and calcium. Anti-rejection medications can also result in changes of appetite. Those people taking prednisone usually experience an increase in appetite and may as a result have problems with weight gain. Those taking Cyclosporine A (CSA) often have reduced appetite and may have problems with weight loss. Diet can help maintain blood pressure, blood sugar and cholesterol levels within the normal limits. Some donor recipients may experience elevations in blood pressure, blood sugar and blood lipid (cholesterol and triglyceride) levels after transplantation. A well-balanced diet that aims to be reduced in salt, sugars and fats is helpful in keeping those levels within the normal range. Most people prior to kidney transplantation are following a special diet. Re-introducing previously restricted foods into the diet can be difficult,

particularly if they have been avoided for several years. Many people are also confused as to what constitutes a balanced diet

It is also common for transplant recipients to develop a taste for some foods that they previously showed a disliking for.

Daryl developed a taste for potatoes and a liking for European foods. This is particularly significant, bearing in mind that Daryl is of Chinese origin and prior to having the transplant he would much prefer Asian foods.

Daryl even commented ".... my eyes are becoming round." Cultural concerns were becoming a problem for Daryl, who was being encouraged to eat more foods by his friends who commented that Chinese men should be fat. Whether or not this is true of his culture, Daryl did increase his food intake initially following his transplant. However, he was put under strict instructions not to increase his weight by his specialist, who also was of Chinese origin. Daryl explained;

*"It is because the doctors tell me not to get too fat. I try to stay lean. I try not to increase my weight anymore. It's easy to become a diabetic if I get fatter and fatter. That's what the doctor told me. It worries me." He continued, "I'm really scared that I will put on more weight. I try not to eat to feeling full. Only about seventy -percent fullness I also eat a lot of fruit. People say I look better since I had the transplant. They say my face doesn't look bony."*

Daryl had a fear of becoming diabetic and as such he would, ".... only eat

to seventy percent fullness." This meant that Daryl would always keep his stomach partially empty, and try to suppress his appetite. Despite these measures Daryl did have an increase in his weight.

Concerns about weight gain were expressed by Maria;

*Interviewer*

*How have you been feeling lately?*

*Client*

*When I go to bed, I wake up three times and have to go to the toilet. That is a nuisance. I still go on walks. I am not eating much. I'm very careful cause I'm putting on weight. I tell Dr. Kelly that I don't believe it. I'm not eating sugar now. Drinking coffee early in the morning with soy milk, and having light cottage cheese too, with vegemite and a light biscuit for breakfast. At lunchtime I eat nothing. Really, I start to eat carrots six, seven eight a day. Do you believe me and he says "don't eat too much carrots." I tell you, if you in the house all day you will always eat. That's why I eat carrots so I won't gain weight, and I exercise, and go to the shop. Other meals I like chicken breast without the skin. Still since hospital I never eat potatoes, not mashed or baked.*

*Interviewer*

*Are you going to try potatoes now?*

*Client*

*I don't know. Perhaps I will. I have salad with no oil, no vinegar, nothing. Sometimes I'm making lunch at 1.30. After 1.30 nothing until breakfast. Nothing, can you believe me.*

*Interviewer*

*Don't you feel hungry?*

*Client*

*I don't feel hungry, but if rarely I like something to eat I eat one apple, three carrots and one drink of tea. A bit of milk perhaps.*

She stated, ".... I do not like being fat."

After being asked, "Do you still miss going to dialysis," Maria continued;

*Client*

*It's still hard for me to believe it. I miss my company. When they see me they say, "you're lucky you're looking very good." They say, "Do you like you can eat and drink anything now?" I tell them, "I'm not sure and I still need to be careful."*

*Interviewer*

*You do?*

*Client*

*Oh yes. Tablets problem. I tell you, last time when I went for blood test the doctor said you are so lucky being not fat. Others tested were big and plumpish. One man I know put on nearly fifteen kilo and he is still young. That is to fat. Now I find myself fifty - six kilo is a surprise. Perhaps I am getting like him. I cried and the man said no, no you are nice, you are looking all right. I said no, no I'm looking too fat. I'm taking to much Prednisone, over one hundred milligrams.*

*Interviewer*

*Is that more than you use to take?*

*Client*

*It's now gone down just a little bit. But still, I'm not happy to be fat. I've never been in my life. Fifty-six kilos. All the time I've been forty-eight kilos no more.*

By the time of the third interview Maria's weight gain was evident. So obsessed with lowering her weight Maria reduced her food intake to a bare minimum of little more than consuming carrots, to the point of not consuming lunch. However, she was dismayed to see her weight still increase and she would comment that, she could not believe it.

Karl had a somewhat philosophical approach about weight gain. He claimed that losing weight was easy for him. His approach was;

*Interviewer*

*So you have increased weight since last time I saw you?*

*Client*

*Yeah, since last two months about four or five kilos, possibly.*

*Interviewer*

*Does that bother you?*

*Client*

*Ah, its easy enough to lose weight. The only reason I'm putting it on is because I'm taking the steroids that make me feel hungry. So I eat. I'm probably not fit enough yet to do enough exercise to get rid of it, but I know once I get fit enough I can lose it fairly quickly.*

*Interviewer*

*How about your diet? Your taste for foods? Has that changed at all?*

*Client*

*Probably been eating a lot more sweet stuff than I had when I was on the machine (haemodialysis). I lost the taste for sugar I didn't like cakes or lollies, didn't eat much of that. Now, basically if it is there I'll eat it.*

*Interviewer*

*Last time I saw you, you said that you are eating a lot of eggs in the morning. Something that you were not doing before.*

*Client*

*I've cut them back actually, because I thought well that's probably one of the things that might be putting me on weight so I cut them back. I only eat them a few times a week now, whereas I was eating them nearly every day. I have also cut back in the last couple of weeks the amount of sugar I've been eating. See when I had a cup of coffee, I started drinking a lot more coffee because I can drink. Probably have three cups a day now, and I had it very sweet, so I cut out the sugar. I've started putting those sweeteners in it; just to see if that can knock back a bit of weight. I have lost a bit actually in the last couple of weeks. That's with walking, cutting back with food. As I say, the steroids are starting to come right down now. So, it will come off. Try not to get to concerned there.*

Karl tended to push the issue of weight aside. This was probably due to his heavy build and a lifetime of fighting excessive weight gain. At times it was difficult to determine if Karl had increased or decreased his weight, despite his eagerness to do so, and his stated willingness to undertake exercise. However, despite Karl's sometimes-brave exterior, he vividly remembers the pain suffering, and unsuccessful transplant attempts he has endured. Keeping this donor kidney means everything to him, as stated

by Karl saying, "Anything is better than going on dialysis."

Although developing a strong liking for chocolate following his transplant, Gary actually lost two kilos in weight, while still craving for chocolate.

*Interviewer*

*How about chocolate? Do you eat chocolate now?*

*Client*

*Do you remember that?*

*Interviewer*

*Yes, I remember that.*

*Client*

*Still got a bit of a chocolate craving, trying to get off it. It's not easy. I like honeycomb bars.*

However, by the time of the second interview Gary was gaining weight, which further increased by the time of the third interview. Gary would comment; "This kidney feels good, and I don't want to lose this one." The prospect of losing a donor kidney was more than a strong incentive for him to reduce weight.

This was Gary's second transplant, and he was the only participant to initially lose weight, posing a question of correlation between a second transplant and weight decrease. Scientific research might one day be able to prevent excess weight increase if a study was to find weight loss

among other second renal transplant recipients and adopt its principles to first time transplant recipients.

From the study issues pertaining to weight gain saw;

Daryl being put under pressure from some of his family and friends regarding his Chinese background, who claim that Chinese men should be heavy in weight, to the point of being overweight. Whether this was factual in relation to oriental culture, I am not certain. However, it did appear to have some bearing on Daryl to the point of irritation, but Daryl was determine as best as he could to keep his weight down. Perhaps this was his family and friends way to show support and encouragement for Daryl, by adopting a type of reverse psychology approach.

The opting for the reverse psychology approach might also have been used by Daryl's nephrologist, who went out of his way to put the fear of diabetes into Daryl's mind. It is true an excessive amount of sudden weight gain can be one causal factor for a person developing diabetes, particular for a person with a history of renal disease: However, I would find it unrealistic to say that Daryl on the evidence of increasing weight would develop diabetes. It would be expected that Daryl, a renal transplant recipient, will have weight increase, through a combination of



medication and diet. Except on very rare occasions, weight gain is unavoidable. I consider the excessive threat by the Doctor to say that Daryl could contract diabetes, to be at the least very stressful and worrying for Daryl. I consider it to be "unnecessary stress," which for a transplant recipient is unwanted, indeed.

Maria, was a women meticulous about her appearance, and especially her weight. You can see how Maria tried everything in her power to keep her weight down, so much so she almost reached the point of starvation.

What Maria experienced was considered to be the normal response to a renal transplant. I'm glad that her Nephrologist did not introduce the threat of developing diabetes to her. It would have been catastrophic, bearing in mind the fanaticism that Maria had about losing weight.

Karl's problems and hardships he endured just to obtain and keep his donor kidney were highlighted. The ever real possibility that Karl would gain much, to excessive weight was offset by his blasé approach to weight gain. However, underneath this exterior was a real fear of losing his kidney, for he would often remind me that, "Anything is better than going on dialysis."

Gary's remark that, "I don't want to lose this one," was a reminder of the importance that he felt in saving his kidney from rejection. His weight loss was a surprise to him and everyone else, but he was always expecting it to increase. He had a realistic approach to his transplant and saw other recipients gaining weight, and new ultimately that his weight would increase; which it did. The initial weight loss could be attributed to this being his second transplant, but as previously stated, this is not known.

#### Adaptation to changes in weight:

If we are to say that medication side effects are the greatest contributor to weight gain, then this would give a reason for medication - side effects being rated at fifth position in the order of stress factors that influence transplant recipients in studies undertaken by Frey (1990), and Hayward et al (1989). In these studies 48 and 60 recipients were surveyed respectively.

This would indicate that Maria is not alone in her anguish about gaining weight, but it would be hardly comforting for her. It is likely that Maria will have a steady weight increase, until such times as her medication (especially Prednisone) is decreased substantially. Unfortunately it is

something she will have to live with, but I feel it could develop into a psychological problem if Maria cannot adjust to the inevitable.

Probably if Maria adopted Karl's blaze approach to weight gain she might be able to cope better. However, Karl would have more of an obesity problem than merely weight gain. In a study of 660 renal transplant recipients Ohkubo (1995), reported that 90 recipients experienced obesity. Although this represents only 13.5% of the recipients surveyed, it does show that Karl is not alone with his problem.

Gary's initial weight loss and the correlation between this and it being his second transplant could not be substantiated. Literature and medical consultations did not offer any insight. The only certainty is that like Maria, Gary will increase his weight. This is something that he expected anyway.

Conversations with the Chinese community dismissed the notion that Chinese men are encouraged to be fat as nonsense. This would tend to have me believe that it was used by Daryl's family and friends as a type of reverse psychology. Add this to Daryl's specialist who remarked that he could become diabetic with any increase in weight, and we see a very determined Daryl to lose weight.

If these strategies were employed to encourage Daryl to maintain his weight, it did so.

However, I am concerned that when Daryl does increase his weight substantially, it could have a profound psychological effect on him. With Daryl consistently having to be encouraged to lose weight, could be an indication that he might require counseling in coming to terms with his increasing weight.

(c) Hair growth:

Excessive hair growth in transplant clients is usually related to the use of minoxidil or androgenic steroids. Minoxidil ingestion results in growth of hair over most of the body (Daugirdas and Todd, 1988). They comment that, a heavy growth of facial hair covering even the forehead and eyelids can be very distressing to men and women transplant recipients (who liken themselves to apes), and at times they might refuse to take minoxidil steroids.

The use of depilatory creams gives some relief, although these creams can cause skin dryness. Women may decide that shaving is a preferable method of controlling their facial hair. Hair growth accompanying the use

of androgens is not as pronounced as that with minoxidil, but hair growth is still significant.

Unwanted hair growth was identified as a significant problem among five out of six participants, with its onset being within the first two months post transplant, and gradually developing into a major concern at six months post transplant.

Gary stated that the turning into, "...a hairy monkey," was very real. Needless to say that he did not relish this idea, as he had prior experience following his first transplant. He stated ;

*Client*

*They all called me Greek because I had so much black hair on my arms and legs and under my eyelids and I had fluffy ears.*

*Interviewer*

*Did this worry you at all?*

*Client*

*It did at first. I got so hairy I shaved my body twice.*

*Interviewer*

*And so you were very self-conscious?*

*Client*

*Yes. I dealt with people but mainly I think it was me. When I went to sign the poker machine book I'd look at my hand and think Christ I look like a dog.*

*Interviewer*

*So what capacity do you work in?*

*Client*

*I work in hospitality game (club RSL). You deal with people all the time.*

Gary also said;

*Client*

*"... It's starting to grow already. I seem to start to get hairy again. I'll be a monkey soon. Eyebrows have gone deeper, and a lot of hair on my chest. Seems to have start growing like grass."*

Daryl commented that he required, ".... regular body shaving," and he added ;

*"It worries me, because I've never been hairy before. People have noticed this. When I go to the hairdresser he said I have a lot of hair on my face, and its growing everywhere."*

This was particularly stressed during his third interview, and it was obvious that this concern was building up over a period of six months it was now reaching a point of embarrassment for Daryl.

Like Daryl, Eric stated that he was regularly shaving unwanted body hair, but he was much more emotional about the issue of unwanted hair growth. Eric commented;

*Client*

*"Hair growth everywhere. Hope I won't be an ape".*

Of all the participants in the study the only participant not to experience hair growth was Anna. She was the exception to the rule. She stated ;

*"My hair is falling down. It's getting thin. I might lose it. I asked for some iron medication, and I take it now."*

*Interviewer*

*Has that helped you?*

*Client*

*I don't know. All I know is my hair was different before. It was stronger and thicker.*

*Interviewer*

*Has there been any other concerns?*

*Client*

*I was worried about facial hair growth, but it hasn't really happened. I think I don't notice it because I am fair, and if the hairs were black it would show more."*

Although she did not say she had no hair growth, if she did it was undetectable. Indeed, perhaps she experienced her scalp hair thinning slightly. Perhaps, she was losing hair. Anna was the only participant to undertake an LRD kidney transplant, which might account for the contrast between her and the other participants.

From the study issues pertaining to unwanted hair growth saw :

Gary developed deep concerns about his unwanted hair growth. Having experienced a previous transplant Gary had previously suffered the indignity of having unwanted hair growth particularly on the face. Perhaps with Gary now holding a managerial position within the hospitality industry, the prospect of dealing directly with the public and looking like, "an ape," was somewhat daunting. No doubt among the club patrons, where Gary worked, his hairy appearance would cause much discussion. The effects for Gary could be emotional, with him being the

butt of all jokes, or even patrons being excessively sympathetic towards him. The latter response can be more distressing for Gary because this constantly reminds him of his difference to other people around him. This would be similar to the embarrassment that somebody with a physical deformity would have when interacting with other people. Should complaints be made about Gary's appearance, the prospects for further employment in his present capacity might be limited.

Daryl was experiencing unwanted hair growth for the first time. He was naturally upset and distressed about the situation. One advantage that Daryl had compared to Gary was that Daryl was not employed in an area involving direct contact with people. This would lessen some embarrassment for him because the majority of people he would come into contact with would already know him and his situation. These people would be less likely to stare, and make comments about him; and most probably accept him for what he is.

Eric was extremely upset about his unwanted hair growth. Although not readily noticed in his written dialogue, Eric was very emotional with his mannerism and gestures. The impression that he exhibited to his wife and two small children appeared to be of paramount importance. He particularly did not want his son to see any negative side to his physical



appearance or weakness in his personality. Working as a teachers aid and the prospect of being "hairy" at school did not appear to worry him, as you would expect. However, his family's response did.

With the exception of Anna, unwanted hair growth was of concern to all participants in the study, but not as significantly as it was with Gary, Daryl, and Eric.

Anna indicated that she had no unwanted hair growth. She was becoming the exception to the rule, compared to the other participants. She was becoming smug in her attitude saying she was expecting things to happen (e.g. unwanted hair growth), but they never did. It was becoming apparent that obvious differences existed between cadaveric donor recipients and living related donor recipients. However, Anna was the only LRD recipient in this study to draw comparisons from.

#### Adaptation to changes in hair growth:

In the study of 660 renal transplant recipients conducted by Ohkubo (1995), 106 claimed to be experiencing hair loss. From my study Anna stated that her hair was thinning, but not of great concern to her. It would appear that Anna will have some significant hair loss sometime in the

future, and with 15.9% of recipients in Ohkubo's study having hair loss, Anna is not an isolated incident. What is not revealed is whether those 15.9% of recipients in Ohkubo's study are living related donors as is the case with Anna. Should this be true, and then a significant problem among LRD recipients could have been identified.

In terms of physical appearance Anna did not experienced any significant side - effects compared to the cadaveric recipients in my study. Hair loss could become a concern for Anna in the future , if a correlation can be drawn with the 15.9% of hair loss recipients identified in Ohkubo's study.

For five of the six participants in my study unwanted hair growth was of concern. Unfortunately it will continue to be a problem until medication regimes are altered. This problem can readily be supported by Ohkubo's study, which stated that 198 of the surveyed recipients experienced unwanted hair growth. With 83.3% of my recipients experiencing unwanted hair growth, it is well above the 29.7% of recipients from Ohkubo's study. However, both studies identify unwanted hair growth as a significant concern for recipients. Unfortunately, once significant hair growth appears, it never totally diminishes for the recipient.

## (d) Swelling:

The swelling of the face described by Salter (1988) is usually common among renal transplant recipients and would usually result in what is known as, "puffy cheeks," and "moon face." This would normally reach a certain level and remain as such.

Daryl experienced additional swelling, or lumpiness around his wound site. For Daryl, who made mention of this "lumpiness," it was of greatest discomfort and embarrassment to him. A fact that was not of concern to the other participants.

However, regarding the "lumpiness", Daryl hesitantly remarked;

*Client*

*Can I say that, "around where my kidney is, it in going lumpy." When I do exercise it shows more. If I go swimming others will see, and might laugh. The doctor told me not to worry, and it might not be so noticeable in two months.*

*Interviewer*

*Has that become worse since last time I saw you?*

*Client*

*I don't know. Just more noticeable since I've become more active. I think my sister was shocked when she seen it.*

*Interviewer*

*If that still worries you tell the doctor again and see what he says. As the doctor said, "it might not be so noticeable in two months time." Remember that you have had a transplant and your body is adjusting to the new organ. It is now apart of you. Soon other people, and you yourself will become more comfortable with the new kidney. However, do not hesitate to tell the doctor if any thing bothers you at all.*

All the participants in the study experienced swelling and puffiness of the face. However, Daryl was more embarrassed about his wound site swelling, which did not appear to be of significant concern to the other participants. This might appear to be a bit odd considering that people are more likely to notice facial swelling, than anywhere else in the body.

From the study issues pertaining to swelling saw;

All the participants had experienced facial swelling. Even Anna had facial swelling, but only slight and not as pronounced as with the other participants. Daryl drew a distinction between facial swelling and swelling around the wound site Surprisingly it was wound site swelling that was of greatest concern to him. This issue is further discussed with relation to another theme.

Undoubtedly as expressed by everybody, (perhaps excepting Daryl), facial swelling was a worry. After all, it is the face that people reputedly notice first in a person, and any distortions to the face are not readily disguised

### Adaptation to swelling:

All participants in the study experienced facial swelling and according to Slater (1987), it is permanent. However, the degree to which facial swelling occurs differs from recipient to recipient.

Ohkubo (1995), revealed that swelling was found in 242 recipients, which was 36.3% of the sample. All of these 242 recipients had facial swelling of varying degrees, and it was permanent.

Consulting with medical doctors revealed that wound site swelling was absolutely normal, and will diminish in time. However, for Daryl it caused him considerable concern that was not expressed by the other participants.

### (e) Teeth Yellowing:

The problem of yellowing teeth and gum problems is usually attributed to medication side effects, particularly Cyclosporine.

Eric, particularly during the third interview became quite alarmed about his swollen gums and teeth that were slightly yellowish. He cried;

*Client*

*I don't like my teeth going yellow. I look silly. I think if I keep cleaning my teeth and reduce Cyclosporine, the yellow will go. I think that I have gone from being cranky to being quiet. Sometimes I try to pray and be quiet, but I become explosive and anxious. Only sometimes.*

Daryl was experiencing bleeding gums and he indicated a desire for a dental consultation.

Yellowing of the teeth was considered a concern by two participants.

From the study issues pertaining to yellowing of teeth saw:

Daryl who sought a dental consultation through concerns of bleeding gums and the yellowing of his teeth, which was quite remarkable considering that swelling of the face was only of minimal concern to him. Perhaps the underlying fear of perceived tooth decay, and root canal damage to his gums was the principle incentive. For no other reason than the pain that dental problems are associated with, would be the most obvious reason.

Eric, quite readily became emotional when explaining something. There were definite changes in his mood continually throughout the interviews. This is discussed in more depth in the relevant chapter. Eric did not like

the thought of his young children commenting about his teeth, or any other physical changes to his body.

#### Adaptation to yellowing of the teeth:

As stated by Mims2000, yellowing of the teeth is a common side - effect to Cyclosporine. A client might experience teeth yellowing, and from my study it was prevalent with Daryl and Eric.

Unfortunately, according to medical doctors, it is unavoidable and might develop in some recipients. Unfortunately figures were not available.

With yellowing of the teeth, you would expect teeth decay to follow, with possible gum damage if not treated. To counter this Daryl and Eric have been advised to seek dental consultation, to help reduce the possibility of tooth and gum damage.

#### In Summary:

The theme of "Physical Appearance" was identified by all participants in the study as being of concern.

The significance of this theme was highlighted with its breaking down into five sub- themes that were once again identified by all of the participants, but now succinctly, and in more detail.

With the sub-themes of Complexion, Weight Gain, Hair growth, Swelling, and Teeth Yellowing, being clearly identified; they were then restated.

This time the significance of each sub-theme was supported by extracts taken from interviews with the participants. It was then followed by an analysis of the issues pertaining to each individual sub- theme.

Having the themes identified, sub-themes stated and analyzed was not adequate to provide insight into the coping or adjustment that the participants had to make to their day-to-day lives. What was required was a section on adaptation to each change that the participant was experiencing. Subsequently, this was included at the end of each sub-theme.

This approach was different to other studies where physical appearance was contained in one category. This is evident in studies undertaken by Hayward et al (1989), and Frey (1990), who were characteristic of the



general trend in research, where physical appearance is looked upon as a number in a rating system that recipients find of significance to them.

Frey (1990), and Hayward et al (1989), in their quantitated studies found, "changes in body appearance", rated 6/48 and 10/60 respectively. Apart from charting this information, no further comments were made in respect of physical appearance.

One quantitative study by Ohkubo (1995), in Japan, did go against this general trend by identifying obesity in 90/660 of its subjects, hirsutism in 198/660 of its subjects and hair loss in 106/660 of its subjects but did not address this as physical appearance and failed to make any further comments.

It could therefore be stated that my study is unique, in that it is qualitative and the participants were able to identify with, what all-specific aspects of physical appearance meant to them. Thereby, giving a more enriched understanding of physical appearance, as apposed to giving a general outline of a perceived physical appearance.

## DIET

It is understandable that diet had an effect on every participant in the study. After all, every body consumes food but the changes in food intake pre and post transplantation can be somewhat dramatic. Changes in the participant's diet following their transplants were due to the cessation of restrictions imposed on the participant when receiving dialysis, which in turn saw the participants wanting to experiment with new taste sensations. Unfortunately, the participants had to contend with the effects of their immunosuppressive medications that became interwoven with their "new" diet. This soon became an unwelcome correlation for the individual participant.

Prednisone, a steroid, is usually prescribed in large doses in conjunction with cyclosporine for the first post-transplant year. Since steroids increase protein catabolism and decrease anabolism, high-protein diets providing 1.5 to 2.0 g protein/kg body weight/day are usually required when the prednisone dose is large. If the client has a tendency to retain sodium and fluid, a 2- to 4-g sodium diet is beneficial, most likely in addition to the use of a diuretic or antihypertensive medication. In some individuals, steroids cause an increase in potassium excretion. Thus, a diet high in potassium or potassium supplementation would be warranted. The

tendency of steroids to stimulate a client's appetite may result in excessive weight gain. Steroids also induce an increase in glucose production. Some clients cannot respond with an appropriate insulin secretion, thus leading to steroid-induced diabetes mellitus (Rodriguez & Hunter, 1981).

At toxic doses, cyclosporine and azathioprene have exhibited effects such as hyperkalemia and anorexia. These effects are usually only transient; once the dosage of the drug is altered, these effects disappear. This in turn, reveals a close correlation between diet and medication. As previously stated, the effects of medications do both directly and indirectly contribute to the recipients desire to consume foods and the type of foods consumed. Reintroducing previously restricted foods into the diet can be difficult O'Shaughnessy (1991), states that most renal transplant recipients are confused as to what constitutes a balanced diet for them.

Bread, cereals, fruit and vegetables are an important source of energy, complex carbohydrate, vitamins and dietary fibre. They also promote small amounts of protein. The importance of consuming meat, poultry, seafood, eggs, legumes, nuts, milk, cheese and yogurt cannot be denied. This is especially important when taking prednisone which increases the

requirement for protein and calcium. Since the waste products of protein are excreted by the kidney an adequate rather than an excessive protein intake is recommended. Blood lipids and body weight are both elevated by excessive intakes of fat, butter, margarine, oil, and cream. It is not uncommon for transplant recipients developing problems with raised blood sugar levels while taking anti-rejection medication, particularly if there is excessive weight gain. Reducing sugar will assist in both decreasing blood sugar levels and decreasing weight. With the kidney involved with the regulating of salt in the body, it is necessary for restrictions to be imposed on end stage renal disease clients prior to receiving a donor kidney, because they have virtually no kidney function and the salt can not be regulated. After transplantation salt intake needs to be reassessed, as they now have a functioning kidney and restrictions need not be necessary. However, reduction in salt intake might be relevant if blood pressure becomes elevated.

Alcoholic beverages supply few nutrients other than energy (kilo-joules or calories) which comes from the alcohol and sugar they contain.

Excessive alcohol intake as well as contributing to number of diseases, accidents and social problems is also associated with lack of appetite and poor nutritional intake. Nevertheless alcohol is part of our social structure. Most health authorities recommend that two standard drinks per

day such as: 2 middies of beer (2 cans low-alcohol beer); 2 nips of spirits; 2 small glasses of table wine; 2 liqueur glasses of liqueur is a safe limit for adults.

It is important to remember that alcohol is a significant source of energy (kilojoules/calories) and can contribute to weight gain. In general it is best to keep alcohol intake to a minimum.

From the interviews it was quite noticeable that two of the participants expressed a significant concern about gaining weight. Despite consuming less food Maria found herself gaining excess weight, to which she became quite alarmed at the prospect of becoming fat. Maria was quick to point out that she followed the doctors' instructions carefully and was determined to "look after herself."

*She spoke, "...I'm look myself and what I'm eat, what I must bring and being five years I never eat salt I never touch it and Dr. Kelly tell me I got to cut out salt and yeast.*

*Interviewer*  
*So you don't eat salt?*

*Client*  
*I use a little bit. I no eat fruit much but he tell me fruit all right for you but now I can have it but I can't eat now.*

*Interviewer*  
*So in other words?*

*Client*  
*Before me eat only one green apple each day, you believe me.*

*Interviewer*

*One apple a day?*

*Client*

*When I am like it eat plums, two very small plums nothing else when I'm like it another day eat strawberries you know very small very, very small 7 pieces for that nothing, When I like eat watermelon.*

*Interviewer*

*Do you like watermelon? I like watermelon.*

*Client*

*I like it but I can't eat it now been five years I can't eat it.*

*Interviewer*

*But now you can eat it?*

*Client*

*No, I'm not interested in any fruit now.*

*Interviewer*

*So in other words you've been on a diet for such a long time.*

*Client*

*Five years.*

*Interviewer*

*And now, your off that diet and you've got to eat normal foods.*

*Client*

*And when I eat watermelon quarter little pieces but fifteen centimetres thicker. I can't take it, peaches apricots nothing when I'm go into the shop what I'm take my hand I read it potassium, potassium.*

*Interviewer*

*You always worry about your potassium but that's all gone now your off dialysis*

*Client*

*And chocolate, you believe me. I'm start eat after five years no good for my mouth one piece I have two.*

*Interviewer*

*So let's get back to chocolate, you haven't had any chocolate for five years and now your eating chocolate. Do you like it.*

*Client*

*I'm eat but not much, my body I'll put on weight.*

*Interviewer*

*What does your family say about your new diet, eating new food? Do they make you eat? Do they say, "Eat more, eat more?"*

*Client*

*Yes, I say no, no.*

*Interviewer*

*How do you feel in yourself? Do you feel bloated do you feel uncomfortable?*

*Client*

*No because I've never been eating big.*

*Interviewer*

*You don't eat big. Does it taste good now you can eat different foods?*

*Client*

*Yes.*

*Interviewer*

*Can you taste it or have you lost your taste for food?*

*Client*

*I lost it when I been in hospital, I like water more than anything. I can drink it in the hospital and after maybe three weeks after operation.*

*Interviewer*

*You've got to drink a lot of water now don't you?*

*Client*

*Yes.*

*Interviewer*

*So your biggest problems are changing your diet and drinking a lot of water?*

*Client*

*Yes.*

*Interviewer*

*That's a big change for you isn't it , with your diet?*

Maria insists that she has never put on more than two kilos in weight. She comments about her weight now, and prior to her transplant

*Client*

*Before on dialysis I like to drink and drink in day a good 800ml, 2 full glasses say up to you drink tea and water and drink that's all very hard, but me everyone put in from Saturday afternoon to Tuesday morning six to seven kilos, do you believe that, me never put on only two kilos.*

*Interviewer*

*So you've never gain weight, excessively, over two kilos?*

*Client*

*No, I push myself, I'm not drink, I'm not eat.*

During the course of the following interviews Maria was exhibiting signs of disbelief and concern about weight gain. She remarked, "...I'm not eating chocolate now. Not any more. Fat, fat. fat my face no eat. " Maria continued to say, "...I eat carrots every day, six seven eight carrots a day."

In the final interview, I felt a concern for her attitudes towards eating. Her diet was decreasing to a point of starvation

She said, "...I am not eating much. I'm very careful cause I'm putting on weight. I tell Dr. Kelly that I don't believe it. I'm not eating sugar now. Drinking coffee early in the morning with soy milk, and having light cottage cheese too, with vegemite and a light biscuit for breakfast. At lunchtime I eat nothing. Really, I start to eat carrots six, seven eight a day. Do you believe me and he says, "don't eat to much carrots." I tell you, if you in the house all day you will always eat. That's why I eat carrots so I won't gain weight, and I exercise, and go to the shop. Other meals I like chicken breast without the skin. Still since hospital I never eat potatoes, not mashed or baked. I have salad with no oil, no vinegar, nothing. Sometimes I'm making lunch at 1.30. After 1.30 nothing until breakfast. Nothing, can you believe me.

*Interviewer*

*Don't you feel hungry?*

*Client*

*I don't feel hungry, but if rarely I like something to eat I eat one apple, three carrots and one drink of tea. A bit of milk perhaps."*



A significant concern about weight gain was also expressed by Anna.

However, Anna confessed that she could not stop eating, but was dismayed by her weight increase. She attributed this to her medication.

She also blame the medication for her wanting to eat more.

*She comments, "...I eat too much. This is my only problem. Since I came out of hospital, I feel that I want to eat all the time. I don't want to put on too much weight because I want to be slim. Sometimes my body weight increases but I lose it again. Sometimes I can control my weight, by stopping myself from eating. The foods I eat now and before the transplant are pretty much the same. I use a lot of salt. Ever since the transplant I've developed a taste for salt, but I try not to eat too much. When I used to live with my sister, I didn't eat a lot. She is shocked when I eat too much. I'm shocked because I eat a lot not like before. I don't eat much before just one piece of chicken, now I eat two pieces. It's like that with all food. I've doubled my food intake." She continues, "...I have to prepare and cook the food I hated cooking before, and I didn't really use the kitchen, but now I like to cook. Now I cook cakes I really hated cooking before, I never cooked anything, but now I cook."*

During her next interview, Anna indicated that she believed a drop in her Prednisone dosage would help with her weight problem

*She remarked, "... I eat too much. Sitting here alone, sometimes I feel bored, and I eat. Sometimes it's worse. My weight goes up when I eat about one or two kilos. Then I go to the gymnasium and walk around, then the weight goes down. I eat then it goes up. It goes around like a circle. I wish the weight was more stable. It is funny. After the transplant I have too much weight, probably because of fluid. After the fluid is gone, the weight still goes up and down. I eat low fat foods but my weight is unstable. I thought dropping Prednisone dose, last week, would help with my weight, but I don't know."*

Anna went on to try and justify her increased consumption of milk, by saying, *"I drink milk with my coffee, because of the calcium. Maybe later I will have a broken bone because I don't drink milk that much I try to use milk in my cooking and coffee because of that."*

Concern about weight gain was also expressed by Karl, however he endeavoured to give the impression that it was of little worry. He tended to dismiss his weight gain as something that would diminish when his Prednisone medication was reduced. When asked about changes in his diet, Karl responded,

*"Yeah, I'm still on low potassium and low salt. He's taken me off the protein restriction. I can eat as much protein as I like and I'm off fluid restrictions, which I was really happy about; because I can just drink what ever I want now."*

*Interviewer*  
*Do you?*

*Client*  
*Yes.*

*Interviewer*  
*So that would be a significant difference between now and before?*

*Client*  
*When they first came in and told me, I went straight down to the canteen and I think I drank about a litre.*

*Interviewer*  
*So now you can go out and drink?*

*Client*  
*Yeah.*

In conversation Karl drew comparison between his food consumption pre and post transplant Karl was asked,

*Interviewer*  
*Is there any food that you really like. That you have eaten now and could not eat before?*

*Client*

*I suppose eggs would be the only one. I've been eating a couple of eggs for breakfast, since I have been off the protein. I wasn't terribly restricted on the machine (diet) because I dialyzed so well. I was a pretty good patient actually. My figures were good; I was pretty lucky that way and I never over did it anyway. If I felt like eating something I'd just have a little bit of it, rather than pigging out. Denying myself for ages and ages and then just getting to the point where I just had to have a lot of it; I might just have a bit every week. and just dialyze it out.*

During the next interview, when asked about his taste for foods. Karl added,

*"Probably been eating a lot more sweet stuff than I had when I was on the machine (haemodialysis). I lost the taste for sugar I didn't like cakes or lollies, didn't eat much of that. Now, basically if it is there I'll eat it.*

*Interviewer*

*Last time I saw you, you said that you are eating a lot of eggs in the morning. Something that you were not doing before.*

*Client*

*I've cut them back actually, because I thought well that's probably one of the things that might be putting me on weight so I cut them back. I only eat them a few times a week now, whereas I was eating them nearly every day. I have also cut back in the last couple of weeks the amount of sugar I've been eating. See when I had a cup of coffee; I started drinking a lot more coffee because I can drink. Probably have three cups a day now, and I had it very sweet, so I cut out the sugar. I've started putting those sweeteners in it; just to see if that can knock back a bit of weight. I have lost a bit actually in the last couple of weeks. That's with walking, cutting back with food. As I say, the steroids are starting to come right down now. So, it will come off. Try not to get too concerned there."*

Karl's final interview found him to be much more concerned about food consumption. His tone of voice was of a more serious nature than before. He said, "... I'm watching my diet fairly carefully now. In the morning I just have a couple of pieces of toast. A sandwich at lunch time and then at ten, I'll either have, steak, chicken or fish.

*Interviewer*

*Any new foods since you have been off dialysis? Have your taste buds changed?*

*Client*

*Chocolate. I certainly didn't crave it when I was on the machine, but then now that I can eat it I'll eat it. I don't eat a lot of it . but I have the odd bit.*

*Interviewer*

*Weren't you eating eggs and toast last interview?*

*Client*

*Yeah, I have gone off the eggs I only eat them once a week now. I just decided it wasn't good to be eating them so much. Only have them once a week now. Plus, getting up to go to tech in the morning, you haven't got time to be cooking them, so a bit of toast will do."*

When interviewing Eric he initially stated that he can eat whatever he likes. Eric commented, *"...When I got the kidney transplant, I eat everything and I eat whatever I like. Unfortunately the hospital told me no salt at all. and they restricted sugar as well, and no fat. They told me not to eat so much, so I follow their instructions because I don't want to go back on the machine again. I eat no salt, I limit my sugar. My weight is very good and I don't eat very much I don't want to get sick."*

During further conversations, Eric revealed that his taste for foods had changed. He spoke...*"I find that since the transplant food tastes different there seems to be more flavour. I want to eat but, don't want to put on weight."* He continued, *".... I find that since the transplant food tastes different there seems to be more flavour. I want to eat but, don't want to put on weight."*

During the third interview with Eric, his attitude appeared to be one of deep concern, to almost anxiety about his increasing weight. Eric remarked, *" I like to eat. I'm eating to much and my weight is increasing. The doctor says too much you will kill yourself. He said to stop eating so much. Now I'm eating everything."* He continued, *" I am now eating fish and lots of rice. I can't eat spicy food. It's to hot for me. I don't eat salt."*

Unlike the other participants Gary was expecting to gain weight. He was determined to keep his weight down and indicated is diet was under control.

He spoke, ".... Diet, pretty well under control now. Mainly because I'm a little self conscious about putting on a lot of weight so, I'm quite careful with the diet. I make sure I have three meals a day. But, I don't like over doing it. Can't control it with the water intake cause you've got to look after the kidney. I've been told to drink a lot of water or fluids. So, that puts on a lot of weight with the Prednisone and all.

*Interviewer*

*Why are you worried about putting on weight?*

*Client*

*Well, I think it would be quite easy if you over indulge that you'd really get big. I'm only a short person anyway so I wouldn't want to be really sloppy.*

*Interviewer*

*So, even now you can eat different foods, you still worry about putting on weight?*

*Client*

*I'm not self-conscious about food or anything; just don't over indulge too much. If I do over indulge too much my body can't take it, probably still use to being on diet with dialysis. If I "pig" out I say the consequences of over eating any way.*

*Interviewer*

*How about the type of foods?*

*Client*

*The type of foods, I don't really have any restrictions that way.*

*Interviewer*

*Do you enjoy food better? Do you have more taste?*

*Client*

*Yes.*

*Interviewer*

*How about chocolate? Do you eat chocolate now?*

*Client*

*Do you remember that?*

*Interviewer*

*Yes, I remember that.*

*Client*

*Still got a bit of a chocolate craving, Trying to get off it. It's not easy. I like honey combe bars..."*

**When asked about taste for new foods Gary responded, "...Only chocolate, I drink a lot of coffee. I don't know if coffee is good for you. I never use to like coffee.**

*Interviewer*

*Do you think that your taste buds have changed?*

*Client*

*Not too much.*

Being asked about his increasing weight, Daryl replied "... *I have to eat a lot. Otherwise my stomach feels now good. It feels painful, when I eat it feels better. I do feel it is the Prednisone and I'd feel better with the dosage reduced. My dose now is 15mg before it was 25mg. My Cyclosporine is 15mg.*"

The painful stomach that Daryl spoke about was of no concern, when in following interviews he indicated a change in his eating habits. he stated, "*I find my eating has changed a lot. Before I liked to eat rice. During dialysis I'd eat rice because I always felt hungry. Now I really potatoes, bread and fruit I like now Australian foods, not Asian. Apples and oranges. All this just recently. But, I only eat little bits, my stomach feels full easily.*" He continued, "*I eat more fresh fruit rather than meat, I eat potatoes and tomatoes more. I want to have more potassium. I eat five pieces of fruit a day.*"

Perhaps the most noticeable change in his taste for foods was also observed by his friends Daryl explains, "... *My friends think it is strange that I don't like rice anymore, but now I really like potatoes. They say, I am no longer Asian. I agree, my eyes might become more round.*"

However, what seemed to cause Daryl significant stress was the comment made by his doctor. Daryl remarked, "*The doctor keeps telling me to reduce sugar and salt and keep my weight. If I increase my weight I could become a diabetic.*"

From the study issues pertaining to diet saw:

Maria, was developing new tastes in food. She was now consuming new and varied foods. With her weight increasing, Maria desired to loose weight. She stopped eating chocolate, and consumed more vegetables,

while not using oil for cooking. Unfortunately, Maria had become so obsessed with losing weight, that she stopped eating lunch. She only consumed a light breakfast, chicken without skin, vegetables without dressing, and eight carrots daily. Despite this, the participant's weight did increase. Whereas, Anna stated that her weight fluctuated, and she did not want to increase her weight. Anna admitted to eating too much. She consumed cakes and "sweet things," and developed an interest in cooking. She added that, she wanted to eat all the time, and would wake up at night then prepare food to eat. By Interview Three, Anna's food intake had doubled. Anna further claimed, she had become bored and would consume food.

However, Karl tried to conceal his concern for diet and food consumption. His heavy build and his ease in gaining weight troubled him. Karl was instructed to reduce sugar intake and was put on a permanent salt restriction diet. A low potassium diet was ceased and there were indications of a slight decrease in weight. Karl was beginning to develop a taste for new foods, especially eggs, and he had a preference for water, 600mls daily as opposed to soft drinks. His basic diet was toast at breakfast, a sandwich at lunch, and a piece of chicken or steak at night.

Initially, Eric had his weight well maintained, but gradually it began to increase. He gained five kilos in weight and was warned of the risk in losing his kidney by the doctors, if his weight did not decrease. Although food intake was reduced Eric's weight increased, to which he blamed his medication (Prednisone). Eric's diet included; peanuts (no salt), one banana daily, he preferred the flavour of water to soft drink, and he never consumed chocolate. He further claimed, that foods tasted differently.

This was different with Gary, who indicated that he had no real diet restrictions, except to eat in moderation. Gary had not noticed any change in food, except he developed a taste for coffee. His basic diet consisted of steak, pasta, reduced fluid intake, and limited amount of chocolate. Gary stated that he surprisingly lost two kilos in weight. However, he expected his medication (prednisone) would soon cause him significant weight gain. Of all the participants, perhaps Daryl was the most stressed through an obsession with developing diabetes, that was evident with him only eating to, "seventy percent of fullness." He would not allow himself to have a "full stomach," fearing weight gain. He complained of his stomach feeling painful but this pain subsiding when food was consumed. Daryl had stopped eating Asian foods preferring, potatoes, bread, oranges, and apples. He experienced a cultural conflict with his family saying it was expected of Chinese to increase weight. Daryl was determined to



maintain his weight, as much as possible. He soon developed a taste for potatoes, preferring them to eating rice.

### Adapting to change in diet:

The largest single issues that transplant recipients face would be curbing their desire to go out and consume as much food as they possibly can. No doubt, this is a somewhat natural reaction, when you consider that prior to receiving their donor kidney, diet restrictions are hard and strict. The rigid extent to their diet regime has previously been discussed in some detail, along with what is expected now that a renal transplant has been undertaken. Notwithstanding any special instructions given to the recipient by the doctors, regarding any specific limitations, the best way to adapt to dietary change is limit food intake to a moderate level. This implies eating foods to a point where the recipient's stomach is not over full and does not feel bloated. It does not mean to starve oneself and restrict foods that constitute a healthy diet. Maria gave the impression that she was beginning to jeopardize her health, in her attempt to lose some kilos in weight. This practice is unhealthy, potentially dangerous and should be avoided. Just as Gary experimented with his taste buds discovering a new taste for honeycomb chocolate, and Eric acquired a new found taste for bread, so should all transplant recipients experiment

with their new taste sensations. It can be one of the pleasures of living a life free from dialysis, however, moderation is the key word, and common sense can be a good indicator for the recipient to know their limitations.

What is disturbing perhaps overlooked, or simply not discussed with the transplant recipient is the correlation between their medications and excessive weight gain. Somewhere along the transplant process this issue apparently has been overlooked or not explained enough. Maria and Anna were somewhat oblivious to the notion of medication affecting their weight, until they could no longer think of a reason for gaining weight. Maria especially had this problem, and Eric had fear of being diabetic but had little understanding that his weight would also be influenced by medication. Only Gary, was totally aware that his weight would increase due to medication dosage. However, Gary had just received his second transplant, and thereby reliving the event. Surprising, Karl expected his weight to decrease once his medication dosage was reduced. However, Karl had a cousin who underwent a renal transplant and during communication between cousins, problems concerning medication side effects were discussed. This would account for Karl's understanding of the effects of medication on weight gain. Regrettably from the study, it is apparent that a knowledge deficit does exist with transplant recipients

regarding the effects of medication in diet and subsequent weight gain.

This is a problem that needs to be addressed.

### In Summary

Diet was an important issue for all recipients in the study. The effects that medication could have on the recipient's diet were discussed in detail as were the required dietary needs of someone who had recently underwent a renal transplant. Personal experiences of the study's participants were quoted and a detailed description of their food intake was presented.

It was observed that overall changes to the participant's diet were attributed to the cessation of restrictions imposed on them when they were receiving dialysis; and the participants wanting to experiment with new taste sensations. Notwithstanding specific restrictions, (if any are imposed by the doctors), the participant should be encouraged to consume a wide range of foods but in moderation. Food should be enjoyed, and considered a benefit of life with a donor kidney.

Unfortunately, a knowledge deficit was noted among some recipients regarding the correlation between medication side effects, food consumption, and excessive weight gain. It would be beneficial to

recipients if they were better educated in this area, thereby avoiding any unnecessary stress.

## OBLIGATION

In order to understand the theme of obligations for the renal transplant recipient, you must remember the somewhat extraordinary circumstances that people with end stage renal disease find themselves in. For the transplant recipient there has been a period of at least three years where they have been waiting for the chance of a "new life." This is a life free from strict dietary, fluid and medication regimes that can require haemodialysis three days a week for six hours at a time. This involves being wired to a machine via the insertion of long and thick needles alternately, the recipient could be subjected to a regime of having a tenhckoff catheter inserted into his peritoneal cavity and drained every four hours. This involves a tube attached to the stomach, which is drained and then replaced by dialysate fluid every four hours. This means every four hours regardless of whether it is day or night. Additionally there are the risks of peritonitis, disequilibrium syndrome and anaemia.

Although obligation would have been felt by all of the participants, it was expressed openly and with much conviction by Gary and Anna. Of all the participants, Gary and Anna could not have been more different from each other, and any other of the participants Gary was the only participant who had received a second transplant, and appeared to exhibit signs of

guilt, that perhaps the rejection of his first kidney could have been avoided. Where as Anna perceived an obligation towards her eldest sister who had graciously donated one of her kidneys. This made Anna the only participant to receive a living related donor kidney. The other participants had received their first transplant all being cadaveric.

For the participants obligation would definitely imply a perceived, “duty of care. “That is a duty by them to ensure that their donor kidney is not wasted or neglected, but used to enhance the recipient’s life, and give them a” new life”. A life free of the restrictions imposed by dialysis. This is viewed by the recipient as a repayment by the recipient to the donor or the donor’s family, in the form of a commitment by the recipient that the donor kidney is appreciated.

Gary showed a strong desire to do all that he could to ensure that his donor kidney would not be wasted.

*Gary remarked, “...It’s really a second chance at life. In one way I’m not over keen on that word but it is a second chance at life...”*

Gary felt some guilt about losing his first donor kidney, and wanted to

make amends with his second kidney transplant Gary spoke openly about what he perceived his obligations to be, and the gratitude that he had for his donor.

Gary spoke, "*...I tend to think the person who donates a kidney in the first place wants that kidney used to the best of its capabilities. They call it a gift of life and virtually that's what it is. I tend to think the person him or her, they don't just give that kidney away for nothing. They want it to go to good use. I suppose they just want the person who use it to the best of its capabilities and enjoy life, to give that person a lot better quality of life than he would have living on dialysis and I think there is some obligation to that person (some might see, some mightn't), to attempt to do as much as they possibly can to improve their lives and make little changes.*

*Interviewer*  
*Tough little changes.*

*Client*  
*Well this is mainly with younger people. Older people it helps without as much medication or gives them a better chance to live but younger people or working class people they have much more a chance to do things in their lives..."*

For Gary, his perception of obligation was not only directed toward the donor, but he claimed that, "there are one hundred people giving him support".

Gary stated, "*...It would be nice to change their life a little bit, especially that person who gave me that kidney to make that kidney worthwhile, not just for that person it goes for the surgeons, the doctors, the nurses, the orderlies they are all sort of banking that this works. They don't do it for money they do it for love. They've got all their hopes up that you will use that kidney to the best of your capability. It's a moral obligation. It's not just you that you are dealing with, you're maybe dealing with a 100 people that are banking that things will get better for you.*"

To show his gratitude to everybody involved in helping Gary with his

transplant, he strongly insisted that he was obligated to promote the cause for organ donation. Gary answered the question that a lot of people have asked him.

*He said, "...A lot of people ask , and I think its a normal question, "Do you know who the donor is?" Its a good question, I don't think I really want to know who the donor was, even if it was legal. It could be really good or could be an obligation .I know the situation will never come up.*

*Interviewer*

*If it did come up would that be too much of a burden or a problem to you?*

*Client*

*It wouldn't be a hassle, Probably be a good experience. I'd take it as it comes, but I tend to think it won't come so it doesn't worry me. I think with some people, it could dwell on their mind a lot, I am much appreciative, and count my blessings that it happened but that's about it. My feelings are completely different to my first kidney, whether that is because I've had two kidneys. After that much time I am a different person. We all do grow up a little bit. I know how much important donation is and all, but it is not on my mind that much. I'd tell anyone who asks me that donation is really important, the pluses for it. Naturally that's an obligation but it always would be on my mind. Sometimes people ask me, I give them all the answers, how much it helps people and if you knew how much people needed an organ; just give them a couple of facts. One of my facts is, that quite surprises them is, "I don't want to be cut up or anything." "Almost everyone who dies has an autopsy." Which they do as far as I know. They don't let you get out of this world to easily. Maybe, one day the Kidney Foundation or the hospital will want me to help them out one way. Yeah, I've got no hesitant I'd come running to help them. Like to give advice, if they ever requested it, I would be first in line. If they don't, I wouldn't push the point."*

However, it is with the donor that Gary has a special obligation.

*Gary remarked, "...I appreciate the person and will always realize that person has given me an organ."*

As stated previous, Anna received her donor kidney from her eldest



sister. The sister came from Jordan, and flew to Australia after receiving the news of her sister, Anna's illness. The eldest sister volunteered one of her kidneys, after discussion with her husband, parents, and hospital staff. Initially, this was objected to by Anna, however, Anna relented and accepted the donor kidney. Anna was pleased and spoke about the match.

*Anna commented, "...My match was good. My sister had a good tissue and blood grouping with me it was the only match for me. Even if my sister that lives in Australia had a good kidney match with me, she would not give me a kidney. My other sister visited without any pressure, she just did."*

Concern about her sister's health was stated by Anna, but this was temporary pushed aside with Anna trying to show that she was a "new person," thanks to her sister's gift of a kidney.

*Anna remarked. "...I am worried about my sister. She has two children. I tried to stop her from donating me her kidney, but she persisted. After the transplant I feel different I'm laughing all the time. My sisters and friends are surprised that after the transplant, I am looking so good. Laughing and talking, not like before. Now, I try to make everyone happy."*

The obligation that Anna felt about receiving a kidney from her sister was directed not only to the sister, but also Anna's brother- in-law, nieces and nephews.

*Anna stated, "...I didn't want her to give me her kidney because she has a family. I believe that it is my God's will that I should have a problem kidney and for me to be sick. I didn't want to hurt my sister, she has two children and she is still young. Now she is left with one kidney, and I don't know what will happen to her in the future. I tried to convince her not to give me her kidney but she wanted to give it to me. Last year when she was visiting me, I was very sick with an infection and she didn't want me to be sick. She told our parents that she was going to help me by giving me a kidney. Her husband and children accepted that. and I had to as well. I was very lucky."*

From the study issues pertaining to obligation saw:

Gary was thinking back to the time of his first transplant, which was three years earlier. Unfortunately, his kidney rejected and Gary attributes this to stressful circumstances in his life at that time, and the possibility that he did not care for his donor kidney as well as he should have. His remark that, "it's really a second chance....," has a double meaning.

Firstly, it is a chance for him to correct any "perceived wrongs," that he might have been guilty of with his first transplant. He had a tendency to blame the break up and subsequent divorce of his wife, emotional upset, and his "general neglect of his health;" for the loss of the kidney.

However, these perceptions were considered to be unfounded by the hospital.

Secondly, receiving a donor kidney is a new life for the recipient. It is one free of dialysis, and a new start, with greatly reduced treatment regimes.

Gary saw this as an opportunity to re - write any of the "perceived wrongs" that he felt associated with his first transplant.

He views the donor of his kidney with great respect. He likens the gift of a new kidney to a type of contract where mutual reciprocation exists between donor and recipient. The obligation felt by Gary is that he has a moral debt to insure that the kidney is used to the best of its capabilities. This means that he does not want the kidney wasted, and he must improve his quality of life, to the extent that donor kidney reaches its maximum potential. In respect, the donor has entrusted his kidney to Gary, who in turn shows mutual reciprocation by enhancing his life with it. The theme of obligation for Gary extends beyond the donor to everybody involved with him obtaining a kidney, successful transplant, and follow up care. He tried to put a tangible number on the people who have helped him saying that it must be at least one hundred. He felt that if his kidney did reject he would let everybody down, and not just the donor. Gary is determined to do all he can to make this kidney transplant successful, not only for himself but also for those who have "invested," in his health. The obligation that Gary felt goes one step further ; into health promotion. He strongly feels obligated to answer any questions pertaining to organ donation, and he expressed a desire to assist any person or organization in the pursuit of obtaining organ donors. Having commented

on his, "perceived obligations", Gary repeated that a special obligation does exist for the person who gave him the gift of a donor kidney.

Where as, the obligation that Anna felt tended to be in the form of a debt, to her family. Anna received a kidney from a living relative, her eldest sister. Anna endeavoured to be cheerful and happy in the presence of her sisters and friends, in order to show gratitude for her sisters gift, and she felt obligated to put on a brave exterior. There is no doubt to the obligation that Anna experienced toward her eldest sister, and that sister's husband and children. Anna constantly stated that she tried to stop her sister from donating a kidney. At times it sounded like Anna was experiencing guilt, and sometimes fear about the thought of her sister becoming unwell. The fact that Anna is a Muslim probably contributed to her saying "that it was her gods' will that she should have a kidney problem," and the inference made that her sister should not intervene in donating a kidney. The obligation to her family however, was strong and following discussions among her family, Anna was told to accept her sister's donor kidney.

Anna stated that her kidney, "was a good match." She conceded that she was happy to have had the transplant, but the obligation and commitment she has to her family was of concern.

### Adapting to feeling obligated:

Whether the participant was obligated or if the participant perceived an obligation was irrelevant, because for the participant any perceived obligation was real.

It would be somewhat difficult if not impossible to discuss any similarities between Gary's perceived obligations and Anna's perceived obligations. The reason being is that they are totally different individuals with a completely different set of circumstances to contend with. Just how Gary and Anna adapt to their feelings of obligation will differ entirely.

Of all the themes discussed obligation, is arguably the most personal and individual for the participant.

Gary felt obligated to ensure that his second transplant was successful. In order to do this Gary would need to follow directions given to him by his doctors and transplant team. This would include, avoiding stress, moderate exercising controlling diet, and adhering to his medication regime. Apart from that, there really is little more he can do, and the transplant success will ultimately depend on the HLA matching, and the

vigilance of the doctor in detecting and correcting any medical problems that could arise. To cope with the feelings of obligation that Gary has expressed toward his donor, he really could not do much more than he was already doing. By using the kidney to its fullest potential and thereby improving his quality of life is precisely how this obligation could be met. It would be beneficial to Gary if he could not burden himself with an obligation, when he should be living his life.

Gary should not feel any obligation to the people who helped him during his transplant experience. Those people who Gary refers to are either, relatives, friends, or health care professionals. It is true when Gary commented, "... that these people have an investment in him." However, this does not imply that Gary has an obligation, because those people involved would agree that the opportunity to help Gary improve his lifestyle was gratitude enough. Gary's desire to answer any questions about transplantation and to discuss organ donation, should not be viewed as an obligation. If Gary chooses to promote organ donation with any organization ( ie. Red Cross, Kidney Foundation etc.) he should be encouraged to do so, but he should not consider it to be an obligation or be pressured into doing that.

Anna had to deal with receiving a living donor kidney from her eldest sister. Initially refusing the donor kidney, Anna was persuaded by her sister and family to accept the kidney. Anna constantly feels obligated to her eldest sister. This has in turn made Anna obligated to put on a bright and cheerful exterior to her personality, that would show her sisters and friends her gratitude for the donor kidney. Just how Anna would cope with her feelings of obligation would be challenging, bearing in mind that she has a part of her eldest sister in her own body. All Anna can do is push her thoughts of obligation aside, strengthen and develop her character, and most importantly live her own life. After all, it would seem to be obvious that her eldest sister wanted to donate to Anna a kidney, other wise she would not have came to Australia from Jordan to do so.

If Anna's sister was pressured by the family to donate her kidney, this would put added obligation on Anna. However, the stringent selection criteria for organ donation, imposed by the hospital would dispel this. Anna should be reminded of that fact. The obligation that Anna had to her eldest sister is based on the assumption that Anna has endangered her eldest sister's life by accepting her donor kidney. If Anna eldest sister's life is at risk. Anna must understand that it was the sister's decision to donate a kidney.

### In Summary:

It is interesting to note that out of six participants only two expressed concerns of obligation during their transplant experiences.

Of the two that felt an obligation, Gary had recently received his second renal transplant, and Anna had recently received a living related donor kidney, from her eldest sister.

Gary expressed an obligation to everybody who had helped him during his transplant experience, and felt a further obligation to promote the cause of organ donation. Anna's obligation was totally fixed on her eldest sister, and the concern that her sister's health might be impaired, either now or at a later date.

The contrast between these two participants in their "perceived obligations", is quite significant as to the comparison between, a second time transplant recipient and a living donor transplant recipient.



## Chapter five

### Discussion

For the discussion chapter it is deemed appropriate by the author to recapitulate on points throughout the study and provide a varied perspective on the issues that have previously been raised.

Perhaps, the most significant point to be raised, that was expressed in the literature review chapter was that almost all articles identified, “fear of organ rejection”, as being the main concern among renal transplant recipients. The author found that in this study, the participants were concerned that they did not know how to minimise the possibility of organ rejection. This caused the participants to have apprehension, and develop mood changes about their health status. Consequently, “apprehension and mood changes”, were identified as a theme and not, “fear of organ rejection”.

As noted in the literature review chapter, articles on renal transplantation were able to be put into very distinct categories. From this, twenty-three

articles focused on the recipients stress and anxiety, and another sixteen articles focused on the families of renal transplant recipients. It must be remembered that there were only forty-seven to begin with, which is a very small number. This leaves only eight articles remaining that could not be categorized as such. The articles that were able to be divided into two distinct categories were all very similar to each other within that category. This would allow anybody to conclude that each article was a duplication of the previous, but in some cases directed at children / families of children with renal transplants, as opposed to adult respondents. The initiation of any discussion concerning facts raised in the literature review would quite clearly need to attempt to offer suggestions on how to resolve this definite knowledge deficit that obviously exists about the delivery of care to the recipient of a renal transplant, for based on the available material found in the literature review, nobody really understands the plight of the recipient. Virtually half of the literature takes this line of thought. With sixteen articles asking the recipient's families (and significant others) to respond to questionnaires, the opinion of the recipient appears to be unimportant. The mere fact that only two studies were qualitative in design, definitely indicates that the recipients have not been asked to express their thoughts about their lived experiences.

However, in this exploratory study the renal transplant recipient has been able to express their individual thoughts and feelings concerning individual lived experiences. This will hopefully be able to provide insight into their circumstances, and promote the need for more research, so as to enable the delivery of better nursing and health care management for the recipient.

It can be debated that only through the interviews, was an insight into the experiences of the renal transplant recipient possible. However, equally significant would have to be the time intervals between each interview. The appropriateness of these time intervals between each interview can readily be seen as stated below:

1. Following discussions with the Australian Red Cross (1998), and the Australian Co-ordinating Committee on Organ Registries (1998), it was revealed that every two months following a renal transplant until six months post transplant, significant changes are noticeable in the condition and "shape" of the graft. Noticeable changes are reported to include decreased swelling and "lumpiness" around the wound site, to six months post transplant. Significant changes are said to occur around two month intervals.

2. Medical appointments for transplant recipients are of significant importance at, two, four and six months post transplant. St. George Hospital stated that at these periods significant alterations in a transplant recipient's medication regime often occur.

3. By aligning my interviews with the reported "time slots," that significant changes in the recipients' biological state and subsequent medication alterations happen, allowed me to observe the transplant recipient at poignant times, in their adaptation to living with a donor kidney.

4. From the author's experience based on observations of renal transplant recipients, I have found that;

At two months post transplant for the recipient, concerns about organ rejection are of prime concern. The recipient feels dependant on the hospital.

At four months post transplant for the recipient, coping with the new donor kidney is of prime concern. Organ rejection is of secondary concern. The recipient is becoming less dependant on the hospital.

At six months post transplant, the transplant recipient desires to break bondage with the hospital, and hopes to embark on a new life, free of any constraints.

5. For the analysis of the data, two month intervals seemed to create a succinct and definite break between the recipients' first interviews, that was able to proceed clearly onward to the recipients' second and third interviews respectively.

Overall the recipients responded well across this time frame. Gary felt that each interview marked a type of “milestone.” For him, it signified that one period of adjustment to the new kidney had expired, and as time went by the possibility of rejection diminished. Eric welcomed the opportunity to discuss his experiences and was pleased that somebody was taking an interest in his welfare. Daryl was similar to Eric, in that he viewed each interview as a type of follow up care, where somebody took the time to listen. Maria was always pleased to discuss her transplant and welcomed the three interviews, as to was Karl. During the first four months post – transplant, Anna was willing to discuss anything about her transplant to any staff member of the hospital, to which the author was included. Following that, her attitude changed, and she rarely spoke to anybody.

This study identified eight themes that were prominent throughout the course of the interviews. These themes were of relief, acceptance, trust, apprehension and mood swings, sleep and bladder habits physical appearance, diet, and obligation. Nowhere in the literature review were these themes so distinctly identified as they were in this study. The significance of these themes to those interviewed cannot be denied, as it was from the transcripts of recipient's interviews that resulted in the identification of their themes.

Relief, for the participants in the study had the meaning of being free from dialysis. This was openly expressed by Gary and Maria, who also indicated that to be "normal," is to be free of dialysis. This poses the question and subsequent discussion on what is meant by "normal." Quite clearly Maria and Gary felt "normal," with a transplant. They perceived it to be abnormal when you are connected to a dialysis machine or a dialysis bag. For them, both haemodialysis and peritoneal dialysis was an intrusion in their lives. When compared to a person not suffering from renal disease, dialysis imposed restrictions on their lives. This included; allowing for time to undertake dialysis, dietary restrictions and the embarrassment of having tubes and bags attached to your body on a regular basis. The renal transplant was a relief, because these "imposed restrictions," have been taken away. The renal transplant recipient would

be almost like anybody without renal disease. It was apparent that all the participants were pleased to have a donor kidney. Whether or not the reason for feeling relieved was because of the perception of being normal could not be stated. However, the feeling of relief was evident, and it was Karl who expressed the most satisfaction of all, to be free from dialysis. This is the same sentiment that was expressed by Buck (1998), in her case study of a renal transplant recipient, which has previously been mentioned in the study.

The need to be accepted by other people was of significance to the participants. As previously stated, Maria felt the greatest desire to be accepted. It can be noted that this theme of acceptance is loosely comparable to the articles in the literature review that focussed on the families of renal transplant recipients. However, these articles were more directed towards the needs of the respective families, whereas this study puts the spotlight directly on the renal transplant recipient and it is not restricted to interaction with family alone but includes interaction with all people. It must be remembered and that being accepted goes beyond family and significant others. There is day-to-day life, work relationships that can also affect how a person perceives his / her acceptance to be. Daryl and Gary, regarded work relations as being a necessity, equal to family acceptance and not devoid of.

Gary was well aware of the procedure and had an understanding of organ rejection. For Gary, this was his second renal transplant. Having lived through one failed transplant Gary had an advantage over the other participants. He was able to recall sensations and pain that he had prior to organ rejection. If these sensations or pain does occur, this would be like an early warning that something is wrong. He could then seek medical intervention and possibly prevent rejection. Other participants, who have not undergone a transplant before, could regard these sensations and pain as being unimportant. This could result in loss of valuable time in seeking medical intervention.

It would be good for pre - transplant recipients and for anyone else involved with such a person, to be aware of the signs of organ rejection as seen through the eyes of somebody who has had the experience. If video taping of Gary and others who have suffered rejection could be made with these people telling their stories, it could prove to be valuable learning aid for all concerned.

A trust in the doctor bought about both positive and negative responses. The participants overall felt a strong bond and trust in the surgeon who conducted the transplant and the renal doctors, in general. However, there existed a very strong distrust for general practitioners with the common



opinion expressed by the participants being, “they should at least know the basics.” With remarks like that expressed by the participants one could question the benefits of consulting the General Practitioner. Surely, if these remarks are indicative of end stage renal disease clients, it poses many questions about General Practitioners and their abilities to deliver the proper and necessary care to the sick. Gary and Karl were especially vocal and rather scathing in their comments, as previously documented in this study. A phone in information line could be beneficial, where doctors (and even transplant recipients) could telephone and obtain information from somebody familiar with transplantation issues

Trust in God, had a mixed and sometimes varied response from the participants. Most of the participants recognised an importance in having a trust in God, to which they felt was of considerable benefit to them, and without this trust in God they could not cope. This was openly stated by Maria, Anna, and Daryl. Daryl commented that some things are just not possible for man, and many circumstances are out of his control. This is where a trust in God is essential. One article from the literature review supported this opinion that a religious conviction proved to be beneficial. The article by Tix and Frazer (1998), examined the effects of religions in helping the transplant recipient to cope with life. It can be hard to measure the benefits of a religious belief on coping with a renal

transplant. Just how this could be done can be open for discussion. What is known is that for some people religion can provide hope when medicine is unable to give an answer.

However, when Karl spoke about religion, he put a new slant on it. He commented, “Why would God allow somebody to die to give me a kidney.” This question no doubt raises many issues that are worth discussion, and perhaps further consultation with religious leaders might give a satisfactory answer. Unfortunately, consultations with religious leaders could not give a satisfactory answer, for Karl.

The theme of apprehension and mood changes was evident throughout all the interviews and in varying degrees. Apprehension was first felt by the participants in not really knowing how to minimise the possibility of organ rejection. Concerns about coping with life after a transplant did promote mood changes among the participants. It can be argued that an element of uncertainty existed concerning rejection of the donor kidney, because the recipients did not know what to expect and how to adapt to life with a donor kidney. It can be said that there is little available literature for the nurse or other health care giver to use as a guideline and consequently; the recipient becomes apprehensive and experiences changes in mood from exhilaration to fear. Maria’s concern about weight

gain and Eric's concern about tiredness has made them apprehensive about continuing with their medication regimes, which can also be attributed to the little available literature. If there was more literature on transplantation, then it probably provide insight into this problem and thereby prevent the problem from reaching the state where there is a refusal from the recipient to comply with the necessary treatment.

From theme of sleeping and bladder habits it was found that irregular bladder habits especially within the first two months of post-transplant were normal. The correlation between irregular bladder habits and altered sleep patterns was particularly evident with Anna and Maria claiming to be woken at regular intervals during the night to use the toilet. It can be safe to say that correlation between sleeping and bladder habits does exist. What is open for discussion would be to what extent, if any, does the altered sleep pattern have on the recipients health status, remembering that it is at most two months post transplant. One would tend to agree that if a person is deprived of sleep, the effect on the person's general health would be of concern. It could happen that the transplant recipient becomes exhausted during the day. This could further lower their immune system resulting in the possibility of infection, and subsequent organ rejection. If their immune system is lowered, medication might need to be increased. Here the problem arises of increased side - effects.

It was interesting to note that only the female participants had concerns with altered sleep patterns and bladder habits. Perhaps a consultation with an Obstetrician might be warranted.

The physical appearance theme saw the renal transplant recipient identifying specific changes to their physical appearance that affected them personally. During the interviews the participants commented on how they saw changes to their appearances. Quite probably this study provided the renal transplant recipient for the first time, an opportunity to say what physical changes were of greatest concern. The participants later commented, they welcomed this opportunity.

The theme of diet identified a knowledge deficit in the recipients understanding of the correlation between diet and medication. The transplant recipients found it difficult to understand that increased doses of medication like Prednisone combined with virtually unrestricted dietary intake, combined to increase the participants weight at an alarming rate. The fact that they were not fully aware of this occurring is somewhat disturbing. Undoubtedly, this is an issue that needs addressing to insure proper health management of the renal transplant recipient.

In the theme of obligation it was worth noting that only two participants found this to be of significance. Gary felt that because this was his second

transplant, he had to try harder to keep this kidney. This would imply that he felt an element of guilt and responsibility for the failure of his first transplant. Although at the time of his first transplant, he had some emotional disturbances it would be hard to blame this on its failure. However, Gary did have a strong feeling of obligation towards everybody associated in the renal transplant process. Anna was obligated to her sister who gave her a donor kidney. She felt a huge debt to her sister, and it was foremost in her thoughts. It is interesting to note that obligation felt strongest in the recipient who had a living related donor kidney, and the recipient who had undergone a second renal transplant. The other participants might have felt an obligation to the donor or donor's families, but it was not as significant to them as it was with Anna and Gary. Perhaps this is cause for a discussion on why this is so. However, a larger study would need to be undertaken to determine this.

In discussing how a renal transplant recipient adapts to life with a donor kidney, it is first necessary to know what their concerns, hopes, and perceptions are. This study took the first step in endeavouring to do this.

## **Chapter six**

### **Conclusion**

#### **Implications for Nursing**

Understanding the special needs and requirements of the renal transplant recipient, appear to have been largely ignored, and it must be remembered that the clients with a renal transplant are special people. Strategies and interventions from health care givers that are directed to clients might not be suitable for the renal transplant recipient. In many cases the treatments and intervention are unique to nephrology nursing. The first step in employing these strategies and understanding the rationales behind them is to listen to what the renal transplant recipient is saying, which is precisely what this study set out to do, in the accomplishment of its objectives.

\*Transplant recipients were given the opportunity to discuss their personal experiences.

\*Observation of commonalities between the responses of each participant were attained.

\*Commonalities and disparities of the participants, between each interview were observed.

\*The development and facilitation of coping mechanisms for health care professionals were made possible because of material contained within this study.

\*The special needs of the renal transplant recipient were presented, as a direct result of the interviews with the study's participants. Thereby, promoting awareness of these participants' special needs.

Although, the study was small in the number of participants it did provide an impetus for issues concerning the renal transplant recipient to be brought forward. In doing so, the study's key research question, ("How does the renal transplant recipient adapt to living with a donor kidney?") was able to find an answer with reference to those participants.

In adapting to a renal transplant, several areas of concern were indicated,

from the interviews which inturn can be directly related to nurse / client interaction in finding a solution.

These areas of concern can be categorised as follows;

### 1.Knowledge Deficit

This category can be divided into, nurse and recipient.

For the nurse, it is important to be up to date with the most modern techniques in treatment modalities.

For the recipient, it was noted that the recipients were perhaps uncertain about aspects of their treatment. One point that was foremost was a concern about organ rejection. The problem was that the recipients did not really know how to identify the signs and how to prevent it from happening.

### 2. Communication

Undoubtedly, it is most important for the nurse to communicate with the recipient, try to develop a rapport, and become familiar with the specific needs of the individual client.



One point that needs to be conveyed to the recipient (probably by the nurse) is that life will not be the same as it was prior to developing renal disease. The recipient should be aware not to have too many high expectations. They must realise that they will always need medications, and at times there might be restrictions on their diet and activities.

Alterations in their physical appearance might not totally diminish as medication - side effects will always be of concern.

However, if these areas of concern can be addressed with nurse / recipient interaction, then a life free of dialysis should be rewarding. The need for follow-up care in the form of discussion with the recipient at regular intervals (eg. two months), would be beneficial. It would allow the recipient to ask questions, and allow the nurse to identify areas of concern that the respondents are experiencing.

It is obvious, as seen in the interviews, that organ rejection was of greatest concern to the transplant recipients. There also appeared to be an uncertainty about trying to identify the onset of organ rejection. One way to overcome this could be to communicate to pre-transplant recipients with a video. On the video, people such as Gary, would be seen discussing their experiences of organ rejection, including a description of sensations and pain prior to the organ rejection. This could be a valuable

learning tool for everybody. It might help the nurse to better communicate to pre-transplant clients about organ rejection.

An information-phone in service manned by registered nephrology nurses could provide necessary information to General Practitioners, who might have an inquiry about a problem involving a transplant client that they might be unsure about. Additionally, the nurse could direct the General Practitioner to services and specialists, if required.

### 3. Social Interaction

A concern was noted that once a client underwent a renal transplantation, there was a period of isolation where the routine of dialysis had ended. The recipient loses friendships that were developed over years among the end stage renal disease clients and the staff of the haemodialysis unit at the hospital

This was particularly evident with Maria. This problem could be minimised by organising social events where friendships could be strengthened and not lost. Even if the transplant recipient was invited back to the unit on a regular basis (perhaps monthly) could be sufficient, and beneficial. People receiving haemodialysis could enquire from their

friend about living with a donor kidney. The renal transplant recipient could renew friendships with clients and staff.

### **Credibility and Limitations of the Study**

The question of credibility (according to Patton, 1990), depends on three distinct and related inquiry elements. These are

- (1) Rigorous techniques and methods for gathering high-quality data that is carefully analysed, with attention to issues of validity and reliability.
- (2) The credibility of the researcher, which is dependent on training, experience, track record, status and presentation of self; and
- (3) Philosophical belief in the phenomenological paradigm, that is, a fundamental appreciation of naturalistic inquiry, qualitative methods, inductive analysis, and holistic thinking.

For this study, the inquiry elements can be applied as possible;

- (1) The techniques employed to obtain data were taped conversations of renal transplant recipients, who through three interviews were given the opportunity to express their thoughts and feelings. The taped interviews were transcribed, and coded systematically. This can be verified by listening to the tapes, and studying the transcripts. All participants underwent a renal transplant at St. George Hospital in Sydney, which can be confirmed by viewing the hospital transplant waiting list, and consulting medical and nursing staff at the hospital.
- (2) Having gained the approval of the ethics committees of both universities and St. George Hospital is an indication of the creditability of the researcher and study. The conditions set out by the Ethics Committees and, obtaining approval from them is an indication of credibility. Refer to the appendix.
- (3) In terms of a philosophical paradigm the adaptation of a phenomenology perspective, is undoubtedly signified by the writings of Spiegelberg, and Merleau- Ponty. These people have been documented throughout the study with their philosophical beliefs followed and endorsed.

For the study the only limitation was the number of participants available. Quite clearly a larger number of participants would have given more substance to the studies findings.

The strength of the study is that the study gave the participants an opportunity to discuss their lived experiences. This is most probably one of the few occasions when this has been done.

In light of any appraisals or despite any criticism, the data collection and data analysis used in this study, did show that the research can be replicated. This can be viewed as being the main requirement of reliability for qualitative research. Meaning that by ensuring that the technique was reliable, would enable another researcher to repeat this study.

## References

- Abram, H.S. and Buchanan, D.C. (1978). Organ Transplantation: Psychological Effects on Donors and Recipients. Medical Times. Aug: 106 (8): (88) 23d – (88), 29d.
- Ahmed, I. and Ahmed, S.H (1991). Psychosocial Adjustment After Renal Transplantation. Journal of The Pakistan Medical Association. May: 41 (5), pp. 97 - 8
- Ahmet, A.B. (1993). First-Hand Experience. A Transplant Recipient's Story. New Jersey Medicine. Apr: 90 (4), pp. 289 – 90
- Australian Co-ordinating Committee on Organ Registries and Donation [ACCORD] (1998). Transplant Registry.
- Australian Red Cross (1998) Organ Donation.
- Berger J. (1972) Ways of Seeing. London: Penguin Books.
- Bouras, M. Silvestre, D. Broyer, M, and Raimbault, G. (1976). Renal Transplantation in Children: A Psychological Survey. Clinical Nephrology. Nov: 6 (5) pp. 478 – 82
- Bremer, S,A, Haffly D. Foxx, R.M. and Weaver, A. (1995). Patients Perceived Control Over Their Health Care: An outcome Assessment of Their Psychological Adjustment to Renal Failure. American Journal of Medical Quality Fall: 10 (3), pp. 149 – 54

- Brownbridge, G. and Fielding, D.M. (1992). Psychosocial Adjustment to End Stage Renal Failure: Comparing Haemodialysis, Continuous Ambulatory Peritoneal Dialysis and Transplantation. Pediatric Nephrology Jul: 6 (4), pp. 405 – 6
- Buck, M. (1998), The Ups and Downs of a Kidney Transplant. Nephrology News and Issues. Aug: 12 (8), pp, 36 – 43
- Bugel, L. (1990) A Welcome Kidney? Thorough Preparation for Transplantation Very Important TVZ Apr: 5 (7), pp 215 – 8
- Chambers, M. (1982). Psychological Aspects of Renal Transplantation International Journal of Psychiatry in Medicine. 12 (3), pp. 229 – 36
- Cole, B.R. (1991). The Psychosocial Implications of Pre-Emptive Transplantation. Pediatric Nephrology. Jan: 5 (1), pp. 158 –61
- Coolican, M.B. Politoski, G. and Casey, K. (1997), Programs for Families of Organ and Tissue Donors. Edthna-Erca Journal: Apr - Jun: 23 (2), pp. 5 - 8
- Crittenden, M.R. Waechter, E.and Mikklesen, C.A. (1977). Taking it Day by Day: When Children Undergo Haemodialysis and Renal Transplantation. Children Today. May – Jun: 6 (3), pp.6 - 9 - 35

Crotty, M. (1996), Phenomenology and Nursing Research,  
Melbourne: Churchill – Livingstone

Daugirdas, J. and Todd, S. (1988) Handbook of Dialysis Philadelphia:  
Little Brown Book Company.

Davis, M.C. Tucker, C.M. and Fennell, R.S. (1996) Family Behaviour,  
Adaptation, and Treatment Adherence of Pediatric Nephrology  
Patients Pediatric Nephrology. Apr: 10 (2), pp. 160 - 6

Disney, A.(1994) Australian and New Zealand Dialysis, and  
Transplantation Registry.

Douglas, J.E. Hulson, B. and Trampeter, R.S. (1998), Psycho – Social  
Outcome of Parents and Young Children After Renal  
Transplantation. Child – Care, Health and Development.  
Jan: 24 (1), pp. 73- 83

Durkheim, E. (1915) The Elementary Forms of The Religious Life  
New York:

Egan, G. (1986) The Skilled Helper (3rd ed) Monterey: Books / Cole  
Publishing Company.

Erikson, E.H. (1963) Childhood and Society (2nd ed). New York:  
Norton.



- Evans, R.W. Manninen, D.L. Garrison, L.P. Hart, G. Blag, C.R..  
Gunman, R.A. Hull, A.R. and Lowrie, E.G. (1985). The  
Quality of Life of Patients With End Stage Renal Disease  
New England Journal of Medicine pp. 312 – 553.
- Fallon, M. Gould, D. and Wainwright, S.P. (1997), Stress and Quality of  
Life in the Renal Transplant Patient: a Preliminary Investigation.  
Journal of Advanced Nursing 25 (3) pp. 562 – 70
- Fenichel, O. (1945) The Psychoanalytic Theory of Neurosis New York  
Norton.
- Fedewa, M.M. and Oberst, M.T. (1996). Family Care giving in a  
Pediatric Renal Transplant Population Pediatric Nursing  
Sep. Oct: 22 (5 ), pp. 402 –7
- Frauman, A.C. Gilman, C.M. and Carlson, J.R. (1996). Rehabilitation  
and Social and Adaptive Development of Young Renal Transplant  
Recipients. ANNA Journal. Oct: 23 (5), pp. 467 - 71, 484
- Frazier, P.A. Davis-Ali, S.H. and Dahl, K.E. (1994), Correlates of  
Compliance Among Renal Transplant Recipients.  
Clinical Transplantation Dec: 8 (6), pp. 550 - 7
- Frazier, P.A. Davis-Ali, S.H. and Dahl, K.E. (1995). Stressors,  
Social Support, and Adjustments in Kidney Transplant  
Patients and their Spouses. Social Work in Health Care.  
21 (2), pp. 93 – 108

Frey, G.(1990) Stressors in Renal Transplant Recipients at Six Weeks After Transplant American Nephrology Nurses Association Journal, 17 (6), 443 – 447.

Frieson, T.C.and Frieson, C.W. (1997). Relationship Between Hope and Self - Esteem in Renal Transplant Recipients. Transplant Proceeding. Dec: 29 (8), pp. 3739 – 40

Fukunishi, I. (1992). Psychosomatic Problems Surrounding Kidney Transplantation Incidence of Alexithymia And Psychiatric Disturbances 57 (1-2), pp. 42 – 9

Fukunishi, I. and Honda, M. (1995). School Adjustment of Children With End Stage Renal Disease. Pediatric Nephrology Oct: 9 (5) pp 555 - 7

Gartland, C. (1987). Organ Transplants Looking After Jodi Nursing Times. Feb 18 - 24: 83 (7), pp. 24 – 8

Gould, R. (Feb, 1975) Growth Toward Self - Tolerance. Psychology Today.

Haq, I. Zainulabdin, F. Naqvi, A. Rizvi, A.H, and Ahmed, S.H. (1991) Psychosocial Aspects of Dialysis and Renal Transplantation. Journal of The Pakistan Medical Association

Hayward, et al (1989). KTRSS. In, Stressors in Renal Transplant Recipients at Six Weeks After Transplant, by Frey, G. (1990) ANNA Journal Dec:17 (6), pp. 443 – 7.

- Hudson, K. and Hiott, K. (1986). Coping With Pediatric Renal Transplant Rejection. ANNA Journal Oct: 13 (5), pp. 261 – 3
- Jacobs, A.R. and Viederman M. (1982). Adaptation to Kidney Transplantation: A Case Presentation and Discussion. General Hospital Psychiatry. Dec: 4 (4), pp. 299 – 306
- Juneau, B. (1995) Psychologic and Psychosocial Aspects of Renal Transplantation. Critical Care Nursing, 17 (4), 66 - 66.
- Kaplan, H. and Sadock, B. (1988). Synopsis of Psychiatry (5th ed). Baltimore: Williams and Wilkins.
- Keogh, A.M. and Feehally, J. (1999) A Quantitative Study Comparing Adjustment and Acceptance of Illness in Adults on Renal Replacement Therapy American Nephrology Nurses Association Journal, Oct, 26 (5), pp. 471 – 7
- Kogarah Municipal Council (1998).
- Kong, I.L. and Molassiotis, A. (1999), Quality of Life: Coping and Concerns in Chinese Patients After Renal Transplantation International Journal of Nursing Studies. Aug: 36 (4), pp. 313 – 22
- Lau, K.O. Vathsala, A. Kong, S. and Li, M k. (1999). Preliminary Results of Heart - Beating and Non - Heart Beating Donor Kidney Transplants - The Singapore Experience. Annals of The Academy of Medicine – Singapore. Mar, 28 (2), pp. 222 - 6

- Levenson, J.L. and Olbrisch, M.E. (1993). Psychological Evaluation of Organ Transplant Candidates. A comparative Survey of Process, Criteria and Outcomes in Heart, Liver, And Kidney Transplantation. Psychosomatics Jul – Aug: 34 (4), pp. 314 – 23
- Lohr, L. (1981), My Kidney Transplant With a Little Help From My Friends. Journal of The American Association of Nephrology Nurses and Technicians Feb: 8 (1), pp 56 - 7
- Merleau- Ponty, M. (1956) What is Phenomenology? Cross Currents 6, 59 – 70.
- Merleau-Ponty, M. (1962) Phenomenology and Perception, London: Routledge and Kegan Paul.
- Moran, A.U. Christensen, A.J. Ehlers, S.L. and Bertolatus, J.A. (1999), Family Environment, Intrusive Ideation Among Renal Transplant Candidates Annals of Behavioural Medicine: 21 (4), pp. 311 – 6
- Mims.(2000) Annual. Crows Nest: IMS Publishing.
- Nadel, C. and Clark, J.J. (1986). Psychosocial Adjustment After Renal Transplants General Hospital Psychiatry. Jan: 8 (1), pp. 41 – 8
- Ohkubo, M. (1995). The Quality of Life After Kidney Transplantation in Japan: Results From a Nation wide Questionnaire. Transplantation Proceedings Feb: 27 (1), pp. 1452 – 7

O'Rourke, L. (1981). Transplantation Patients Point of View.  
Journal of The American Association of Nephrology  
Nurses and Technicians Feb: 8 (1), pp. 54 - 5

O'Shaughnessy, D. (1991). Healthy Eating on a Renal Diet:  
A Cookbook For people With Renal Disease. Sydney:  
 MacLennan and Petty.

Patton, M Q. (1990). Qualitative Evaluation and Research  
Methods. (2nd ed). Newbury Pack: Sage Publication

Poznanski, E.O. Miller, E. Salguero, C. and Kelsh, R.C. (1978)  
 Quality of Life for Long Term Survivors of End Stages  
 Renal Disease. JAMA Jun 2: 239 (22). pp. 2343 - 7

Rabinowitz, S. and Van der Spuy, H.I. (1980). Psychological  
 Adaptations to a Renal Dialysis and Transplant Program: A  
 Longitudinal and Cross Section Investigation.  
International Journal of Rehabilitation Research.  
 3 (1), pp. 73 - 75

Real Estate Institute of New South Wales (1998).

Reinharz, S. (1983) Phenomenology as a Dynamic Process  
Phenomenology and Pedagogy, 1 (1), 77 - 79.

- Rodriguez, D.J. and Hunter, V.M. (1981). Nutritional Intervention in the Treatment of Chronic Renal Failure. Nurse Clinician of North America. 16 (1), PP. 573 – 585.
- Reynolds, J.M. Garralda, M.E. Postlethwaite, R.L. and Goh, D. (1991). Changes in Psychosocial Adjustment After Renal Transplantation. Archives of Disease in Childhood. Apr: 66 (4), pp 508 – 13
- Sampson, E. and Marthas, M. (1981). Group Process For The Health Professionals (2nd ed). New York: John Wiley and Sons.
- Salter, M.(1988) Altered Body Image: The Nurses Role. Chichester: John Wiley and Sons.
- Schilder, P. (1935). The Image and Appearance of the Body London: Kegan, Paul, Trench and Truber.
- Sensky, T. (1989) Psychiatric Morbidity in Renal Transplantation Psychotherapy and Psychosomatics. 52 (1-3), pp 41 – 6
- St. George Hospital (1998) Renal Transplant Registry.
- St. George Hospital (1998) Renal Unit.

Sharp, G. Caputo, J. and Price, C. (1991). Case Study:  
ESRD After Living Related Donation ANNA Journal.  
Aug: 18 (4), pp. 423 – 5

Spiegelberg H. (1965) The Penomenological Movement: An Historical Introduction, (2nd ed). Vol I-2, The Hague: Nijhoff.

Spiegelberg, H. (1975) Doing Phenomenology, The Hague: Nijhoff.

Starzomski, R. and Hilton, A. (2000), Patient and Family Adjustment to  
Kidney Transplantation With and Without Interum Period of  
Dialysis. American Nephrology Nurses Association Journal,  
Feb, 27 (1), pp. 17 - 8

Streltzer, J. Moe, M. Yanagida, E. and Siemsen, A. (1983 – 84).  
Coping With Transplant Failure: Grief Versus Denial.  
International Journal of Psychiatry in Medicine.  
13 (2), PP. 97 – 106

Strauss, A. and Corbin, J. (1994). Grounded Theory  
Methodology – An Overview. In Handbook of  
Qualitative Research (eds) NK. Denzin and Y.S.  
Lincoln. Thousand Oaks: Sage Publications.

Streubert, H. and Carpenter, D.(1995) Qualitative Research in Nursing:  
Advancing The Humanistic Imperative, Philadelphia: Lippincott.

Sutton, T.D. and Murphy, S.P. (1989). Stressors and Patterns of Coping In Renal Transplant Patients. Nursing Research. Jan – Feb: 38 (1), pp. 46 – 9

Tisza, V.B. Dorsett, P. and Morse, J. (1976). Psychological Implications of Renal Transplantation. Journal of The American Academy of Child Psychiatry Autumn: 15 (4), pp. 709 – 20

Tix, A.P. and Frazier, P.A. (1998). The Use of Religious Coping During Stressful Life Events. Journal of Consulting and Clinical Psychology. Apr, 66 (2), pp. 411 – 22

Van Gorp, M.E. (1984). Psychosocial Problems of Patients Treated With Kidney Function Replacement Therapy. Tijdschrift Voor Ziekenverpleging. Jan 17: 37 (2), pp 36 – 43

Voepel-Lewis, T. Starr, A. Ketefian, S. and White, M.J. (1990). Stress, Coping, and Quality of Life in Family Members of Kidney Transplant Recipients ANNA Journal. Dec: 17 (6), pp. 427 – 31

Vruk, P. Mau, R. Taut, K.H. Khudemann, B. and Ernst, K. (1985). Relation Between the Frequency of Complaints by Neurologic Patients and Their Solving Personal Problems. Zhurnal Nevropalologii Psikhatrii Imeni S - S Korsakova. 85 (11), pp. 1689 – 91

Weems, J. and Patterson, E.T. (1989). Coping with Uncertainty and Ambivalence. While Awaiting a Cadaveric Renal Transplant ANNA Journal. Feb: 16 (1), pp. 27 – 31



White, M.J. Ketefian, S. Starr, A.J. and Vopel-Lewis, T. (1990). Stress, Coping, and Quality of Life in Adult Kidney Transplant Recipients ANNA Journal. Dec:17 (6), pp. 421 - 4

Wilson, P.G. (1983). When Transplantation is not the Answer Clinical and Experimental Dialysis and Aphaeresis. 7 (4), pp. 325 – 33

Wilson, H.S. (1988). Research in Nursing. (2nd ed). California: Addison - Wesley.

## **Appendix one**    Ethics Approval



**FACULTY OF NURSING & HEALTH STUDIES**

Phone: (02) 685 9020  
Fax: (02) 685 9023

The Chair,  
South Eastern Sydney Area Health Service Ethics Committee  
Southern Section  
c/o Roselyn Drake, Secretary  
The St George Hospital  
Gray Street  
Kogarah NSW 2217

November 1, 1996

**Re The renal transplant recipient's perception of body-image (96/107 Bouvet)**

Edwin Bouvet has requested me, as the principal supervisor of his research project, to recommend his study to you. Edwin is a candidate for the Masters in Nursing (honours) degree in the Faculty of Nursing and Health Studies at UWS Nepean and hopes to transfer his candidature to a PhD if his progress is satisfactory by the end of 1997. His study is original - there has been little nursing research, or indeed research of any kind in this area - and his findings are likely to be of real value to nurses working with renal transplant patients.

I am familiar with Edwin's Ethics application and I have no doubt of his integrity as a researcher. He has the added advantage of having worked as a nurse in this area and is fully aware of the need for sensitive interviewing and confidentiality in his research.

I therefore recommend that he be enabled to proceed with his study at St George Hospital as soon as possible.

(Dr) Catherine J. Garrett  
Senior Lecturer  
Behavioural and Social Sciences  
Faculty of Nursing and Health Studies

cc Dr Annette Walker (Co-supervisor)



# The St. George Hospital

Gray Street

Kogarah NSW 2217

Australia

Telephone: (02) 350 1111

Facsimile: (02) 350 3999

Our Reference: 96/107  
Your Reference:  
Writer's Direct Tel: 9350 2986

3rd December, 1996

Mr. E.M. Bouvet,  
36 Serpentine Street,  
MERRYLANDS WEST 2160.

Dear Mr. Bouvet,

RE: The renal transplant recipient's perception of the  
body-image (96/107 Bouvet)

Thank you for your letter dated 7/11/96 together with enclosures.

The Committee reconsidered your application at its most recent meeting held 26th November, 1996. As you have now fulfilled all necessary conditions I hereby notify you that the Committee has agreed to approve the study.

I wish you well in this study and request a final report at the conclusion of the project.

Yours sincerely,

Roselyn Drake  
Secretary  
South Eastern Sydney Area Health Service Ethics Committee -  
Southern Section.

**Appendix two**    Consent Form

## CONSENT FORM

### TITLE OF STUDY - The Renal Transplant Recipient's Perception of Body Image

You are invited to take part in a research study. "The Renal Transplant Recipient's Perception of Body Image." The research aims to obtain your ideas regarding your body image at the time prior to and after your kidney transplant.

If you agree to participate I, Edwin Maurice Bouvet will ask you to:

Participate in three interviews, with each interview being at two months interval. The first interview two months following your transplant, the second interview four months following your transplant, and the third interview six months following your transplant. Each interview will last one to one and a half hours.

There will be no physical harm to you, and if at any time you feel distressed in any way arrangements will be made to have a counsellor available to you. Any information obtained in connection with this study and that can identify you will remain confidential and will be disclosed only with your permission. By signing this document you consent to the disclosure of information that will not identify you.

Your decision whether or not to participate will not affect your future relationship with any part of the South Eastern Sydney Area Health Service. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time. Any such withdrawal will not affect any

Signature of Participant  
Date:

Signature of Investigator  
Date: