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**FEMALE PATIENTS' EXPERIENCES OF CONFLICTING EXPECTATIONS
CONCERNING PREGNANCY WHEN GETTING LONG-TERM KIDNEY
DIALYSIS**

by

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**Department of Nursing Science
School of Health Care Sciences
Faculty of Health Science
University of Pretoria**

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July 2016

DECLARATION

I, Hester Cecilia Coetzee, hereby declare that the dissertation, '**Female patients' experiences of conflicting expectations concerning pregnancy when getting long term kidney dialysis**', is my own work. This work has not been submitted for any degree purposes to any other university. All citations and sources used have been indicated and duly acknowledged by means of complete references.

Hester Cecilia Coetzee

Student number: 25400178

Date

DEDICATION

I dedicate this work to my heavenly Father who carries me up paths I could not tread on my own strength.

Also my husband Theo who motivates and enables me to accomplish what I could never envision

The participants who inspired this study and shared their experiences with me.

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ABSTRACT

Title: Female patients' experiences of conflicting expectations concerning pregnancy when getting long-term kidney dialysis

Aim: The aim was to explore and describe female patients' experiences of the conflicting expectations concerning pregnancy when getting long-term kidney dialysis.

Method: A descriptive phenomenological study was conducted. The context of the study referred to the dialysis unit in a level 3 hospital (an academic hospital) in Gauteng, South Africa, where patients receive haemodialysis and continuous ambulatory peritoneal dialysis on an outpatient basis. The study population comprised of female patients of childbearing age who received dialysis in this unit.

In-depth interviews were conducted with eight participants who were purposively selected. Female patients who met the inclusion criteria and who wished to have children or declared conflict with significant family members about getting pregnant were invited to participate. Only one main question was asked: *How do you experience the expectations of your husband/partner and other family members that you should get pregnant while the doctors and nurses tell you that you should not get pregnant while you are on kidney dialysis?* Probing questions were used to make sure relevant and rich data were collected.

Field notes made by the researcher during and immediately after the interviews added to an accurate description of the participants' experiences. The recorded interviews were transcribed verbatim by the researcher. The interviews and field notes were read and re-read thereby allowing the researcher to get a good understanding of the initial whole of the data. Thereafter, the data were divided into units of meaning which were grouped into clusters of meanings that were then used to detect a provisional pattern to recognise the essential meanings (constituents). The constituents were linked to each other to define the essence of the phenomenon which represented the whole of the experiences.

Findings: The essence (meaning) of the experiences was: ‘being-for-oneself’ and ‘being-for-others’ in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis. The essence was supported by the following constituents (meaning units): living with contradictory expectations from their mothers and future families-in-law; living with cultural transition; and attempts to be composed by living in the present and hoping for the future. The description of the essence and substantiating constituents were followed by a discussion in which literature was used to add to the understanding of the essence the phenomenon

The participants experienced their mothers and future families-in-law wished for them to bear grandchildren. Their mothers accepted their pregnancy limitation and supported their ‘being-for-oneself’ whereas their future families-in-law demanded grandchildren and did not support their ‘being-for-oneself’ but placed the burden of ‘being-for-others’ on them. Participants demonstrated cultural transition by making the informed choice to postpone pregnancy until after a kidney transplant or by considering alternative methods of having children. However, future families-in-law who held on to traditional African cultural beliefs that necessitated women to bear children, placed demands on the participants’ ‘being-for-others’ that they could not comply with. The participants attempted to avoid conflict by not discussing their pregnancy limitation. The participants experienced emotional pain related to the effect of childlessness on themselves as well as on their mothers, partners and supporting family members. The possibility of pregnancy after having a kidney transplant gave participants, their partners and their family members the hope of having children in the future and resolving the conflict in expectations they were experiencing in the present time.

Keywords:

Female patients, experiences, conflicting expectations, pregnancy, dialysis

TABLE OF CONTENTS

	Page
DECLARATION	ii
DEDICATION	iii
ACKNOWLEDGMENTS	iv
ABSTRACT	v
TABLE OF CONTENTS	vii
LIST OF ABBREVIATIONS AND ACRONYMS	xi

CHAPTER 1: BACKGROUND TO THE STUDY

1.1	INTRODUCTION.....	1
1.2	BACKGROUND TO THE PROBLEM STATEMENT.....	2
1.2.1	TREATMENT OF PATIENTS WITH CHRONIC KIDNEY FAILURE.....	4
1.2.2	PREGNANCY AND LONG-TERM KIDNEY DIALYSIS.....	5
1.2.3	INFERTILITY AND CHILDLESSNESS.....	6
1.3	PROBLEM STATEMENT.....	7
1.4	RESEARCH QUESTION.....	8
1.5	AIM AND OBJECTIVES.....	9
1.6	SIGNIFICANCE OF THE STUDY.....	9
1.7	CONCEPT CLARIFICATIONS.....	10
1.8	DELINEATION AND CONTEXT OF THE STUDY.....	11
1.9	RESEARCH METHODOLOGY.....	12
1.10	ETHICAL CONSIDERATIONS.....	12
1.11	SUMMARY.....	13

CHAPTER 2: PARADIGMATIC PERSPECTIVE, PHILOSOPHICAL FRAMEWORK AND RESEARCH METHODOLOGY

2.1	INTRODUCTION.....	14
2.2	PARADIGMATIC PERSPECTIVE.....	14
2.2.1	Research paradigm.....	14
2.2.2	Meta-theoretical assumptions: constructivist paradigm.....	15

2.3	PHENOMENOLOGY AS PHILOSOPHICAL FRAMEWORK AND RESEARCH APPROACH.....	16
2.4	RESEARCH DESIGN.....	24
2.4.1	Research method.....	25
2.4.1.1	Assuming the phenomenological attitude	25
2.4.1.2	Researcher’s role	27
2.4.1.3	Research setting	28
2.4.1.4	Selection of participants	28
2.4.1.5	Inclusion criteria	30
2.4.1.6	Data collection	30
2.4.1.7	Data analysis	34
2.4.1.8	Description of findings	37
2.4.1.9	Literature review	38
2.4.2	Measures to ensure trustworthiness.....	38
2.4.2.1	Credibility	39
2.4.2.2	Dependability	39
2.4.2.3	Confirmability	40
2.4.2.4	Transferability	40
2.5	SUMMARY.....	40

CHAPTER 3: DESCRIPTION OF RESEARCH FINDINGS

3.1	INTRODUCTION.....	42
3.2	FINDINGS.....	42
3.2.1	Living with contradictory expectations from their mothers and future families-in-law.....	44
3.2.2	Living with cultural transition.....	48
3.2.3	Attempts to be composed by living in the present and hoping for the future.....	59
3.3	SUMMARY.....	66

CHAPTER 4: DISCUSSION OF FINDINGS

4.1	INTRODUCTION.....	67
4.2	THE ESSENCE OF THE EXPERIENCE ‘BEING-FOR-ONESELF’ AND ‘BEING-FOR-OTHERS’ IN ORDER TO LIVE WITH CONFLICTING EXPECTATIONS REGARDING PREGNANCY WHEN GETTING LONG-TERM KIDNEY DIALYSIS.....	67
4.2.1	Living with contradictory expectations from their mothers and future families-in-law.....	69
4.2.2	Living with cultural transition.....	76
4.2.2.1	Own cultural transition	76
4.2.2.2	Cultural transition of family members and partners	79

4.2.3	Attempts to be composed by living in the present and hoping for the future.....	82
4.2.3.1	Avoiding conflict with self and others	82
4.2.2.3	Dealing with emotional pain	85
4.3.3.3	Living with the hope for a kidney transplant	88
4.3	SUMMARY	90

CHAPTER 5: SUMMARY OF FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

5.1	INTRODUCTION	91
5.2	SUMMARY OF THE FINDINGS	91
5.2.1	The essence: 'being-for-oneself' and 'being-for-others' in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis	92
5.2.2	Living with contradictory expectations from their mothers and future families-in-law.....	93
5.2.3	Living with cultural transition.....	93
5.2.4	Attempts to be composed by living in the present and hoping for the future	94
5.3	LIMITATIONS OF THE STUDY	95
5.4	RECOMMENDATIONS	95
5.5	CONCLUSION.....	96

LIST OF REFERENCES 97

LIST OF ANNEXURES

ANNEXURE A: FACULTY OF HEALTH SCIENCES UNIVERSITY OF PRETORIA ETHICAL COMMITTEE APPROVAL	113
ANNEXURE B: STEVE BIKO ACADEMIC HOSPITAL PERMISSION TO CONDUCT STUDY	115
ANNEXURE C: INFORMATION LEAFLET AND INFORMED CONSENT	117
ANNEXURE D: UNSTRUCTURED INTERVIEW GUIDE	122
ANNEXURE E: SAMPLE OF AN INTERVIEW TRANSCRIPT	124
ANNEXURE F: SAMPLE OF BRACKETING INTERVIEW	134
ANNEXURE G: SAMPLE OF REFLEXIVE JOURNAL	136
ANNEXURE H: SAMPLE OF DESCRIPTIVE NOTE	138
ANNEXURE I: SAMPLE OF METHODOLOGICAL NOTE.....	140

ANNEXURE J: SAMPLE OF THEORETICAL NOTE142

ANNEXURE K: SAMPLE OF PERSONAL NOTE.....145

ANNEXURE L: DATA ANALYSIS – MEANING UNITS..... 148

LIST OF ABBREVIATIONS AND ACRONYMS

Abbreviation / acronym	Meaning
CAPD	continuous ambulatory peritoneal dialysis
CKD	chronic kidney disease
ESRD	end stage renal disease
HD	haemodialysis
KDIGO	Kidney Disease Improving Global Outcomes
NKF	National Kidney Foundation
PD	peritoneal dialysis
SARR	South African Renal Registry
TOP	termination of pregnancy

Chapter 1

Background to the study

1.1 INTRODUCTION

Female patients of reproductive age who are getting long-term kidney dialysis are normally advised by the dialysis team not to get pregnant while on treatment because pregnancy increases the health risks for both the mother and infant (Piccoli et al. 2010: 69). It is well documented that bearing children is highly valued in many traditional cultures. In some societies childless women are confronted with disinheritance, exposure to intimate partner violence, and isolation from their families (European Society for Human Reproduction and Embryology Task Force on Ethics and Law (ESHRE) task force on Ethics and Law 2009: 1008). Therefore, to be informed of the dire consequences of becoming pregnant by the dialysis team on the one hand while on the other being pushed by family members to fall pregnant, caused a dilemma for many of these female patients.

Patients maintained on long-term kidney dialysis experience various physical, psychological and social difficulties. They need positive, ongoing support and understanding from the dialysis team as well as their families to stay motivated and comply with the demands and restrictions of maintaining their treatment. Luders et al. (2010: 77) state although the dialysis does not cure them, it does improve their quality of life. These authors add with today's cutting edge advances in new treatment developments giving long-term dialysis patients more options than before, their life expectancy is increasing and quality of life bettered.

During her five years of practising in a kidney dialysis unit, the researcher became aware of the inner conflict female patients of reproductive age experience whenever families started pressurising them to have a baby. She also observed two out of every three female patients receiving long-term dialysis treatment in the unit were of reproductive age (18 – 45 years). Although no written dialysis unit or hospital policy could be found to support or clarify it, the prevailing practice upheld at the institution where the study was done was that female patients who receive long-term kidney dialysis are advised by the dialysis team to

take preventative measures not to get pregnant. These patients are advised to delay planned pregnancies until after they have had a kidney transplant and, in cases where they do become pregnant, termination of the pregnancy (TOP) is advised.

Over time, certain situations occurred which made the researcher realise there is a gap in existing knowledge with regard to female patients of specifically reproductive age who receive long-term kidney dialysis and how they experience the advice of the dialysis team versus the expectations of their families on the pregnancy issue. These female patients are advised by the dialysis team not to get pregnant; on the other hand, the family expects and pushes them to get pregnant. One particular female patient, who became extremely depressed after she had had more than one pregnancy terminations, made the researcher aware of the need to investigate the conflicting expectations between the family and the dialysis team regarding pregnancy while on long-term kidney dialysis. In another instance, a female patient begged the dialysis team to help her to get pregnant as her culture prescribed that she should have a child in order to get married. She was distressed because her boyfriend's family had been planning to pay *lobola* ('bride price') and the family did not understand why she was not allowed to get pregnant. These patients' plight invigorated the researcher's determination to conduct this study.

The aim of this study was therefore to explore and describe female patients' experiences of the conflicting expectations concerning pregnancy when getting long-term kidney dialysis.

1.2 BACKGROUND TO THE PROBLEM STATEMENT

Almost a decade ago, Barsoum (2006: 997-999) observed the rise in incidence and the prevalence of chronic kidney disease (CKD) contributed significantly to the morbidity, mortality, and decreased life expectancy of young adults in sub-Saharan Africa who were in their economically productive years. Late presentation to the hospital, limited renal replacement therapy and its unaffordability, poor awareness of kidney disease in communities, and the absence of kidney disease prevention programmes in most sub-Saharan countries were listed as contributory factors. In 2010 Ifeoma and Chinwuba

(2010: 1 of 6) again noted “the magnitude of the problem of chronic kidney disease (CKD) is enormous, and the prevalence keeps rising”.

To highlight the current global burden of CKD it is vital to obtain an accurate and a complete picture of the prevalence and treatment of CKD and end stage renal disease (ESRD) in a country. Unfortunately, as Arongundada and Barsoum (2008: 515-518) and White et al. (2008: 229-237) confirm, the scarcity or total lack of national registries, representative surveys, and treatment centre and hospital records in low- to middle-income countries (including those in sub-Saharan Africa) makes it impossible to determine the type of kidney disease, the exact number of patients on dialysis, and the treatment gender distribution. Arongundada and Barsoum (2008: 516) further state in most sub-Saharan countries CKD is difficult to compute and unreliable hospital prevalence reports must be relied on for estimates. For example, according to Abu-Aisha and Elamin (2010: 24-25), statistics estimated the number of kidney dialysis patients in Africa in 2007 was “about” 69 800.

Concerning South Africa, the recent South African Renal Registry SARR 2012 informs that the previous registry, “the South African Dialysis and Transplantation Registry, last reported data from 1994” and there had been a dearth of “reliable data on RRT in South Africa for the previous two decades” (Davids, Marais & Jacobs 2014: 3). The SARR 2013 reflects the provision of RRT across South Africa indicates the number of patients in the country with ESRD on treatment as 8840 in 2013 (Davids, Marais, Balbir Singh & Jacobs 2015: 19).

Davids, Marais and Jacobs (2014: 11 & 12) report dialysis units in the South African health sector have increased from 31 to 191 between 1994 and 2012 and thus the treatment rate for dialysis patients increased from 70 per million population to 164 per million population over the last almost two decades. The SARR Report (Davids, Marais, Balbir Singh & Jacobs 2015: 9) that shows figures from all nine of the provinces indicate Gauteng as having the highest prevalence of patients on RRT (2922). The mean age for patients treated in the public sector was “43.0 ± 13.5 years and in the private sector 53.4 ± 14.3

years” with the gender distribution 40.4% female and 59.6% male (.Davids, Marais, Balbir Singh & Jacobs 2015: 13).

1.2.1 TREATMENT OF PATIENTS WITH CHRONIC KIDNEY FAILURE

Chronic kidney failure results from loss of kidney function caused by chronic kidney disease (CKD). (National Kidney Foundation [NKF n.p.]: <https://www.kidney.org/kidneydisease/aboutckd>). Chronic kidney disease originates from various causes of which the most common sources in South Africa are glomerulonephritis and hypertensive nephropathy (Davids, Marais, Balbir Singh & Jacobs 2015: 14). Stage 5 of CKD is the final stage of kidney function decline and is defined by a glomerular filtration rate (GFR) to less than $15 \text{ mL/min/1.73m}^2$. This measurement indicates that the kidneys have lost 85-90% of their function (also known as end stage renal disease [ESRD]). (National Kidney Foundation [NKF n.p.]: <https://www.kidney.org/atoz/content/dialysisinfo>).

End stage renal disease is life-threatening and requires treatment with either kidney dialysis or a kidney transplant. Kidney dialysis does not cure kidney disease. The purpose of kidney dialysis is to remove waste products from the blood, dispose of excess fluid in the body, and maintain safe levels of electrolytes in the blood as well as to assist in blood pressure management. The typical life expectation for a person receiving long-term kidney dialysis is 5 – 10 years (National Kidney Foundation [NKF n.p.]: <https://www.kidney.org/atoz/content/dialysisinfo>).

The ideal treatment for ESRD is a kidney transplant. A kidney transplant may improve the quality of life of the recipient and offer greater independence when compared to kidney dialysis. During a kidney transplant operation a kidney from a human donor (living or deceased) is implanted into a recipient. The recipient is required to take immunosuppressant medication continuously to prevent the body from rejecting the transplanted kidney and impairing it's functioning. (National Kidney Foundation [NKF n.p.]: <https://www.kidney.org/atoz/content/kidneytransnewlease>).

Unfortunately, the availability of kidneys from deceased donors for transplants is declining in South Africa. Conversely, the numbers of people waiting for organs are increasing, necessitating the petition for living kidney donations (Muller 2013: 220). In South Africa

there were 6295 patients receiving haemodialysis and 1238 patients receiving peritoneal dialysis as treatment modality in 2013 compared to only 1307 transplanted patients (Davids, Marais, Balbir Singh & Jacobs 2015: 11). The distribution of patients with kidney transplant as treatment modality has reduced from 55.5% in 1994 to 18.8% in 2012 (Davids, Marais & Jacobs 2014: 14). The limited dialysis locations and scarcity of the availability of kidneys for transplant compelled dialysis units in the government sector to set criteria for people to be eligible for the transplant waiting list. “Only patients who can tolerate surgery and postoperative immunosuppression” are on the kidney transplant list (Muller 2013: 220). Patients’ waiting time for a transplantable kidney is unpredictable and affected by their blood group (Muller 2013: 220). This author adds that patients with the O blood group have the longest waiting time because it is compatible and functional for recipients from other blood groups but not vice-versa.

At the hospital where this study was done, 72 patients (male and females) were receiving long-term kidney dialysis in January 2013. Of the 34 female patients 22 were of reproductive age (Hospital dialysis statistics 2013). Over the previous five years (from 2009 to 2014) the average number of kidney transplants done in this hospital was only five per year (Hospital transplant register 2014). The waiting period for a kidney transplant can take years; it cannot be predicted or estimated. In the meantime, patients with ESRD are kept functional with long-term kidney dialysis while waiting for transplants (National Kidney Foundation [NKF n.p.]: <https://www.kidney.org/atoz/content/dialysisinfo>). Without such long-term treatment, ESRD patients inevitably develop complications that can lead to death (Kidney Disease Improving Global Outcomes [KDIGO] 2013: 19).

Two types of long-term kidney dialysis are offered on an outpatient basis at the selected hospital, namely haemodialysis (HD) and continuous ambulatory peritoneal dialysis (CAPD). This study was applicable to female patients of reproductive age from both dialyses types. It must be noted that from here onwards in the study, the concept ‘long-term kidney dialysis’ will refer to both HD and CAPD.

1.2.2 PREGNANCY AND LONG-TERM KIDNEY DIALYSIS

After a successful transplant patients do not need dialysis any longer and their general condition usually improves dramatically; a woman's fertility may return to normal after a successful kidney transplant (Harilall & Kasiram 2011: 2 of 10). Conversely, the fertility of female patients receiving long-term kidney dialysis is reduced (Al-Saran & Sabry 2009: 175). Ashuntantang et al. (2014: 2-3 of 5) report pregnancy is rare in the resource constrained dialysis centre in Cameroon with a 7% incidence in 11 years. The outcomes of pregnancies that occur in women after commencing long-term dialysis vary. The variations in outcomes differ because the resources to provide optimal care vary from being available or accessible to being available but not accessible or not available. Ashuntantang et al. (2014: 2-3 of 5) further report in the Cameroon government-funded dialysis centre, six pregnancies were recorded, but only one live birth was produced. Piccoli et al. (2010: 69 - 70) estimate the risk of babies being born premature to women receiving kidney dialysis to be between 67% and 100%. They suggest a counselling plan for female kidney dialysis patients of reproductive age should focus on the risks of complications during pregnancy for female patients as well as the poor outcome for the babies.

Provided that her kidney function is stable, the KDIGO (2009: S107) recommends a waiting period of at least one year after a kidney transplant before a female patient attempts pregnancy. These guidelines also recommend that the immune suppression medication of the female kidney transplant patient should be adapted as preparation for a safer pregnancy and to ensure better outcomes for both mother and infant.

1.2.3 INFERTILITY AND CHILDLESSNESS

Almost all women who share pregnancy and birth view it as a special and fulfilling experience. Greil, Slouson-Blevins and McQuillan (2010: 145) state "while all societies are pro-natalist, some emphasise the centrality of motherhood to women's identity more than others". For example, having children is considered both a personal and social blessing in some traditional African cultures whereas not having children or not being able to conceive a child may be considered a misfortune or a sign of a curse. Greil Slouson-Blevins and McQuillan (2010: 145) emphasise the importance of understanding "the socio-cultural context [that shapes] the lived experience of infertility" [researcher supplied clarification] when attempting to describe how women feel when they are advised not to have children.

Perhaps the traditional Tanzanian saying, “*Pay attention to the pregnant woman, for there is no one more important than she*” (Guttman cited by Newman & Newman 2011: 124) best reflects the fulfilment and significance an offspring can bring to not only to the mother and father, but also to the whole family circle.

Studying the implications of childlessness should be done through the understanding of the people (in this case ‘people’ represent ‘female patients on long-term kidney dialysis’) who wish to have children as only they can describe their experiences (Dyer 2008: 32). A woman who desires a child and/or whose family expects her to produce an offspring, but is constantly advised by the dialysis team to wait for a transplant, is subjected to additional uncertainty due to the negative effect that the immune suppressive treatment may have on the foetus after a kidney transplant (KDIGO 2009: S107).

1.3 PROBLEM STATEMENT

For female patients of reproductive age receiving long-term kidney dialysis, the demand from the family for pregnancy aggravates the existing stress and anxiety they endure while on long-term dialysis treatment. In contrast to contemporary western attitudes, the traditional African culture dictates that personal fulfilment for the African is achieved principally through having children. This means the attitude and belief on pregnancy and childbirth of some families are so deeply rooted that they may, although unknowingly, expect the female dialysis patient to conceive a child in spite of her disease or the effect it can have on her and the infant’s health. Then again, these female patients are advised and warned by the dialysis team that getting pregnant may compromise their own as well as the infant’s health. Obviously, the contrasting expectations from the family on the one hand and those of the dialysis team on the other hand can cause extreme tension and inner turmoil in the female patients which can impact negatively on her emotional as well as physical health.

Many female kidney dialysis patients invariably turn to the dialysis team for support and guidance on how to cope with the conflicting demands and expectations because they believe the team will understand their dilemma. However, the dialysis team can also find it

challenging because they might not always understand how the female patients feel about postponing pregnancy. The female patients often express their anger and frustration to the dialysis team. The patients may, for example, feel many other females lead a normal life while they have to suffer mentally and physically by constantly undergoing repeated medical procedures.

The researcher further observed that the professional staff members often have the tendency to identify with patients and project their values regarding dialysis onto the patients regarding what they (the staff members) would do if they had renal failure and had to undergo dialysis. But, the professional dialysis team members are highly skilled and experienced in life education – they therefore need to be aware that they have to be strict while handling female long-term dialysis patients of reproductive age, but also gentle and supportive when needed. They must set realistic goal for these female patients, make them aware of the possible problems not only for themselves but also for their infants should they fall pregnant. The dialysis team members have to also advise particularly the female patients on how to approach the pregnancy issue in their household or family. They need to be aware and monitor the emotional difficulties present in female long-term dialysis patients.

Understanding the conflicting expectations female patients experience when getting long-term kidney dialysis might help to develop support that focus more specific on the patients' needs (Dyer 2008: 32). It is essential that these patients receive applicable emotional support and guidance as to prevent stress and emotional problems that may affect their treatment and well-being that is already compromised (KDIGO 2009: S107).

1.4 RESEARCH QUESTION

The research question for this study was:

“How do female patients of reproductive age experience the conflicting expectations concerning pregnancy when getting long-term kidney dialysis?”

1.5 AIM AND OBJECTIVES

The aim of this study was to explore and describe the female patients of reproductive age's experiences of the conflicting expectations concerning pregnancy when getting long-term kidney dialysis.

The objectives of the study were to:

- explore and describe the experiences of female patients of the expectations of their family regarding them getting pregnant during long-term kidney dialysis;
- explore and describe the experiences of female patients of the expectations of the dialysis team regarding them not getting pregnant during long-term kidney dialysis;
- explore and describe the experiences of female patients of the conflicting expectations between their family and the dialysis team regarding them getting or not getting pregnant during long-term kidney dialysis.

1.6 SIGNIFICANCE OF THE STUDY

The ESHRE task force on Ethics and Law (2009: 1010) recommends training of individuals and the society as a solution to problems related to infertility to “reduce social exclusion and stigmatization of infertile persons”. This applies to long-term dialysis patients as they receive treatment on an outpatient basis and continue with their “normal” lives in society. Some of them work or attend school or university in-between dialysis sessions. They meet friends, fall in love, get married and want to get pregnant.

The findings of this study can enhance the dialysis team's understanding of the emotional and psychological trauma that female patients of reproductive age who are getting long-term kidney dialysis treatment experience. By understanding and accepting the specific problems and issues these female patients have to deal with – apart from the long-term dialysis treatment itself – may enable the professional dialysis team caring for them to

render holistic care to female patients of reproductive age. The findings will expand the basis for future research on the experiences of patients receiving kidney dialysis. It will also provide guidance to adapt nursing education curricula related to nursing care provided to female patients on long-term kidney dialysis. Most importantly, recommendations emerging from the study findings may improve the emotional well-being of female patients with kidney failure.

1.7 CONCEPT CLARIFICATIONS

For the purpose of this study the following terms are used as defined below.

“**Family**” refers to all significant others regarded by the participants as family, thus including parents, grandmothers (who fulfilled the role of mothers to some participants) and other extended family members. This also includes previous, current and future spouses/partners and families-in-law/prospective families-in-law.

The “**dialysis team**” refers to the registered nurses, dialysis technologists, doctors and social workers who provide care to patients (male and female) in the dialysis unit where the study was conducted.

“**Kidney dialysis**” refers to a treatment for end stage renal disease (ESRD) with the aim to remove waste products, salt and extra water from the patients’ blood and tissue fluid to prevent it from building up in the body (NKF n.p. <https://www.kidney.org/atoz/content/dialysisinfo>). Kidney dialysis includes two types, namely haemodialysis (HD) and peritoneal dialysis (PD). Haemodialysis is the process of filtering blood to remove waste products and extra fluid from the blood using a designed, external blood filter. Haemodialysis treatments are usually done three times a week and each treatment lasts between three and five hours (NKF n.p. <https://www.kidney.org/atoz/content/hemodialysis>). Peritoneal dialysis filters the blood inside the body. The lining of the abdomen (the peritoneum) acts as a natural filter. With continuous ambulatory peritoneal dialysis (CAPD), patients are taught to do the exchanges

themselves four to six times a day with an exchange lasting about 30 minutes each (NKF n.p. <https://www.kidney.org/atoz/content/peritoneal>).

“**Experience**” refers to the subjective experience of an objective phenomenon. According to Husserl, the subjective experience is the most reliable source to be studied when one wants to study a phenomenon (Cogswell 2008: 85). Pascal et al. (2010: 178) explains Husserl’s phenomenology is the exploration of the conscious lived experiences of the phenomenon (conflicting expectations between the dialysis team and the family regarding pregnancies) as it is seen in daily encounters by participants (female patients of reproductive age who are getting long-term kidney dialysis) who have been exposed to the phenomenon.

1.8 DELINEATION AND CONTEXT OF THE STUDY

Women who are suffering from chronic diseases find their reproductive decisions are influenced by health care providers and community attitudes (Harries et al. 2007: 3-5 of 7; Myer, Morrioni & Cooper 2007: 774). The fact that a female patient of reproductive age who is getting long-term kidney dialysis is advised by the dialysis team not to get pregnant, but is also pushed by her family to produce an offspring, may make her feel incomplete or unfulfilled in her role as a woman or wife. She may experience feelings of loss and struggle with emotional difficulties that may lead to her feeling negative about herself.

The focus of this study was therefore to describe the experience of female patients of reproductive age receiving long-term kidney dialysis who experience conflicting expectations: from the dialysis team who advise them not to get pregnant and their family who expect them to get pregnant.

The setting was the dialysis unit in a level 3 hospital (an academic hospital) in Gauteng, one of the nine provinces in South Africa, where patients receive long-term HD or CAPD on an outpatient basis.

1.9 RESEARCH METHODOLOGY

A qualitative research design with a descriptive phenomenological approach was used to study the phenomenon (conflicting expectations of the dialysis team and the family) as it was experienced by female patients on long-term kidney dialysis in the natural world where no variables were manipulated (Schneider et al. 2007: 106). Refer to Chapter 2 for a comprehensive description of the methodology.

1.10 ETHICAL CONSIDERATIONS

The ethical principles of beneficence, respect for human dignity and justice as articulated in the Belmont Report served as the standards for ethically conducting this study (Polit & Beck 2012: 152). Beneficence requires from the researcher to “minimise harm and maximize benefits” (Polit & Beck 2012: 152). The benefit of this study is that it could contribute to the body of knowledge in that it may be used to adapt practices to support other female patients in a similar situation as the participants. The possible harm could be the emotional distress that the participants could experience. However, although they discussed episodes of severe distress with the researcher, none of the participants displayed anxiety or distress during the interviews. On the contrary, they appreciated the opportunity to talk openly about their experiences and feelings; they felt they were being supported.

Respect for human dignity includes the right to self-determination (Polit & Beck 2012: 154). Detailed information about the study was given in writing to potential participants to enable them to make informed decisions about participating or declining participation. Voluntary informed consent was obtained from all the participants before data gathering began. (Refer to Annexure C).

The principle of justice means the right to fair treatment and privacy (Polit & Beck 2012: 155-156). Fair treatment in this study implied treating participants who decided to withdraw after having consented and those who declined participation in the study no different from other patients in the unit. None of the participants withdrew from the study after consent

was obtained. To maintain the privacy of the participants, confidentiality was maintained during and after the research process by codenaming their records and keeping them safe. In future publication of the research reports (dissertation and article in a research journal) no information will be included that can lead to the identification of the participants.

The research proposal was approved by the Faculty of Health Science Research Ethics Committee of the University of Pretoria under whose patronage the research was conducted. (Refer to Annexure A). The management of the hospital where the study was conducted gave permission for the data to be gathered. (Refer to Annexure B).

1.11 SUMMARY

In Chapter 1 an in-depth description of the background to the study was given. The research question, objectives of the study and the problem statement were presented and the concepts clarified. In Chapter 2 the assumptions and methodology of the study will be presented.

CHAPTER 2

PARADIGMATIC PERSPECTIVE, PHILOSOPHICAL FRAMEWORK AND RESEARCH METHODOLOGY

2.1 INTRODUCTION

Research studies attempt to expand, refine and develop the body of knowledge (Polit & Beck 2012: 3). Nursing research improves the understanding of concepts central to the discipline and informs nursing practice through exploring the effectiveness of current practices and developing new or improved nursing interventions. The contemporary highlighting of evidence-based practice in nursing necessitates a wide-ranging, up-to-date research databank to base clinical practice on (Polit & Beck 2012: 11).

The aim of this study was to explore and describe the female patients of reproductive age's experiences of conflicting expectations concerning pregnancy when getting long-term kidney dialysis treatment.

This chapter provides a critical overview of the paradigmatic perspective and philosophical framework that form the foundation of the research process. The overview is followed by a description of the research methodology used in this study.

2.2 PARADIGMATIC PERSPECTIVE

In this study a constructivist paradigm was used.

2.2.1 Research paradigm

A paradigm is an overarching philosophical world view or “general perspective on the complexities of the world” (Polit & Beck 2012: 11). It assists the researcher in deciding what to study and how to conduct the study (Botma et al. 2010: 40). The **constructivist paradigm** (also called the naturalistic paradigm) originated as a countermovement to the

positivist paradigm. In the positivist paradigm, much research activity is directed at determining the underlying causes of and reasons for the occurrence of phenomena. Tight control of the research context and objectivity of the researchers are desirable to promote reliable and valid findings (Polit & Beck 2012: 12). Positivism has “a methodical objective opinion that endorses results from scientific investigation that supports pre-formulated theories” (Cogswell 2008: 85).

Opposing the positivist view, constructivist researchers believe meaning is socially rather than individually constructed by people experiencing a phenomenon. This meaning becomes a “heritage or custom that can be reinterpreted” using the constructivists’ viewpoint (Barkway 2001: 193). Reality is the outcome of a constructive development that exists within a context (De Vos et al. 2011: 310). This context or life-world is full of meanings; therefore, researchers need to interact with study participants to get an understanding of the latter’s constructed realities (Polit & Beck 2012: 12).

2.2.2 Meta-theoretical assumptions: constructivist paradigm

The type of research paradigm used in research is recognised in its response to ontological, epistemological and methodological questions. A world view answers **ontological** questions about the nature of reality and the characteristics of the phenomenon under study (Botma et al. 2010: 40). The scientific view of the researcher relates to his or her world view and concerns **epistemological** questions such as “what counts as valid knowledge” and **methodological** questions regarding the methods chosen to obtain that knowledge (Polit & Beck 2012: 13).

Constructivist researchers operate under certain **ontological assumptions**. They view the world not as an objective reality, but rather as subjective mental constructions selected, built and enhanced by individuals based on their experiences. Reality is flexible because several interpretations are possible and probable between different human beings (Polit & Beck 2012: 12). The researcher used the subjective perspective to explore the reality of the participants’ (female patients) experiences of the phenomenon (conflicting expectations between the dialysis team and the family regarding pregnancies). Every

participant was given the opportunity to share her perspective of the phenomenon constructed from each one's own experiences.

Within the **epistemological assumptions** underlying a constructivist paradigm, knowledge regarding a phenomenon is believed to be best interpreted when the inquirer personally interacts with the participant who has knowledge regarding the phenomenon of interest (Polit & Beck 2012: 12). According to constructivists, knowledge is subjectively assembled from the participant's interaction with the phenomenon in the environment. People do not construct meaning objectively or individually anew as they come across phenomena (Crotty (1998) cited in Caelli 2000: 372). Meaning is socially constructed and interpreted from the basis of relations and practices (Barkway 2001: 193). The researcher's role in this study was to facilitate the participants' descriptions of their experiences (knowledge of the phenomenon) through interaction with the researcher.

Certain **methodological assumptions** are generic to the different methodologies and approaches used within a constructivist paradigm because it is dedicated to understanding the lived experiences of the participants (Polit & Beck 2012: 14). The qualitative method is suitable for the constructivist paradigm because studies are usually conducted in the field with participants in a natural environment. In the current study, the researcher used the real-life setting of the dialysis unit which formed part of the participants' lives due to regular visits for treatment and monitoring of the effectiveness of the treatment. Data collection and analysis advanced simultaneously; questions were adapted to clarify the phenomenon as meanings evolved. The findings were based on the experiences of the participants.

2.3 PHENOMENOLOGY AS PHILOSOPHICAL FRAMEWORK AND RESEARCH APPROACH

In this study a descriptive phenomenological approach was used to explore and describe female patients' experiences of conflicting expectations concerning pregnancy when getting long-term kidney dialysis. Phenomenology is a research approach within the constructivist paradigm which aims to "return to embodied, experiential meanings aiming for a fresh, complex, rich description of a phenomenon as it is concretely lived" (Finlay

2009: 6). Edmund Husserl (1859 – 1938), German philosopher and founder of modern phenomenology, (cited in Streubert Speziale & Carpenter 2007: 78) asserted that phenomenology as a philosophy should become the guiding foundation for scientific thinking. Husserl viewed humans as “subject(s) in a world of objects and it was the study of the conscious awareness of those objects that he called phenomenology” (Schneider et al. 2007: 109). Phenomenology takes note of the researcher’s relationship with the participant by asserting the objectivity needed for science while findings are still grounded in human lives (Dahlberg, Dahlberg & Nyström 2008: 31).

Husserl’s descriptive phenomenology is “a philosophy that looks on human experience as a mixture of feeling, awareness and consciousness” which aims to infiltrate the impression of reality to determine the fundamental underlying reality (Higgs & Smith 2006: 55-56). Using the descriptive phenomenological research method requires an exploration of phenomena through direct interaction between the researcher and the participants (Wojnar & Swanson 2007: 174). It involves the “careful description of ordinary conscious experience of everyday life” (Polit & Beck 2012: 495). Husserl advocated a return “to the things themselves” as the slogan of phenomenology; hence, the researcher should repeatedly return to the sources themselves (the participants) to get information about or confirm information regarding the meanings of the experiences concerning the phenomenon (in the case of this study the conflicting expectations between the dialysis team and the family and regarding pregnancy) (Cogswell 2008: 86).

Descriptive phenomenological studies commonly involve the following: “bracketing, intuiting, analysing and describing” (Polit & Beck 2012: 495). By bracketing their own perceptions regarding the phenomenon, researchers can explore the phenomenon and experiences by examining it from the point of view of the person experiencing it (Cogswell 2008: 86). This allows the experience of the phenomenon to be analysed and described according to its own meaning, and not a meaning enforced by the researcher (Merriam & Associates 2002: 84).

a) Epistemological and ontological assumptions

- **Consciousness**

Husserl (cited in Solomon & Higgins 1996: 251) described phenomenology as “the scientific study of the essential structures of consciousness”. Consciousness is intentional and exists only because it is focused on an object. In this study ‘object’ referred to the conflicting expectations of the dialysis team and family regarding pregnancies (Zahavi 2003: 17).

Cogswell (2008: 87) states that through a study of the focused (intentional) consciousness of the participants, the phenomenon is revealed. A study of the consciousness of the phenomenon reveals the phenomenological attitude (the meaning of the experience) of the phenomenon instead of the natural attitude (the experience) of the phenomenon (Solomon & Higgins 1996: 92). Through studies of the participants’ intentional consciousness of the phenomenon researchers are able to explore and describe the phenomenon. In this study it required the researcher to bracket-out her own perceptions relating to the phenomenon so that she only focused on the consciousness of the participants who attached meaning to their experiences of the phenomenon.

- **Phenomenon**

A phenomenon is described as “that which shows itself in itself” (Heidegger (1998) cited in Dahlberg, Dahlberg & Nyström 2008: 32). It could therefore be “an object, a matter, a ‘thing’ or a ‘part’ of the world, as it presents itself to, or, as it is experienced by, a subject” (Dahlberg, Dahlberg & Nyström 2008: 33). Husserl described “psychical phenomena (as) pure phenomena which have no possibility of ‘presenting themselves in experience according to diversely varying ‘subjective appearance’” (Solomon & Higgins 1996: 91). According to LoBiondo-Wood and Haber (2010: 131), the “things” that our senses can perceive include physical and emotional pain.

Wojnar and Swanson (2007: 174) explain the “frames of reference” that can be used to define the phenomena as: transcendental subjectivity (neutrality and openness to the reality of others); eidetic essence (universal truths); and the live-world plane of interaction (interaction between researcher and participants).

- **Intentionality**

Intentionality refers to the “relationship between a person and an object or events of her/his experience, or... one’s directed awareness of an object or event” (Dahlberg, Dahlberg & Nyström 2008: 47). Intentional relationships exist within the things that surround us (what we use, see, do or where we are) as it is experienced and it has meaning for us. In phenomenological research the focus is on the meaning of ‘things’ and how researchers attempt to give meaning to it.

According to Solomon and Higgins (1996: 251), intentionality of consciousness is essential to Husserl’s phenomenology. The acts of consciousness are always focused towards an object – physical or conceptual. “Consciousness travels towards bodily experiences and bodily experiences, in turn are reflected back onto consciousness.” (Rapport & Wainwright 2006: 233). The meaning of an experience is intentionally consciously present in the mind of the person who experiences the phenomenon. The meaning is also superimposed by the mind on the phenomenon (Cogswell 2008: 87).

- **Meaning**

The meaning of a phenomenon evolves as a “determinate relationship between an act of consciousness and (the) object” (Giorgi 2005: 82). Through intentional consciousness of the object the person attaches meaning to it. Intentionality thus provides the framework for the construction of the meanings of the phenomenon. The following terms are applicable to the understanding of the meaning of a phenomenon, namely the “act of consciousness, the object towards which the act (of consciousness) is directed, and the sense with which the object is presented” (Giorgi 2005: 82). It can be explained as follows: the acts of

consciousness are focused on phenomena. The purposeful focus on phenomena is its meaning. Meaning thus refers to the way the object is experienced.

The phenomenological research method is focused on the “meaning” of experiences for the participants (Dahlberg, Dahlberg & Nyström 2008: 47). Botma et al. (2010: 190) affirm the aim of phenomenological inquiry is to identify the essence of the lived experiences of participants. The focus of this research was to understand the meaning participants attached to conflicting expectations concerning pregnancy.

- **Essences**

Essences are “the essential invariant structure” that “makes a phenomenon what it is, and without which it would not be what it is” (Polit & Beck 2012: 494). Husserl’s ideas of intentionality declare that “when the phenomenon presents itself as something, it presents its essence” (Dahlberg 2006: 12). Essences are not constructed by the researchers, but are there in the “intentional relationship” between the researcher and the phenomenon. The essence of the experience of the phenomenon is revealed during the research process (Dahlberg 2006: 11-14).

Lopez and Willis (2004: 728) explain that “for the description of the lived experience to be considered a science, commonalities in the experience of the participants must be identified, so that a generalized description is possible”. In this study the essence of the studied phenomenon represents the core meaning of the participants’ conflicting expectations concerning pregnancy.

- **Intuition**

Intuition is “to call attention to what is immediately given to us in experience” (Hintikka 1995: 86). Swanson-Kauffman and Schonwald (1988) (cited in Wojnar & Swanson 2007: 177) state intuiting gives an indication of what the participants’ lived experiences feel like. Researchers ‘intuit’ the essence of a phenomenon and do not observe it (Solomon & Higgs 1996: 93). The researchers’ intuition is stimulated by the data generated during

data collection as well as through thinking about similarities between different participants' descriptions and by trying to understand "what it must be like" to experience the phenomenon (Swanson-Kauffman & Schonwald (1988) cited in Wojnar & Swanson 2007: 177).

In descriptive phenomenology "intuiting occurs when researchers remain open to meaning attributed to the phenomenon by those who have experienced it" (Offredy & Vickers 2010: 101). Husserl recommended that researchers initiate the intuition process by starting with a concrete example of the phenomenon of which they want to grasp the essence and imaginatively vary it in every possible way to distinguish essential features from those that are incidental. The features that represent the essence of the phenomenon are present in all the experiences and descriptions of experiences (Wertz 2005: 168).

- **Life-world**

The life-world is the context in which we perceive the world (Dahlberg, Dahlberg & Nyström 2008: 37). It refers to the experiences of persons, the understanding thereof and the feelings that people have regarding these experiences (Todres & Wheeler 2001: 3). Gadamer (1995) (cited in Dahlberg, Dahlberg & Nyström 2008: 35) describes the life-world as "tacit" and thus difficult to pinpoint and to describe. The life-world of research participants are complex and their experiences cannot be separated from it (Todres & Wheeler 2001: 3). It includes the participants and also their subjective relations with their surroundings (Wertz 2005: 169).

In research the life-world becomes the object of study when aspects in the life-world which have always been taken for granted, are questioned. The "taken-for granted" becomes the phenomenon that phenomenological studies are interested in (Husserl (1970) cited in Todres & Wheeler 2001: 3).

b) Methodological assumptions

Methodology refers to a theory of producing knowledge through research and provides a rationale for the way research proceeds. The Oxford Companion to Philosophy (n.d.) (cited in Dahlberg, Dahlberg & Nyström 2008: 23) defines methodology as “the philosophical study of the scientific method”. This is applicable to the question, “how, in what way”. For example: “how, in what way, shall we go about” obtaining a description of the phenomenon of interest?

Giorgi (1997: 235) describes three criteria that must be implemented when using the method of descriptive phenomenology. These criteria, namely assuming phenomenological reduction, giving description from others, and searching for invariant meaning, are discussed next.

- **Assuming the phenomenological reduction**

The philosophical phenomenological method requires the philosopher to apply phenomenological reduction – this means to “bracket” a person’s conviction in “factual” reality in favour of “the sphere of consciousness” and to use this to “study what is immanent in it” (Hintikka 1995: 79). Giorgi (1997: 239) describes phenomenological reduction as a “methodological device invented by Husserl in order to help make research findings more precise”.

The focus of this study was on the intentionally consciousness of the phenomenon by the participants and not on the researcher’s observation of the experiences of the participants of the phenomenon (conflicting expectations between the family and the dialysis team regarding pregnancies). The observable reality (the natural attitude) was put on hold; it was therefore neither denied nor confirmed while the researcher “lifted off the ground to look down and back upon a world with clarity” to intuit the phenomenological attitude of the phenomenon (Rapport & Wainwright 2006: 232). When researchers withdraw themselves from the world they overcome the hurdles of the natural attitude (Rapport & Wainwright 2006: 232). The natural attitude of the phenomenon refers to a description of what happened without the researchers being critically aware of it, while the phenomenological attitude applies when researchers study what they have been told by the research

participants (Dahlberg, Dahlberg & Nyström 2008: 33). Through the process of phenomenological reduction natural attitudes of the phenomenon are changed into phenomenological attitudes.

Phenomenological reduction is a conscious act that is often called 'bracketing'. According to Husserl, using this method is an attempt to bracket the natural attitude or "naive belief in the reality of things" that takes "the things" of the world for granted. To change the natural attitude to a phenomenological attitude, Husserl challenged researchers to "begin examining this very 'presence'"; meaning our relationship with the world within which we intentionally experience "the things" of the world". The phenomenological attitude makes inquiries into the life-world or phenomenology as opposed to the natural attitude that takes it for granted (Dahlberg, Dahlberg & Nyström 2008: 55).

Husserl developed several phenomenological reductions to limit the influence of the researcher's experience and viewpoints on the data. This includes the *epoch* or "suspension" used to "bracket" demands for truth value to allow the description of the "contents of consciousness" (Solomon & Higgins 1996: 252). By bracketing their own past knowledge of the phenomenon, researchers can examine the phenomenon and the experience of examining it (Cogswell 2008: 86). Ashworth (1996) (cited in Finlay 2009: 12) identifies three particular areas of presupposition that need to be bracketed. Firstly, scientific theories including knowledge and explanation must be bracketed. In this study the researcher bracketed her own pre-knowledge, for example, research articles she read when writing the background to the study. In the second place, the truth or falsity of claims being made by the participants must also to be bracketed. Finally, it is necessary to bracket the personal views and experience of the researcher that would cloud descriptions of the phenomenon itself. The researcher bracketed her own experience of childlessness in the bracketing interview with her supervisor. (Refer to Annexure F for an example). The researcher applied bracketing throughout the data collection and analysis processes in this study.

- **Descriptions from others**

Husserl was interested in understanding and describing the essential nature of consciousness from a first-person perspective of the people experiencing the phenomenon (Giorgi 1997: 235). Kvale (1996) (cited in Dahlberg, Dahlberg & Nyström 2008: 183) asks the following question, “if you want to know how people understand their world and life, why not talk to them?” Research interviews result in collaboration between the researcher and the participants to develop descriptions of a phenomenon. It is important to focus on the experience of the participant while bracketing the experiences of the researcher (Dahlberg, Dahlberg & Nyström 2008: 184). In this study the researcher obtained descriptions from the participants who experienced the phenomenon under study by talking to them in unstructured interviews.

- **Search for the invariant meaning**

Eidetic reduction is derived from the Greek word *eidos* meaning ‘essence’ (Dahlberg, Dahlberg & Nyström 2008: 54). The researcher used eidetic reduction to search from particular to general “essences” (of the conflicting expectations between the family and the dialysis team pregnancies) for invariant meaning (Hintikka 1995: 79). Zahavi (2003: 39) describes eidetic reduction as “a kind of conceptual analysis where we attempt to imagine the object as being different from how it currently is”. Invariant meanings are thus deliberately searched for to differentiate the essence of the phenomenon from other incidental explanations.

2.4 RESEARCH DESIGN

A qualitative research design, using the descriptive phenomenological method, was useful to explore and describe the participants’ lived experiences of the conflicting expectations between dialysis team and the family regarding pregnancies during long-term kidney dialysis and the meaning attributed to it by the participants. The individual participants’ unique perceptions were taken into consideration as they provided in-depth descriptions of the meaning that they attached to their experiences (LoBiondo-Wood & Haber 2010: 102).

The study was undertaken in the natural world with no variables being manipulated (Schneider et al. 2007: 106). The research method and measures to ensure trustworthiness are discussed next.

2.4.1 Research method

The descriptive phenomenological method required the researcher to assume the phenomenological attitude, plan information gathering, and do data analysis in a systematic way.

2.4.1.1 Assuming the phenomenological attitude

To assume the phenomenological attitude the researcher used an open life-world approach and bracketing.

a) An open life-world approach

Gadamer (1995) (cited in Dahlberg, Dahlberg & Nyström 2008:76) illuminates that the life-world cannot be understood by a scientific method but needs an “open way” to understanding. This natural way of belonging to the world is needed for an open mind to determine something new or see its “otherness”. Hence, the open life-world approach to “understanding” formed the basis for this descriptive phenomenological study. The researcher used an open phenomenological attitude to suspend judgment while performing data collection and analysis (Finlay 2009: 8). The researcher attained an open life-world approach by remaining open to the descriptions of the meaning of their experiences by participants during the unstructured interviews and by making use of these descriptions to probe for deeper meaning.

b) Bracketing

Bracketing was used to recognise and suspend the researcher’s prior opinions about the study phenomenon (Offredy & Vickers 2010: 101). As recommended by Wojnar and Swanson (2007: 174), the researcher bracketed (or set aside) all previous assumptions

about the phenomenon under study. This allowed the phenomenon (conflicting expectations between the family and the dialysis team regarding pregnancies) to be truthfully explored through interaction between the researcher and participants without the researcher leading the participants to expected answers guided by her own beliefs and presumptions (Merriam & Associates 2002: 84).

Bracketing was achieved when the researcher did not use a “theoretical filter” to observe the participants’ experiences, but viewed it as being “open” to the way it presented itself (Cogswell 2008: 86; Gearing 2004: 1433). By bracketing her own perceptions regarding the phenomenon, the researcher could explore the phenomenon and the experience of examining it from the point of view of the participants (Cogswell 2008: 86).

Gearing (2004: 1432-1433) identifies three phases of bracketing, namely abstract formulation, research praxis, and reintegration. Applying these phases to the study, the researcher did abstract formulation by making an orientation standpoint of an ontological and epistemological world view (described previously see 2.2.2). Research praxis captured the foundational elements of bracketing including the **what**, **when** and **how**. Reintegration was achieved by un-bracketing and integrating the previously bracketed data into the study. This was done during the data analysis. Un-bracketing refers to the process when the information that has been obtained from the participants is discussed together with literature references.

The researcher bracketed all previous understanding of the phenomenon before the data collection began by using a reflexive journal to document her thoughts, feelings and personal experiences in. She was (and is still currently) a full-time professional nurse in the dialysis unit of the selected hospital.

Patients often expressed their concerns to her about the conflict they experience due to the demands of their families to bear children while the dialysis team encourages them not to get pregnant. It was thus important that she acknowledged and bracketed her experiences of the distress of female patients of reproductive age. The reflexive journal was used throughout the data collection as a bracketing tool (Refer to Annexure G for an

example). The researcher reflected on her knowledge and previous experiences of the phenomenon in an interview with one of her supervisors to bracket what she knew and to be open to the experiences of the participants (Refer to Annexure F for an example). A thorough literature review was delayed till after data analysis to prevent it from clouding the researcher's judgment and creating expectations of what the findings should be. The researcher ensured that the findings were embedded in the collected data (Hammill & Sinclair 2010: 18; Wojnar & Swanson 2007: 175) by using quotations from the interviews to substantiate the constituents (meaning units) of the essence. (Refer to Chapter 3).

2.4.1.2 Researcher's role

Streubert Speziale and Carpenter (2007: 93-94) explain the role of the researcher according to the five steps that occur in phenomenological transformation as described by Reinharz (1983). The first step is to transform the participants' experiences into language. In the second step the data obtained from the participants are transformed into an understanding of the participants' experiences. Thirdly, the researcher transforms the understanding into meaning units and essences. The fourth step is to transform the essence into text, and the fifth step is to transform the text into a description of the steps and findings.

Phenomenological transformation was applied in this study as follows: transformation started when the participants were given the opportunity to verbalise their experiences of the phenomenon (conflicting expectations between the dialysis team and the family regarding pregnancies). The researcher transformed the data into a description that promoted understanding of the participants' experiences. Data analysis was done to determine the meaning units and essence of the phenomenon. The essence was transformed into a written document on the researcher's thoughts about the collected data. Finally, the researcher transformed the written document into a description that stimulates understanding of the meaning of the phenomenon.

The researcher interacted with the participants during the interviews to obtain knowledge of each participant's experience of the social reality surrounding the phenomenon. She

applied certain skills to facilitate data collection from the participants (Reinharz (1983) cited in Streubert Speziale & Carpenter 2007: 94). Clear communication was ensured by explaining the unstructured interview method and the reasons for deep probing questions to every participant. Informing and assuring the participants that the study was about their experiences and no answer would be perceived as 'right' or 'wrong', set the participants at ease. The researcher made sure she avoided mannerisms that could distract the participants. This was necessary because the researcher served as the data collection instrument and facilitated expression of experiences in as much depth and as vividly possible. The findings were the product of this interaction between the researcher and the participants (Polit & Beck 2012: 15).

2.4.1.3 Research setting

The research setting is the specific place where information is gathered. Naturalistic settings ("in the field") were considered useful for this qualitative research (Polit & Beck 2012: 49-50).

The setting for this study was the dialysis unit in a level 3 hospital (an academic hospital) in Gauteng, South Africa, where participants receive HD or CAPD on an outpatient basis. This setting was used for data collection interviews. The participants were comfortable with the setting because they visited it often and knew the personnel and their fellow patients well. The researcher ensured privacy by securing the use of an office where interviews could be done free of disruptions. The interviews could not be overheard by others.

2.4.1.4 Selection of participants

The target population for this study was female patients of reproductive age (18 – 45 years) who were on long-term kidney dialysis and were advised by the dialysis team not to become pregnant as opposed to the wish of their family for them to get pregnant.

Purposive sampling was done to choose participants in a deliberate manner with the goal of involving participants who experienced the phenomenon and were considered capable to provide rich data on the topic of the study (Yin 2011: 88). Patton (1990) cited in

Streubert Speziale and Carpenter (2007: 94) explains information-rich cases are needed for an in-depth study. The data quality was increased with purposive sampling because study participants were selected based on their experiences of the phenomenon (Polit & Beck 2012: 521).

The researcher informed the dialysis unit managers of the study and requested them to identify potential candidates (female patients who had discussed with them their desire to get pregnant or reported conflict surrounding potential pregnancy). Participation was open to any patient who fulfilled the inclusion criteria. The researcher invited the potential participants to take part in the study and discussed the proposed study and the information leaflet (refer to Annexure C) with them. Appointments for data collection interviews were made with the participants who gave informed consent to participate in the study.

Dahlberg, Dahlberg and Nyström (2008: 175-176) state the general indication of data saturation that determines the sample size in some qualitative research does not apply to phenomenological studies as understanding and meaning are unlimited. It was impossible to predetermine the number of participants and interviews that would be necessary in the current study. As Dahlberg, Dahlberg and Nyström (2008: 175) suggest, five participants were interviewed and the number of participants was adapted after the first collected data had been analysed. The researcher interviewed another three participants (bringing the total number of participants to eight) until she was satisfied that she had a thick description of their experiences and the sample was exhausted. Other women of reproductive age who were approached to participate in the study reported not experiencing conflicting expectations regarding pregnancy since they had produced at least one child. All the participants were black African women.

The youngest participant was 19 and the oldest 37 years. One had completed Grade 11; six had completed Grade 12 and one held a degree. Seven participants described their marital status as single (see explanation in next paragraph) while one was engaged. All the participants lived with their parents or grandparents except the one that was engaged to be married who was staying with her fiancé.

Two of the participants who stated they were single were in long-term relationships. Two other participants had previously been in long-term relationships, but these were both terminated when the participants could not produce a child. Their partners subsequently became involved in other relationships and soon had children. Two other participants had also previously been in relationships, but both relationships ended when the female partners started receiving kidney dialysis. One participant was in a long-term relationship with a partner with whom she had a twin pregnancy that ended in intrauterine death, a hysterectomy, and chronic kidney failure that resulted in long-term kidney dialysis. Six participants had never been pregnant. One participant had two terminations of pregnancy: the first when she started with kidney dialysis (the reason was not discussed in the interview) and the second two years later on recommendation of her dialysis team. All eight participants admitted that they wanted to have children and hoped to have a kidney transplant.

2.4.1.5 Inclusion criteria

The inclusion criteria for this study were female patients of reproductive age (18 – 45 years) who had been diagnosed with chronic kidney failure and who received long-term kidney dialysis at the selected hospital. The potential candidates were patients who experienced conflicting expectations concerning pregnancy when getting long-term kidney dialysis. They needed to be able to conduct a conversation in English. This, however, was not a problem as all eight were English literate.

2.4.1.6 Data collection

Data gathering in life-world research involves seeking “descriptions, utterances, characterizations, narrations, depictions and all possible expressions” of the experience of the phenomenon under study (Dahlberg, Dahlberg & Nyström 2008: 172). The data collection was focused on searching for understanding of the meaning of the phenomenon as determined in an inter-subjective relationship with the researcher (Dahlberg, Dahlberg & Nyström 2008: 172).

Unstructured phenomenological interviews were used for the data collection. (Refer to Annexure E for extracts of these). The interviews were supported by field notes. Data collection and data analysis progressed concurrently. This necessitated continuous bracketing of the researcher's beliefs and assumptions (Streubert Speziale & Carpenter 2007: 96).

a) Unstructured phenomenological interviews

In this study unstructured or in-depth interviews were used as the main data collection instrument (Polit & Beck 2012: 495). These authors add unstructured interviews are interactive in nature; the researcher cannot predict the outcome of the interview as no set of questions is prepared before the interview itself (Polit & Beck 2012: 536). Giorgi (1997: 245) states when collecting verbal data "what is sought is a concrete, detailed description of the subject's experience and actions, as faithful as possible to what happened as experienced by the subject".

- **Preparing for the interview**

In preparation for the interview the researcher did the necessary data gathering groundwork as explained by Botma et al. (2010: 203-204). Comprehensive information concerning the proposed study was verbally explained to possible participants and given to them in written form, namely an information leaflet. The researcher assured the participants that they could refuse to participate or withdraw from the study at any stage without it having any negative influence on their dialysis treatment. The participants were encouraged to ask questions for clarification of the research process or any other aspect of the study or participation that they did not fully understand.

Polit and Beck (2012: 534) highlight that the qualitative researcher needs to gain and maintain the participants' trust, particularly if the study phenomenon concerns disease or taxing tribulations. The researcher, employed at the kidney dialysis unit of the selected hospital and known to the participants at the time of study, therefore made it clear to the participants beforehand that the study was separate from the treatment environment and

participation would not have any influence on their treatment. The information given by the participants would be kept confidential as stipulated in the informed consent document.

After obtaining informed consent from the participants, appointments were made for the interviews. The venue, time and place of data collection were planned to minimise disruption to the participants' dialysis treatment and activities of daily life. The interview dates were planned to coincide with days participants had appointments at the institution to lessen disruption of participants' daily work or study schedules. All the participants chose to do the interviews at the hospital where they receive dialysis treatment. This arrangement saved the participants the time and transport cost of travelling to the interview venue. The interview venue and timing was planned so other patients would not know the participants were being interviewed for the study. The researcher confirmed each appointment with the specific participant a day before the planned interview. The researcher secured the usage of the chosen venue and also tested the audio recording equipment before every interview.

- **Conducting the interview**

The phenomenological interview (unstructured and in-depth) method of data collection is conversational and interactive; therefore, there was no set of prepared questions for the study (Polit & Beck 2012: 536). An initial broad question was asked to all participants and subsequent probing questions were determined by the response to the broad question. The broad question was:

“How do you experience the expectations of your husband/partner and other family members that you should get pregnant while the doctors and nurses tell you that you should not get pregnant while you are getting kidney dialysis?”

The researcher explained to the participants that “husband/partner” included previous, current and potential future relationships experiences. The researcher also explained “family members” are any person they regard as a family member, and who influenced their experience of the research phenomenon. The researcher encouraged the participants

to describe comprehensively how they experienced the conflicting expectations between their family and the dialysis team in order to uncover the essence of the experience (Merriam & Associates 2002: 93). The interview remained focused around the data thus “interrogation” of the participants was avoided (Streubert Speziale & Carpenter 2007: 94). The researcher used open-ended and clarifying questions to assist participants in describing their experiences of the phenomenon. This encouraged the participant to move from “accounts of her experiencing to what is experienced” (McNamara 2005: 699).

In closing the interview, the participant was encouraged to add information and ask questions. The participants were informed of the possible need for follow-up interviews and that permission would be obtained from them if such interviews were necessary (Polit & Beck 2012: 543). No follow-up interviews were conducted as the researcher was confident that the female patients’ experiences were abundantly probed. Debriefing conversations were held after the interviews to allow participants to discuss the experience of the interview. Applicable information was included in the field notes.

The interviews lasted between 20 – 50 minutes per participant. The researcher conducted all the interviews herself. Audio recordings of interviews were done with approval of the participants.

b) Field notes

According to Polit and Beck (2012: 548-550), field notes “are broader, more analytic, and more interpretive than a simple listing of occurrences”. The researcher made field notes during as well as immediately after the interviews to minimise the risk of forgetting or misrepresenting the data. Descriptive (or observational) notes aimed to objectively describe conversations, actions, and the background of the interviews. (Refer to Annexure H for an example).

Reflective notes included methodological, theoretical and personal notes (Polit & Beck 2012: 549). Methodological notes were made around reflections about the interview and

data collection strategies. It was used to note what methods were effective, ineffective and possible new approaches that could be followed. (Refer to Annexure I for an example).

Theoretical (analytical) field notes were used to attach meaning to observations and were used in the data analysis. (Refer to Annexure J for an example). Personal notes were used to detect influences of feelings on the researcher's involvement in the study. It was also used to help the researcher to practice bracketing during data collection and analysis. (Refer to Annexure K for an example).

2.4.1.7 Data analysis

According to Banonis (1989) (cited in Streubert Speziale & Carpenter 2007: 96), the purpose of data analysis is "to preserve the uniqueness of each participant's lived experience while permitting an understanding of the phenomenon under investigation".

The process of data analysis began with the change of attitude as the researcher transformed the natural attitude which is presented by the participants to the phenomenological attitude in order to produce an understanding of the phenomenon (Norlyk & Harder 2010: 428). "Natural attitude" refers to a naïve perspective used by people in everyday life not questioning experiences. In research the natural attitude would result in a description of what participants say without exploring it (Dahlberg, Dahlberg & Nyström 2008:33). To study the data obtained from the participants in this study, the researcher had to apply a phenomenological approach that did not focus "on things but on the consciousness of the things" (Solomon & Higgins 1996: 251). This (see section 2.3(b)) allowed the researcher to 'see' the meaning of the described data in a scientific light.

a) Eidetic reduction

The researcher used eidetic reduction in the process of data analysis. Zahavi (2003: 39) describes the process as "a kind of conceptual analysis where we attempt to imagine the object as being different from how it currently is." Giorgi (2005: 81) claims that eidetic reduction improves the possibility that the findings may be generalised to similar contexts.

The researcher used eidetic reduction in the current study with the aim to clarify the essential contents of the data from a phenomenological perspective. She focused on providing a reliable description of the phenomenon by making use of the precautionary measures of implementing eidetic reduction (Giorgi 2005: 75).

b) Essences

“An essence could be understood as a structure of essential meanings that explicates a phenomenon of interest. The essence or structure is what makes the phenomenon to be that very phenomenon.” (Dahlberg 2006: 11). Husserl’s ideas of intentionality declare that “when the phenomenon presents itself as something, it presents its essence” (Dahlberg 2006: 12). Essences are not constructed but are there in the “intentional relationship” between the researcher and the phenomenon. The meaning of the experience of the phenomenon is revealed during the research process (Dahlberg 2006: 11-14).

Essences were discovered during the process of free imaginative variation (Giorgi 1997: 242). In this process the researcher attempted to determine what the critical features of the phenomenon was by using her imagination to contrast its descriptive characteristics. A characteristic feature was considered essential if a change in the characteristic changes the distinctiveness of the phenomenon (Beck 1994: 255).

c) Descriptive analysis

The descriptive analysis started with the preparation of the data. The subsequent data analysis involved reviewing the initial whole, breaking it into phenomenological parts, and searching for the essence of the phenomenon to form a new whole.

- **Preparation of data**

To stay “close to the data” only the original data collected from the participants and the field notes of the researcher were used (Dahlberg, Dahlberg & Nyström 2008: 241). All data including the audio-taped interviews and field notes were clearly marked, categorised and grouped together per participant and date to simplify finding specific information. The

audio-taped interviews were transcribed verbatim, with care taken to include non-verbal communication.

The researcher prepared the data for analysis by listening to the audio recordings and reading the transcriptions of the interviews. The initial reading focused on the participant's broad description to identify parts that form smaller "meaning units" (Wertz 2005: 172). The researcher underscored unnecessary data that did not contribute to the description of the phenomenon. The meaning units were named and redundant data identified to assist in organising the data in preparation for the thorough analysis phase (Wertz 2005: 172).

- **The initial whole**

The researcher used the phenomenological attitude of curiosity to view the phenomenon from the participants' viewpoints. This attitude helped her to enter their life-world to gain understanding of the participants' experiences of the phenomenon (Wertz 2005: 172). The data analysis involved the "movement from the whole to the parts and to the whole again" in an attempt to find meaning or essence. This meaning or essence was supported by constituents (essential meanings) (Carlsson et al. 2004: 193).

The analysis focused on the information obtained from the participants by excluding other external sources (Dahlberg, Dahlberg & Nyström 2008: 241). The researcher familiarised herself with the research data by reading it as a whole to get a comprehensive sense of what it involved before starting the analysis (Giorgi 1997: 245). The researcher used a "bridled" approach to prolong the "indefiniteness" through careful reflection during the initial reading and not taking anything for granted (Dahlberg, Dahlberg & Nyström 2008: 241).

- **Phenomenological parts**

The researcher's attention during this step was centred on parts of the data as it began to emerge. Giorgi (1997: 246) explains that through "meaning discrimination" the researcher should divide the text into "constituting parts". The text was thus divided into parts which

were grouped into “clusters of meaning” and used to detect a provisional pattern of meanings to recognise the essential meanings which are known as “the constituents”.

- **Searching for an essence of the phenomenon – a new whole**

The constituents were linked to each other to identify a pattern that defined the phenomenon’s essence (Dahlberg, Dahlberg & Nyström 2008: 244). The essence describes the whole of the phenomenon and was “disclosed in the researching act that takes place between the researcher and the phenomenon” (Dahlberg, Dahlberg & Nyström 2008: 247). The researcher made use of bridling to make sure she did not attach meaning to any of the data prematurely. Through the process of bridling the researcher held back her understanding of the phenomenon and did not make “definite what is not definite” in order to ensure that the findings will reflect what is “lived” by the participants (Dahlberg, Dahlberg & Nyström 2008: 242).

The data reflected in the notes were used to add to the richness of the data and the comprehensiveness of the end product, namely the essence and the supportive constituents. Notes regarding how the thoughts and the ideas of the researcher concerning the phenomenon evolved were kept to ensure the trustworthiness of the findings (Starks & Trinidad 2007: 1376).

2.4.1.8 Description of findings

Once the essence and the supporting constituents had been identified, it was described in a comprehensive manner. The discussion of the findings is done in a separate chapter, Chapter 4, of this study. Both the research and theoretical literature were used to discuss the constituents. The essence was explained according to the perspectives of Husserl regarding the subject, the object, and the meaning. According to the tradition of phenomenological research, the essence was described first and then the constituents. Dahlberg, Dahlberg and Nyström. (2008: 255) explain if such descriptions are not done in the aforementioned order, it is difficult to see or determine *what* the constituents are constituents of.

Quotations from the interviews with the participants were used to illustrate and support the constituents. Sandelowski and Barroso (2002: 217) warn against the misuse of quotes to substantiate findings that are not related to the quotes. The researcher guarded against such misuse and verified the quotes to support the constituents with her supervisor. It is not applicable to phenomenological research to include too many quotations as the focus is on “how the phenomenon is” and not on “what the perspectives of the participants are” (Norlyk & Harder 2010: 428).

2.4.1.9 Literature review

A review of related literature was done after the data collection and analysis processes had been completed. The aim was to prevent information from other sources influencing the data collection, analysis and findings (Streubert Speziale & Carpenter 2007: 97). A brief preliminary literature review was done before the study commenced to determine the necessity of the study. It also helped to formulate and refine the research question.

Applicable literature was extensively reviewed after the process of data analysis to serve as literature control for the findings. The review was also used to link the findings to the existing body of research knowledge (De Vos et al. 2011: 305). Furthermore, the literature review contributed to the trustworthiness of the study findings.

2.4.2 Measures to ensure trustworthiness

According to Starks and Trinidad (2007: 1376), researchers’ honesty about their previous beliefs reflects the trustworthiness of the findings in phenomenological research. The strategies of *bracketing*, *reflexivity* and *eidetic reduction* were used to enhance the trustworthiness of the findings of the current study.

To ensure the trustworthiness of this research project, Lincoln and Guba’s framework (1985) was used as explained in Polit and Beck (2012: 584-585). The four criteria for qualitative studies, namely credibility, dependability, conformability, and transferability were applied.

2.4.2.1 Credibility

The provision of credible findings is regarded by Lincoln and Guba as the main purpose of qualitative research and relates to the “confidence in the truth of the data” (Polit & Beck 2012: 584). Data collection in this study was done according to the strategies associated with the descriptive phenomenology research method.

The researcher ensured that her preconceived ideas about the phenomenon did not influence the data collection and analysis. She had a bracketing interview with one of the supervisors before the onset of the data collection and also kept a reflexive journal. (Refer to Annexure G). Reflexivity is defined by Finley (2002: 532) as being “thoughtful, conscious, self-awareness” of own ideas that could cause bias in the data collection and analysis processes. Bracketing of the researcher’s previous perceptions was done in an attempt to limit the influence thereof on the study processes and findings (Gearing 2004: 1432-1434).

Prolonged engagement with the participants helped the researcher to ensure that she grasped the meanings the participants attached to the phenomenon (Lincoln & Guba (1985) cited in Polit & Beck 2012: 589). The researcher allowed sufficient time for collecting the data and follow-up interviews. This helped the researcher to clarify her understanding and also gave participants the opportunity to add to their descriptions.

2.4.2.2 Dependability

Dependability deliberates the stability (reliability) of the data if applied to the same (or comparable) participants in the same (or comparable) setting (Polit & Beck 2012: 585). The researcher kept an audit trail to demonstrate the processes of data collection and analysis so that other researchers can repeat the processes. (Refer to Annexure L). A comprehensive description of the methodology used in this study was provided.

2.4.2.3 Confirmability

Polit and Beck (2012: 585) describe confirmability as “the potential for congruence between two or more independent people about the data’s accuracy, relevance, or meaning”. The aim of confirmability is to demonstrate that the conclusions are based on the data collected from the specific participants.

The researcher used the data obtained through in-depth interviews and field notes to study the meaning of the phenomenon. The bracketing interview with one of her supervisors and reflexive journal, kept throughout the research process, assisted to prevent her perceptions from causing bias. She deliberately bracketed any knowledge gained through previous experience to ensure that she worked with the information provided by the participants.

2.4.2.4 Transferability

Transferability is referred to by Polit and Beck (2012: 585) as the degree to which the findings of one study can be used in another setting or group. These authors agree with Lincoln and Guba (1985) (cited in Polit and Beck 2012:585) that the researcher must supply comprehensive descriptions of the data collection and analysis processes.

The researcher gave a description of her paradigmatic perspective, philosophical framework and the research methodology. This assists a professional person interested in transferring the findings to a selected setting or population to decide whether it can be done or not.

2.5 SUMMARY

This chapter provided a detailed description of the paradigmatic perspective, philosophical framework and research design used for this study. The constructivist research paradigm and the meta-theoretical assumptions associated with it were deliberated. The descriptive

phenomenological framework and research approach used for this study were also discussed. The research design explained the research method and measures taken to ensure trustworthiness. The next chapter presents the findings of the data analysis of the interviews and field notes.

CHAPTER 3

DESCRIPTION OF RESEARCH FINDINGS

3.1 INTRODUCTION

The previous chapter provided a detailed description of the paradigmatic perspective, philosophical framework and research methodology used for this study. This chapter presents the findings of the study. The essence and the supporting constituents are described.

The findings are presented as explained in Dahlberg, Dahlberg and Nyström (2008: 255-256). The essence is presented first followed by a detailed description of the constituents. Quotations from the interviews, presented in italics, are used to illustrate and support the descriptions of the constituents. The participant will be indicated in brackets (e.g. A2 is participant A, page 2 of her interview). The theoretical description of the findings (essence and constituents) will be discussed in the next chapter.

3.2 FINDINGS

The essence is exemplified in ways of **“‘being-for-oneself’ and ‘being-for-others’ in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis”**. ‘Being-for-oneself’ and ‘being-for-others’ are meanings which evolved from the data and showed similarity with concepts characteristic to existentialism, a philosophical movement that developed from phenomenology (Cox 2009: 20).

Seen from an existential viewpoint, patients getting long-term kidney dialysis are responsible for their actions towards themselves and other people. ‘Being-for-oneself’ represents the participants’ experiences of the phenomenon, their daily struggle for survival with their kidney disease and treatment as well as adapting to the undetermined period of avoiding pregnancy. ‘Being-for-others’ represents the experiences the participants had of other people’s expectations regarding them getting pregnant or not. These ‘other people’ that influenced the participants’ experiences of the phenomenon

included the dialysis team and the significant others mentioned by participants. The latter group included the participants' mothers as well as past, present and future partners and the partners' family (called family-in-law).

All the participants acknowledged the expectation of the dialysis team that they should not get pregnant while receiving kidney dialysis due to the detrimental effect pregnancy can have on their own and their unborn infants' health. The participants experienced that, in contrast to the dialysis team's advice, their family members expected them to bear children. The contradictory expectations of the dialysis team and the family members caused conflict in their experiences of 'being-for-others'. They wanted to satisfy both groups, but could not because of the contradictions in expectations. Conflict in 'being-for-themselves' was caused by the participants' eagerness to meet the demands of both groups.

The participants desperately needed the support of the dialysis team to survive their CKD, but on the other hand they were equally desperate to meet the expectations of their family members. They did not want to disappoint their own family or stand the chance to lose their partners and thus the support from their future families-in-law. Poor communication between the dialysis team and the family members contributed to the conflict. 'Being-for-themselves' was negatively influenced by 'being-for-others' while they required all the support they could get from these 'others' to cope with the kidney failure and treatment. The prospect of pregnancy after kidney transplant could have offered solutions for the conflict between 'being-for-others' and 'being-for-oneself.' However, the long waiting periods for kidneys for transplant caused some of the participants not to be positive about the chances of getting transplants.

The essence of ways of **“being-for-oneself” and “being-for-others” in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis**” is supported by the following constituents: living with contradictory expectations from their mothers and future families-in-law; living with cultural transition; and attempts to be composed by living in the present and hoping for the future. The constituents and its meanings are described below accompanied by supporting quotations from the interviews.

3.2.1 Living with contradictory expectations from their mothers and future families-in-law

While the participants were fighting to stay alive ('being-for-oneself'), they also strived to live fulfilled lives as expected by their families ('being-for-others'). They experienced that their mothers valued them as human beings and wanted what was best for their daughters; therefore, they supported the participants' 'being-for-oneself'. Contradictory expectations were experienced from their future families-in-law who valued them for the grandchildren they were supposed to produce ('being-for-others'). The future families-in-law did not make allowance for the participants' difficulties to bear children and thus did not support the participants' 'being-for-oneself'.

The participants experienced contradictory expectations between their mothers and future families-in-law regarding them getting pregnant. Although both their mothers and future families-in-law wanted to have grandchildren, their mothers accepted that it was not possible for the participants to be pregnant due to the negative effects that it could have on their daughters' health and that of their unborn infants: *She (the mother) was like: ... but then it makes sense; you can't fall pregnant while you're like... (ill). So it was never much of a bigger deal, and then she never put pressure (on me to get pregnant) (A11)*. In contrast, the participants experienced that their future families-in-law demanded grandchildren notwithstanding the threats pregnancies could cause to the participants' and unborn children's health: *... so it's gonna to be difficult for ... the in-laws to accept that ... for now you (the participant) can't have children ... they will tell you (the participant) they want grandchildren (A12)*. The demand for grandchildren placed the burden on the participants' 'being-for-others'.

The participants identified their mothers as the most important persons in their lives. Their mothers raised them and took care of them when they were sick during childhood. Once they had started with kidney dialysis, their mothers accompanied them to hospital appointments and visited them when they were admitted to hospital. Those participants who discussed their experiences with others did so with their mothers: *... because me and my mom we ... talk openly with each other ... even with difficult issues ... she's a person*

who is listening and who gives advice (A11). For this reason their mothers' reaction had a major influence on the participants' experiences of their illnesses and their inability to be pregnant.

Some participants, who were cared for by their grandmothers, received the same kind of support as that which others received from their mothers. Therefore the term "mothers" was used for grandmothers who fulfilled role of mothers in some of the participants' lives. These grandmothers were more concerned about the health of the participants than them having babies: ... *my grandmother understands. She's saying like: you should put your life first ... not other people* (future in-laws) ... *you have to concentrate on you getting well first* (D1). This demonstrated the grandmother's support for their granddaughters' 'being-for-oneself'.

The participants had the impression that their mothers understood their disease and treatment. They described their mothers as supportive of the dialysis team's expectations that the participants should not be pregnant while they are sick (having chronic renal failure) and getting treatment (kidney dialysis): ... *if it's not possible for you to get pregnant, I don't want you to risk your life* (C1). This was specifically true in cases where the dialysis team explained to the mothers and the latter comprehended that the participants should not get pregnant: *Okay, now she understands the reason why I can't have children now. It's not affecting her that much because there is a valid reason* (why the participant could not get pregnant). However, other relatives, including the future families-in-law, who had not received information about kidney failure and dialysis, did not understand why the participants were reluctant to get pregnant: ... *my relatives, cause they don't know deeper into my ... problems ... they don't understand it* (unlike) *my mother ... (who) got the explanation* (B2). This reveals the essential role the dialysis team has to fulfil in gaining understanding for female patients of reproductive age who are on long-term kidney dialysis. Dialysis team members have to explain their expectations to the patients as well as their families and others (such as in-laws) to develop support for female patients with CKD.

Although the participants felt their mothers supported and accepted the expectation that they should not get pregnant while receiving long-term kidney dialysis, the participants knew that their mothers still wished to have grandchildren: ... *and then she* (mother said) ... *I won't be able to have so many grandkids of my own...* (C11). The mothers who previously required their daughters to first obtain further education, a job and/or be in a committed relationship before having children, sometimes expressed regret in having done that and wished that their daughters had children before they got sick and started kidney dialysis: *She told me that maybe I should have had a child that time....* (A18). The mothers' need for grandchildren placed claims on the participants' 'being-for-others'.

Moreover, the participants sensed their mothers were concerned about their future prospects in terms of relationships. They felt their mothers desired for them to be secure and in steady relationships: *But what she's praying for me is to have a family of my own ... stability ... that is what she wants the most...* (B12). Their future wishes for their daughters were: *To get married and have children...* (B12). The mothers thus also wished for their daughters to have the support of a husband.

The participants got the impression that their mothers tried to protect them from rejection by their future families-in-law. The mothers realised the expectation for the participants not to get pregnant was a problem as far as the possibility of marriage was concerned: *It frustrates her that they* (future family-in-law) *might reject me...* (B12). Some mothers tried to warn their daughters about the possible rejection from future families-in-law: ... *because you can't have children, so what are you going to do about that? What if the family wants children?* (D1). The mothers' concerns revealed care for the participants as 'being-for-oneself' and the desire to protect their daughters from the future families-in-law and their demands on their daughters (the participants).

The term "future family-in-law" was used for the past, present and future partners' families. Some participants recalled familial relationships they had had previously: *I used to love those kids* (future sister-in-law's children). *I used to go there ... to visit them. And they* (the children) *would also call* (the participant and ask): *when are you coming* (to visit us) (D12). One participant described how she used to be welcomed by her previous partner's family and the supportive role they used to have in her life: *They were like a family to me. When I*

was ... *admitted in hospital, they used to come (and visit me). They were understanding (that she was ill) (F17).* The relationship this participant had with her future in-laws before they realised that she could not get pregnant, portrayed significant support for her 'being-for-oneself.' When they no longer supported her due to her inability to produce an offspring, she felt rejected and it caused her to experience doubts about her relationship with them.

The participants experienced rejection and loss when future families-in-law realised they could not have children: *Like they were ... fine with me at first ... but when they found out that I was not able to have children (they changed) ... when I call (to arrange a visit, my future mother-in-law said): No, we (are) not at home (D12).* This exclusion from a future family-in-law was described by a participant as: ... *it is like a loss of family (F17).* The loss of support from the future families-in-law was detrimental for the participants' 'being-for-others'. It negatively influenced their relationships with 'others' (their partners and future families-in-law).

One participant experienced that, in spite of explaining her disease and treatment to them, her future family-in-law was unaccommodating of her situation: *I did (explain to my mother-in-law) ... even (to) his sisters... I explained everything to them ... but ... his mother (still) said: I can't do anything and I don't have a say (expressing her unwillingness to become involved) (D3).* In hindsight, this participant realised her future mother-in-law was not supportive of the relationship between the participant and her son because the participant would not be able to produce a grandchild: ... *(be)cause she wanted ... (a) grandchild (D3).* Another participant experienced that, because she was not in a position to bear a child, her future in-laws would warn her partner that she would not be a suitable wife: ... *they will say to their son: we want ... grandchildren (G5).*

Future families-in-law put extraordinary demands on the participants. They could only accept them as future daughters-in-law if the latter were prepared to jeopardise their health (in fact, also that of the grandchild) to bear children. The expectation of the future families-in-law that the participants should produce grandchildren put the participants' relationships with their partners under immense pressure. The demand from the future

families-in-law for grandchildren placed a huge emotional burden on the participants who could not live up to the former's expectations as a result of their disease.

3.2.2 Living with cultural transition

As described by participants, the traditional African cultural background of the participants and their families required women to become mothers and wives. They should thus bear children if that is the expectation of the partner, husband or families-in-law. The advice of the dialysis team that the participants should postpone pregnancies until they had kidney transplants was not in line with the expectations of partners and/or family members who supported traditional African cultural values. However, because of the modern cultural transition phenomenon, younger members of cultural groups (such as the participants and some of their partners) tended to be less stringent about following traditional African cultural norms.

- **Participants' cultural transition**

The participants were uncertain about their own cultural perspectives. They wanted to fulfill the wishes of the traditional members of their cultural groups (mostly older people; especially their future mothers-in-law) and bear children, but due to their poor health pregnancy was too much of a risk. In 'being-for-themselves' they wanted to postpone their pregnancies, but this caused conflict in their relationships with traditional family members and thus in their 'being-for-others'. The participants could not live up to the expectations of others and felt they failed in their 'being-for-others'.

On the other hand, not all the older family members adhered to the traditional African cultural expectation that women should bear children despite their circumstances. Their mothers and also grandmothers supported them as they understood that pregnancies could jeopardise their daughters' and/or granddaughters' health.

The participants explained how, on the one hand, they grew up with and were still expected to follow traditional African culture while on the other hand they were expected to

(and wanted to) follow a biomedical treatment model and a liberated way of thinking. The participants described the cultural expectation linking motherhood to marriage as: ... *black people ... if they marry ... they expect you (the woman) to bear children...* (A12). In adherence to traditional African cultural expectations, their partners were expected to compensate the future brides' families: *He was planning to pay lobola ('bride price')* (F7). Traditional African cultural values were also reflected in believes that having children would contribute to future financial security: *Mostly, when you bear children, you are expected to care for them (and) ... in future you expect them to at least help you when you are older...* (A12). Without children there may not be someone to take care of the participants when they are aged and need the support of others. The conflict between the cultural expectations related to pregnancies and bearing children and the biomedical model of healthcare the participants experienced created much uncertainty about how the participants viewed themselves in 'being-for-oneself' and also their relationships with others in 'being-for-others'.

Cultural beliefs were challenged by the participants. The following quotation illustrates one participant's disillusionment with traditional African healing practices demanded by some family members: *When I was sick for the first time (some of) my relatives ... told my mom that (she) must take (me) to the traditional healer... My mom never wanted to take me there ... but they kept on talking (trying to convince her to take me to the traditional healer) ... so she (agreed)... (The traditional healer's trainees) threw their bones and they said things that shocked me to this day they said ... there are people bewitching me* (A20). This experience challenged the participant and her family's traditional African cultural beliefs and contributed to her uncertainty about whether she should adhere to the cultural expectations of others to bear children or adhere to the biomedical model of healthcare.

The participants' cultural beliefs were also affected by their exposure to the biomedical model of kidney dialysis. A participant explained how her experience of the negative effects of non-compliance to medical treatment affected her beliefs: ... *what changed (increased my trust of medical treatment) when I don't take my medication ... I don't feel good ... it's better (to) comply, to do what they (the dialysis team) tell you, for you to keep yourself healthy* (A16). Personally experiencing the positive results associated with

compliance to the dialysis team's prescriptions motivated this participant to trust the dialysis team and comply with their expectation to avoid a pregnancy: *That is why now I make sure ... even with the pregnancy thing ... I make sure not to (get pregnant)* (A16). The experiences associated with compliance with the expectations of the dialysis team compared to the experience of the outcomes of the encounter with traditional African healers (described in the previous paragraph) steered this particular participant towards conforming to the biomedical treatment model. Cultural transition was experienced when she moved away from traditional African cultural beliefs and adopted the biomedical model belief.

One participant described her cultural transition as: *I'm an independent woman* (D14). She concentrated on her 'being-for-oneself' and less on what others wanted her to do as in 'being-for-others'. Another participant emphasised that she wanted to do what was best for herself in terms of marriage and having children: *I put up ... rules for myself ... (when others say) ... I should have a baby once I'm married (and I do not want to) ... I don't have to...* (A8). This standpoint was shared by another participant who said: *... you can get married even if you ... won't have children ... it's possible to ... find a person who loves you and who'll accept you for what who you are...* (C8). The possibility for female CKD patients to have loving childless relationships and marriages is expressed in the words of hope uttered by the following participant: *For me, without a child, a relationship is possible... It is a matter of ... understanding ... why a person (woman) does not have a child* (B9). Cultural transition regarding the acceptance of childless marriages and relationships gave hope to some participants; the focus was very strong on 'being-for-oneself.'

Some participants asserted cultural transition by exploring alternative methods of having children without getting pregnant: *And there are also other options of having children. You can also adopt ... we (my partner and I) did talk about it..* (C14). One participant considered the method of surrogate pregnancy: *... life ... gives you options ... you look at the options: I can't have a baby... But there is someone who can carry a baby for me ... it doesn't matter as long as it (the baby) is from me ... even if it's being carried by someone else...* (B15). Alternative methods of having a baby would fulfil the sick women's need for

having children. These alternative ways to become mothers enabled them to cope with ‘being-for-oneself’ and at the same time to satisfy others’ expectations regarding grandchildren and ‘being-for-others’.

The participants’ experiences of traditional African cultural demands varied. Some participants decided not to get too involved in relationships out of fear for rejection: ... *if I’m married my husband ... will never get a child of his own ... he will look down on me ... it can even lead to divorce...* (B15). Some participants had already experienced failed relationships due to their poor health: ... *we (my partner and I) were planning ... to have babies ... but I did understand (when the relationship got terminated) that ... it is because of me not giving him a baby* (F16). Clearly, the individual participants experienced different perspectives on their own cultural transitions. Some felt they had to postpone their pregnancies to cater for ‘being-for-themselves’, but this meant they would fail in their ‘being for others’ (living up to the expectations of traditional African family members).

- **Cultural transition of partners and family members**

The participants’ experiences of family members’ reactions towards changes in culture as experienced in cultural transition resulted in them questioning their own transition. Although one of the participants described herself as an “*independent woman*”, she also said “*you need to have a child, before (you can get married)*” (D19). This participant’s contradicting statements (being “*an independent woman*” versus “*you need to have a child, before (you can get married)*”) clearly illustrate the emotional dilemma female patients with CKD who are on long-term dialysis are confronted with on a daily basis. This inner conflict becomes part of their everyday existence: the ‘being-for-themselves’ versus the ‘being-for-others’. This particular participant viewed herself as a person who could make her own choices; yet, the belief that women must adhere to traditional African cultural norms which require them to prove their fertility before marriage (a cultural belief shared by some traditional African people) was deeply instilled in her being.

Another participant shared that, for her personally, having children does not necessarily guarantee a successful or happy marriage. However, she added her cultural transition

presented a major concern regarding marriage as she might fall in love with a man who honoured traditional African cultural norms: ... *not having a child ... I am going to waste a person's time ...* (because I) *cannot satisfy* (his) *needs* (regarding children) (B20). Her concern was that her partner might live according to traditional African cultural norms and thus expect his wife to bear children: *I will deprive him ... from getting a woman that will have a child with him* (B8). The challenges to cultural transition the participants themselves experienced and which they experienced in their relationships caused much uncertainty regarding their 'being-for-themselves' and 'being-for-others'.

Furthermore, according to the participants, cultural transition was expressed by some partners, but their actions disputed it: ... *he would just say: no, it's my life. I choose where I want to be* (D4). This partner minimised the importance of pregnancy and tried to soothe the participant's concerns: *he said you ... stress too much, stop worrying ... this is the 21st century they (the family) will not force me to do anything I do not want* (he referred to leaving her as she was not in a position to give birth to a grandchild) (D4). Yet, although this partner assured the participant that children did not matter, he had a relationship with another woman who soon became pregnant by him. This participant described her partner's treachery as follows: ... *he didn't say anything about that* (wanting to have children) ... *he was pretending* (that her poor health and childlessness was not a problem) ... *he is a good pretender...* (D5). The inconsistency between their partners' words and actions and their deceit confused the participants. Their partners' expressions of cultural transition towards making their own decisions, which supported the participants in 'being-for-oneself', were directly contradicted by their actions.

Some participants were challenged by their partners' demands which were embedded in traditional African culture; these partners wanted and expected them to have children despite being on long-term kidney dialysis: *African men ... believe that ... if you love them ... you must have a baby* (G5). One of the participants, who on recommendation from the dialysis team had had two terminations of pregnancy, received no support or understanding from her partner: *He said that I don't love him. I must fall pregnant, so that I can show him that I love him* (F3). When this participant tried to use contraception to prevent another pregnancy her partner got rid of the tablets: ... *he was throwing them* (the

contraceptive pills away) *when he found them...* (F12). The partners' strong cultural beliefs placed unattainable demands on the participant's 'being-for-others'.

Other participants found their partners to be very supportive after learning of the dangers that pregnancy on dialysis posed. One participant recalled her partner's interest in the possibility of pregnancy on dialysis. He even assisted her with getting information from the Internet: *He asked me what are my chances of getting pregnant while I am on dialysis; I (said) ... I don't really know exactly what my chances are. So, he said: okay, let's go and search on google...* (C4). This partner expressed acceptance of the information and of a childless relationship: *And he was like: okay, its fine then. The chances are too low (to get pregnant) ... and they said the risks are too high (C4) and went as far as to inform his family of his commitment to the participant against their wishes: But, eventually, he told them (his family) ... that he will be with me; even it means that I won't have kids. It's fine. He'll still be with me (C4).* The partner's cultural transition supported the participant in complying with the expectation not to become pregnant and her 'being-for-oneself'. This enabled her to have a fulfilling although childless relationship.

For some partners the consequences of cultural transition and a childless relationship seemed overwhelming: *He said ... its fine, but eventually, you could see in his eyes, that it wasn't fine ... (be)cause ... he really wanted to have kids of his own (C5).* The need for a child steered some partners to extreme measures. A participant described how her partner tried to force her to become pregnant against her will: *... I was gonna risk with my life. If I was going to die and maybe if the baby survives, who was going to take care of the baby? So, I didn't want to (D7).* When she did not bear a child her partner was no longer committed to the relationship and turned to another woman to have a child: *So ... maybe he saw ... this one (the participant) she's not serious, so I must just get another girl (D7).* It was this participant's perception that her partner expected her to prove her long-term commitment to him by carrying his child – even if her health and life as well as that of their baby were at stake: *... that's what they (partners who lived according to traditional African cultural expectations) believe (D7).* She terminated the relationship when she learned that her partner had had a child with another woman. However, he soon regretted having left the participant: *... he wants to come back to me (D4).* The participant shared that her

former partner's deceitful actions hurt her deeply and she could not continue with the relationship even though she still loved him: *He hurt me ... even now, I'm still hurt* (D4). The partner's actions were driven by his need for a child which the participant could (and would) not satisfy thereby strengthening the 'being-for-oneself' meaning.

The participants assumed that their partners' reactions were influenced by demands from their families: ... *maybe it's because of his family is pressurising him* (F6) and also by their own need for children. A participant described her realisation that her partner desired to have a son as follows: *He would bring up* (refer to a child of his own) ... *you know* (by saying) ... *my baby boy, he will be everything I want in this world...* (D5). The partners' demands for children caused the participants to feel rejected.

The traditional African cultural beliefs of partners were affected by their exposure to different circumstances. One participant presumed that her partner accepted her inability to have children and that he understood and supported her because of his mother's chronic illness: *I think my boyfriend ... he understands better, because his mother is also sick... So I think the experience gives him this ... courage of being with me* (H4). She also ascribed her partner's acceptance of her situation to his religious beliefs: *So, he said, no problem ... it is only God who knows ... because he ... believes very much in God* (H4). The partner's cultural beliefs were influenced by his experiences of his mother's illness and his religious beliefs. It encouraged him to accept the participant's childlessness.

The lack of support from her partner's family was an issue that worried one couple who supported cultural transition. The female partner (the participant) admitted both she and her partner felt confused about them as a couple having embraced cultural transition while his family still lived according to traditional African cultural values and beliefs: ... *what we still confused about. If his family don't support him getting married to a person who doesn't have kids, how are we going to handle them? ...He's still confused about that ... and I am still confused...* (C18). Her partner's cultural transition strengthened the participant in 'being-for-herself' and being acceptable to her partner. However, the lack of support from the future family-in-law who held on to traditional African cultural beliefs confused the couple and prevented them from getting married.

The attitude and belief in an inherently traditional African cultural society is that children are a blessing; therefore, having children is closely linked with marriage: ... *because you know the rural people they want to have babies. They (believe) ... marriage is all about babies. It's not about love* (H5). The participants acknowledged the demand on a woman to have children before she can be considered as a suitable wife. According to them, acceptance of marriage depended on their ability to bear children: ... *when you're a woman, you're supposed to have a baby ... a child ... like they say: a man can't marry without having children. So that's the other problem we have like in our culture* (D1). traditional African cultural beliefs place the emphasis on women 'being-for-others' in terms of the children they are expected to bear.

Especially older family members attached significant cultural value to bearing children. One participant explained the families' deep conviction that having offspring leaves a legacy through which the self and the family are expressed and perpetuated: ... *the parents wanting ... the children to take the surname ... and make it grow ... it's every parent's dream... They feel their children ... would expand ... the surname ... further* (B10). A second participant also experienced the conviction of her partner's family that children principally brought fulfilment; having children assured the family multiple descendants would ensure their surname in future generations: *In their family, they believe that you cannot marry a ... woman who doesn't give you children, because he's not going to extend the family's surname* (C5). Children ensured the survival of the family and its heritage.

According to the traditional African cultural beliefs marriages, and acceptance thereof, was dependent upon the women having children. Not being able to produce children to enlarge the family resulted in being excluded from the family-in-law: ... *you are not women enough, if you can't have children, then, you are not supposed to marry our child (son)...* (D1). Those participants who lived in accordance with the expectation from the dialysis team to avoid pregnancy were viewed as "*not the marriage type*" (C18). Not being able to fulfil the cultural requirements of motherhood threatened to exclude the participants from marriage and therefore their 'being-for-others' were violated.

Traditional African culture requires the husband's family to come to an agreement with the bride's family about the *lobola* before a wedding ceremony can be arranged. A participant described the "struggle" she had when her partner's family refused to continue with wedding arrangements because she had not had a child: *So, when time went on then ... then my boyfriend told me that ... his uncles, (were) supposed to come to my place... So they said: no we can't, cause you don't have children with this lady, have children with her first. Then, he (the partner) told them, even (his) mother ... told them ... they explained everything to them, but they still said: no, we can't accept someone who won't bear children for you (D2).* The family-in-law held on to their traditional African cultural values and beliefs, thus, not supporting the participant and her partner's belief in cultural transition.

The older family members upheld their cultural beliefs, even when their sons believed in cultural transition. A participant experienced rejection from her partner's family after he told them he was devoted to her in spite of her childlessness: *But, there's still part of me that thinks they want him to be with another person ... Because ... I won't be able to have kids... They do act strange sometimes ... you can see or feel ... when people are talking about you behind your back. Or when they do strange things to show that, we don't really appreciate you being around here... Sometimes, they wake up and just be angry and be moody (C6).* Her partner did not realise this was a problem because when he was around his family acted "normal" towards the participant: *... cause when he's around, they (his family) are fine. They act all nice, but when he is not around they become moody and all this kind of stuff (C7).* The subtle rejection of the participant without her partner knowing prevented her from obtaining her partner's support and protection against his family's antagonism.

The participants felt that, by holding on to their traditional African cultural beliefs and customs with regard to a woman being able to produce offspring, their future families-in-law did not make allowance for their devastating disease and treatment which necessitated avoiding pregnancy: *... it is a problem in the family (future in-laws) ... and people don't understand... I don't know if they won't or they don't (try to) understand... (B17).* No allowance was made for these women that lived through the hardship of chronic kidney disease and long-term dialysis. Her future family-in-law added to her distress and

degraded her because she did not have children, a participant said: *They start calling you names... (they) will say ... she's barren ... that's very insulting ... it makes you feel like you're not a woman* (B17). Such insults upset the participants' 'being-for-onself' by rejecting their 'being-for-others'.

Traditional African cultural family beliefs linked men's manhood to them having children: *And they think it (having children is) making him man enough ... that he's a proper man* (C14). Participants explained their future families-in-law did not understand why their sons would want to marry childless women. This left the participants feeling vulnerable and extremely hurt: *... like if a ... woman cannot conceive they will swear at her, they will curse her, they will call her a witch* (B13). One participant feared that rejection by her future family-in-law would also put her partner at risk of being rejected: *Especially, if the husband is very supportive they will tell ... you that ... you have bewitched our child... Look now, you can't even have children, but he's busy after you. What is wrong with him?* (B13). The families did not trust childless women and claimed that such women might be 'evil' and hence 'bewitch' their sons: *Did you do anything to him...?* (B13). The childless participants with partners that supported and wanted to marry them were mistrusted by the future families-in-law.

One participant predicted that marriage without children would not be respected by her future family-in-law: *So, that will be the weakest point of our marriage ... because they will just say, you don't have kids, you don't have a say in his life. So, they'll be looking for a woman who will be giving him kids, who will be woman enough ... to him* (C9). A childless marriage would offend the family-in-law: *... that his family will think that it's very disrespectful to get married without the support of the mother and they think it brings bad luck...* (C19). Women in childless marriages are at risk of being blamed by their families-in-law for all the problems their husbands encounter: *Lack of money, lack of job, job losses and being poor* (C19). The participants experienced stigmatisation in terms of their 'being-for-others' because of the traditional African cultural beliefs that they could not comply with.

Intolerance from older family members of childless marriages prevented the participants from fulfilling their desire to be married. They feared the future families-in-law would interfere with their marriages: ... *that's the part that keeps on confusing me, if they will accept me for who I am, or ... they want him to take another girlfriend...* (C8). Some traditional African cultures support polygamy: *He can have as many wives as he like* (C8). It was clear that some families would support a man who wants to have children when he decides to marry more than one woman: *Sometimes, they just talk to each other and tell them ... if only he could meet a different person from me, maybe ... he'll like her and maybe that's the chances for him of getting to have kids. Or in the coming future ... they should get him to marry another wife, so that, he can have kids ... a second wife...* (C14). Polygamy would put the childless women in inferior positions in the family.

Future families-in-law who rejected childless potential daughters-in-law put pressure on their partners and attempted in this way to disrupt their relationships. The participants feared the devastating consequences it could have on them and their partners should they get married: *It can lead to divorce. A fight can occur in the family. And then maybe, the guy ... doesn't care (about traditional African cultural beliefs), he loves me and he has to choose ... between the family and the wife. So, it's a bad thing ... it's a terrible thing...* (B12). The family-in-laws' rejection of childless future daughters-in-law might put pressure on their sons to abandon either their own families or their childless wives.

Possible rejection of their marriages by their families-in-law had distressing consequences for the participants. One of them was convinced that her future family-in-law would try their best to get her partner interested in marrying a second wife. She therefore wanted her partner not to insist that they live with his family. She wanted them to live far from his family: *So where his family will be living, I will be a makoti (daughter-in-law), it will be a living hell for me ... they will be pressurising him to get another wife ... so, they'll be bringing more girls into the house ... for him to meet them ... while I am there ... they won't respect anything I say, cause I won't be able to give him children* (C9). The participant knew her and her partner's belief in cultural transition would not be supported by the future family-in-law and they would reject her for being a childless daughter-in-law. They would create conflict between her 'being-for-oneself' and as well as her 'being-for-others'.

The prospect of pregnancies after kidney transplants changed some of the future families-in-laws' attitude towards the participants. A participant recollected how excited her family-in-law was when they thought she was pregnant: *And they said, you are pregnant and they started ... come and sit down, let me make food for you...* (D3). The participant tried to explain she was not pregnant, but her future family-in-law would not believe her: *No, you are pregnant look at your tummy ... and they start calling XXX* (partner's name not mentioned to maintain anonymity and confidentiality), *you know she's pregnant* (D3). This misunderstanding caused major trauma to the participant as she had to explain to them that she was only bloated, a side-effect of her treatment. Thereafter they avoided her: *... when I say, .. I am coming to visit this weekend* (partner's mother would say), *No ... we're not going to be home ... she's* (partner's mother) *started to making excuses ...* (D3). The incident proved that acceptance by and support from future families-in-law was linked to the ability of the participants to bear children. The focus was on 'being-for-others'.

3.2.3 Attempts to be composed by living in the present and hoping for the future

The participants were living in the present moment having little control over their future disease process, treatment outcomes and the possibility of a kidney transplant. They appeared to be composed in terms of their 'being-for-oneseff', to live life despite the conflict they experienced within themselves and with 'being-for-others'. The participants attempted to avoid conflict with others, but they could not escape the emotional pain they experienced. Seen from the existential viewpoint, the participants' emotional pain was caused by the profoundly difficult choices they were forced to make. The agonising emotions they experienced reflected their attempts to find meaning in their suffering and pain. Hope for a kidney transplant shaped their way of thinking because it represented a way out of a profoundly sad situation. They had no control over the future.

The participants' strategies to live with kidney failure were shaped by an interrelationship of being composed by living in the present and hoping for the future. They attempted to avoid conflict with the 'self' and with 'others'. They endeavored to find meaning in their emotional experiences which enabled them to live meaningful lives as 'being-for-oneseff'.

They were living in the hope for a kidney transplant which would satisfy their needs regarding 'being-for-oneself' and also the expectations of the dialysis team and their family and their 'being-for-others'.

- **Avoiding conflict with self and others**

Opportunities for conflict with themselves and with others about their inability to become pregnant existed. The participants could not comply with the expectations of both future families-in-law and the dialysis team. Not being able to have children caused conflict within themselves which affected them emotionally: *So if I ... I'm not able to have the children ... that will also break my heart* (G5). The participants were acutely aware of the conflict they unintentionally caused for those who could not accept their difficult situation: *Mmm it's a havoc ... to think about it, it's a havoc ... you just feel like ... you don't even wanna go there ... like ... I can't deal with that ... I can't...* (B12). Conflict was caused by not being able to comply with the demand for children on their 'being-for-oneself' and 'being-for-others'.

The participants attempted to avoid conflict by engaging in different coping practices. Some participants avoided the risk posed by conflict by not thinking about it: *I don't think of any children now* (H8). Others tried not to talk about their fears of conflict with loved ones: ... (the conflict causes) *sadness and sometimes you feel like you will be judged* (by others) (B6). Not thinking about the expectations of others prevented painful emotions and supported their 'being-for-oneself'; unfortunately, avoiding such thoughts also hindered their 'being-for-oneself' as it prevented the participants from dealing with their painful emotions.

Although it hurt deeply, keeping a distance in their relationships was another way in which the participants tried to avoid conflict: ... *but then in terms of relationship it is very difficult because you want someone who will love you and who will treat you like somebody who is just fine* (not ill)... (A2). Participants were aware there was no possibility to be in a marital relationship where no pressure would be put on them to bear children: ... *obviously, a guy who's married wants a child...* (A8). The avoidance of possible conflict that may accompany a relationship was considered to be a barrier when the participants attempted

to build relationships which could end in marriage: ... *you know it become(s) a problem...* (married men) *want to have children....* (A2). Consequently, avoiding involvement in meaningful relationships prevented the participants' 'being-for-others' to their partners.

Some participants avoided conflict by not informing their family members of the expectation of the dialysis team that they should not get pregnant: ... *they don't know ... I am not allowed to have a baby ... what they know is that I have kidney failure and I am on dialysis, but about pregnancy ... we never talk* (G1). A participant who declared she discussed everything with her mother, did not discuss the expectation of the dialysis team: *I think maybe I am ignoring it ... I brush it off ... I pretend like it's not there ... I think so ... that's why ... I am not discussing it with her* (her mother) (B3) even though she knew sharing would ... *lift of some weight ... you know off me ... it will be easier for me ... to tell her how I feel...* (B3). Not talking about the issue to her mother prohibited her from sharing her feelings with the person she had the deepest emotional connection with.

Conflict was also averted by avoiding the people who disapproved of their relationships. A participant described how grateful she was that distance allowed her to avoid her future family-in-law who did not support her relationship with their son: ... *normally, they are not into our lives that much ... because they stay very far ... and thank God they stay very far* (C16). She intended to stay away from her future family-in-law to "avoid those conflict things" (C16). Avoidance of the family-in-law could be a temporary solution, but there was no assurance staying away from them would solve – or save – the strained relationship.

One participant and her partner both tried to deny the possible negative impact her disease and inability to have children might have on their relationship: (He said) *at least there is still hope ... it is not like it is the end of the world ... just hang in there...* (after a transplant) *you will have your chance ... you will have a child...* (B8). The partner of another participant also tried to deny the consequences of kidney failure and consoled his partner: *We can still manage it and then we can still get pregnant* (B13). The denial of the consequences of kidney failure gave the participants false hope for future relationships and 'being-for-others'.

Another participant preferred to have a partner that lived far from her in order to cope with the discrepancies in expectations of the dialysis team and him regarding future pregnancies. Because he was also a kidney dialysis patient, he was aware and understanding of the participant's dilemma: ... *he knows everything (and) will not push me...* (to get pregnant) (D8). She did not have any long-term relationship plans with him, but just knowing he understood her difficult situation made it possible for her to intentionally avoid any conflict about the expectations of others regarding her being pregnant or not: *It's just ... for the moment* (D8). This temporary relationship provided support for her 'being-for-oneself'. No demands regarding childbearing were made.

- **Dealing with emotional pain**

The contradictory expectations of the dialysis team and the family members caused the participants to experience deep emotional pain. One participant described the pain she had to cope with when she could not get pregnant in a previous relationship as follows: *Horrible ... very sad ... depressed ... angry ... disappointed in myself ... what was I waiting for, all this time ... why didn't I have a child maybe around 21, 22 (years old before the kidney failure)* (B5). Another participant described the profound emotional pain, which was accompanied by suicidal thoughts, she experienced when she discovered her partner had cheated on her, made another girl pregnant and the termination of her (the participant's) relationship with her partner: *It is pain – like you feel a pain, like someone's got a knife, like they put a knife in your heart... I would sit and cry (all day) ... even, if I was sitting with my friends or family (I was crying) ... all the time, I was crying* (D17). Suicidal thoughts kept surfacing in her mind: ... *killing myself ... I was not thinking about anything else ... thought of taking my life ... I just wanted to kill myself; then I would be fine ... I won't feel any pain* (D17). The thought of the effect it would have on her grandmother stopped her from committing suicide: *But, asking myself how am I going to do it ... and even if I drink this whole lot of water ... if I die ... what about my grandmother ... she will be hurt ... I want to take care of her ...* (D17). What motivated this participant to cling to life was her desire to take care of her grandmother; hence, her 'being-for-others'.

A participant who had kept her illness and the concomitant constraints with getting pregnant private and had not discussed it with anyone, expressed her terrible fear of even contemplating to have a relationship: ... *scared (to be in a relationship) ... because I have to explain myself and if I can meet someone who wants to have a babies ... I will have to tell him that I am not allowed because of my condition (G5)*. She feared the pain she would experience if she told others about her condition: ... *people will run away ... and that will break my heart ... I admit that I am scared (G5)*. This fear stopped her from seeking support from others.

Fear also prevented another participant from attempting to have a long-term relationship. Her fear resulted from an emotionally challenging experience in a previous relationship. She was rejected by her previous boyfriend's mother: *I think, scared ... of someone who is not (understanding and supportive) ... like this guy's mom ... they did not understand...* (D9). Her fear prevented her from finding a partner and the opportunity of her 'being-for-others'.

Feelings of guilt were experienced by the participants. The guilt they experienced was related to feeling they were depriving their partners from having children: *I'm depriving him, you know, from getting a woman that will have a child with him (B8)*. Some participants preferred partners that already had a child with another woman to avoid the conflict it would cause if she could not bear him more children. By doing this, they put their partners' needs before their own and focused on their 'being-for-others'.

Reflecting on her life, a participant pondered about the reasons for her suffering. She tried to find meaning in her suffering: *Troubles keep coming into my life ... so I end up asking myself what is the purpose of for me to live ... what is it ... do I have a purpose here ... am I going to be in this world to suffer until I die. Those are my questions ... why can't I be like other people ... what have I done so wrong ... that I should be sick ... when is this going to end ... is it really going to end? Or is it how it's going to be for the rest of my life? Those are the question that pops out in my head, in most cases (B14)*. She contemplated that having a child would have given her life a possible purpose: *I would have strife (strived) for more... I will have something to live up for ... to be happy...* (B14). On the other hand, she

experienced doubt about the joy of having a child: ... *what if I had a child and be sick like this ... who would look after the child* (B14). Having a child would give meaning to her life in terms of 'being-for-others' for the child. At the same time, she was concerned for the child who would in all likeness suffer (although in a different way, for example, not being with its mother and having nobody to care for it) as she was suffering due to her illness.

Importantly, the participants derived emotional growth and strength from their suffering: ... *you grow stronger ... challenges make you a better person, like this illness have made me grow stronger...* (B14). They voiced they appreciated life itself and loved ones more; they also developed more empathy for the suffering of others: *To see how life is precious, to respect it and to respect people who are sick ... not to take a person for granted...* (B14). The meaning they attached to their suffering promoted their 'being-for-oneself' as well as their 'being-for-others' by appreciating and caring for other people.

- **Living with the hope for a kidney transplant**

The possibility of a kidney transplant gave participants hope for a prospective pregnancy. Even a participant who planned a marriage without having children, had hope of having children in the future after having a kidney transplant: *Unless I have another kidney (transplant). I am hoping to have one (kidney transplant) ... I am praying for one* (H8). The participants were aware of the possibility of pregnancy after a kidney transplant. They also knew it would take time to start trying for a baby: *I was told that it is possible to get a baby once you transplanted (had a kidney transplant) ... but you must stay (wait) at least two years after the transplant ... before you can start trying for your baby...* (A10). The possibility of a transplant and pregnancy influenced participants' hope for future relationships and/or having children. One participant was convinced a transplant would change her life "*in terms of relationship wise*" (A10). Having a kidney transplant would afford the participants the opportunity to become mothers ('being-for-oneself') and meeting the expectations of others ('being-for-others').

The prospect of a kidney transplant also offered hope to the family members. A participant described her experience of the peace it would bring to her mother: *She told me if I should get a transplant and it works properly after two years, and then, she will be fine, cause she will be knowing that there is nothing to worry about, because I will be looking after myself and I will have a kidney and then I will be taking my medication ... and then ... whatever happens ... if I do get kids or not ... she' will be supporting me* (C17). This hope was demonstrated in the mother's support for the participant's 'being-for-oneself'.

The uncertainty of the waiting period for a transplant affected the participants' ability to plan for the future and they became doubtful about whether a transplant would ever be done: *I was having hope of being transplanted since one of my sister was a match ... and she told me that she wanted to give me her kidney ... but now ... she is having ... second thoughts and ... now I am thinking ... my transplant is not going to come any time soon...* (A10). The uncertainty surrounding a kidney transplant left the participants moving between hope and despair; these feelings had an emotionally detrimental effect on their future expectations.

The age limit for pregnancy mentioned by most participants was 35 years. Living with the hope for a kidney transplant, the aging process and possible infertility associated with maturity threatened the participants' expectations of having children after a kidney transplant: *... the clock is ticking, you know, my age ... I am going to be a 26-year-old soon ... what if by the time it (the transplant) comes ... it is too late and ... I cannot conceive ... due to the age ... it will destroy me ... it will destroy me ... it will destroy me...* (B14). Another participant said she would be very upset and feel useless if she cannot conceive and have a baby after a transplant: *... it will make me very upset ... it will make me to think that I'm useless...* (B15). For the participants, being unable to have children meant not being able to fulfil a requirement set by themselves ('being-for-oneself') as well as their families, partners and in-laws ('being-for-others').

3.3 SUMMARY

In this chapter the essence “**‘being-for-oneself’ and ‘being-for-others’ in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis**” as well as the substantiating constituents were described. In the next chapter a discussion of the constituents with reference to literature is presented.

CHAPTER 4

DISCUSSION OF FINDINGS

4.1 INTRODUCTION

The previous chapter presented a description of the findings of the study. The essence of the experiences of the participants was identified **“‘being-for-oneself’ and ‘being-for-others’ in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis”**. The substantiating constituents, namely living with contradictory expectations from their mothers and future families-in-law; living with cultural transition; and attempting to be composed by living in the present and hoping for the future, were described.

In this chapter a theoretical discussion of the findings is presented to create an improved understanding of the essence and constituents (Dahlberg, Dahlberg and Nyström 2008: 272-273). According to the descriptive phenomenological research method, the constituents are discussed using literature references, but the essence is not. Hence, the applicable literature was extensively reviewed to serve as a literature control for the findings and to link the findings to the existing body of research knowledge (De Vos et al. 2011: 305).

4.2 THE ESSENCE OF THE EXPERIENCE ‘BEING-FOR-ONESELF’ AND ‘BEING-FOR-OTHERS’ IN ORDER TO LIVE WITH CONFLICTING EXPECTATIONS REGARDING PREGNANCY WHEN GETTING LONG-TERM KIDNEY DIALYSIS

The essence of the experience was identified as: **“‘being-for-oneself’ and ‘being-for-others’ in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis”**. ‘Being-for-oneself’ and ‘being-for-others’ are concepts described in existentialism, a philosophical movement that developed from phenomenology.

Cox (2009: 36-37) explains people 'being-for-oneseff' are "conscious of themselves and conscious of the world". Each person creates perspectives for her- or himself through choices and actions. As such, the participants were conscious of themselves while experiencing the phenomenon of conflicting expectations regarding pregnancy. They chose how to react to the experience and how to cope with it.

The participants' experiences were influenced by other people. Cox (2009: 37-39) expounds on a person's 'being-for-others' by stating other people view and judge a person as an object in their (other people's) experienced world. Other people might force people to be what they are for others ('being-for-others') rather than for what these people are for themselves ('being-for-oneseff'). In this study, 'other' people affected the way the participants experienced conflicting expectations regarding pregnancy when receiving long-term kidney dialysis. The participants were influenced by 'others' to experience contradictory expectations regarding pregnancy. These 'others' were also the source of the experience of conflict in living with cultural transitions. The participants strived to be composed by living in the present while hoping for improvement of their situation in the future. Their mothers, partners as well as their future families-in-law were identified as the 'others' who influenced the participants' experiences of conflicting expectations regarding pregnancy.

Attempting to achieve 'being-for-oneseff', the participants tried to adapt to their current situation in which they were expected not to become pregnant for an undetermined period of time. They experienced support for their 'being-for-oneseff' from their mothers and grandmothers (who fulfilled the role of mothers) and who accepted that the participants should not get pregnant while receiving kidney dialysis. In contrast, the participants experienced rejection of their 'being-for-oneseff' because all future families-in-law (and some partners) demanded grandchildren without consideration or acknowledgment of the possible negative consequences for the participants' health.

The participants hoped that the cultural transition which people in South Africa experienced at the time of the study would make it easier for them to be accepted as future daughters-in-law in spite of the biomedical restrictions placed on them with regard to

pregnancy. Unfortunately, the participants were additionally exposed to conflicting messages from partners who struggled to balance their own desire to have children while at the same time also trying to meet the demands of their own families. The participants experienced poor support for their 'being-for-others' from their future families-in-law who adhered to traditional African cultural beliefs which include the inbred demand for daughters-in-law to bear children for the family. In trying to 'being-for-others', the participants experienced much agony because they felt their partners and the latter's family members viewed them as objects of judgement. They were rejected because they could not fulfill the cultural requirements of motherhood and thereby promoting their partner's and his family's heritage.

Furthermore, the participants attempted to be composed ('being-for-oneself') by living in the present and hoping for the future. They tried to avoid conflict with others ('being-for-others'). Various coping mechanisms were used by the participants to deal with their emotional pain. For some participants, a way of coping was to demonstrate denial; other participants put their lives on hold while waiting for a kidney transplant. The everlasting hope, namely that once they had had a kidney transplant and pregnancy was possible, they would continue with their lives as previously planned (before they needed kidney dialysis) strengthened their resolve to 'being-for-oneself'.

The essence of ways of "being-for-oneself" and 'being-for-others' in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis" is supported by the following constituents: living with contradictory expectations from their mothers and future families-in-law; living with cultural transition; and attempts to be composed by living in the present and hoping for the future.

4.2.1 Living with contradictory expectations from their mothers and future families-in-law

CKD is a life-threatening disease which necessitates life-long kidney dialysis treatment or a kidney transplant (NKF n.p. <https://www.kidney.org/atoz/content/dialysisinfo>). People living with CKD may spend many years receiving dialysis treatment on an outpatient basis.

The participants in this study were mostly cared for by their mothers. Mothers viewed the participants as very sick offspring who simply had to be taken care of. The mothers therefore sought treatment for their daughters, accompanied them and supported them to cope with the requirements of the treatment. In rural South Africa taking care of a child, even an adult child, is viewed as the mother's responsibility (Schatz 2007: 152). Mothers and grandmothers take care of their sick adult children and grandchildren even when they themselves are past retirement age. Such care includes financial aid, physical care, and accompaniment to treatment facilities (Schatz 2007: 151). Whyte and Whyte (2004: 89) add adult women with chronic diseases often return to their parents' home and are cared for by their mothers.

The female patients in this study who had been raised by their grandmothers received the same type of care and support as those who were looked after by their mothers. Schatz et al. (2014: 150-151) report in Africa older women often take care of defenceless family members including sick adult children, fostered or orphaned grandchildren and parents- or children-in-law. Knight and Yamin (2015: 3 of 11) agree with Schatz et al. (2014) by stating orphaned children in traditional African culture are usually cared for by female family members; often the grandmother.

In the South African context, three generation households are not a novelty – grandmothers often take care of their grandchildren's needs and act as surrogate parents for their foster or orphaned grandchildren. They take on the parenting role with such purpose and devotion that grandmothers often do not differentiate between their children, grandchildren and foster children (Schatz 2007: 152). According to Schatz (2007: 153), the older women's contribution in multigenerational households may include financial and/or physical care. They anticipate that, in return for taking care of these children, they would be compensated by their children or grandchildren in the future who will support the former, take care of them and pay for their funeral. Although caring for sick children and grandchildren places physical, emotional and economic burdens on them, older women perceive "taking care of their own blood" as their sole responsibility to ensure the latter will in return take care of them (Schatz 2007: 153). Some participants' mothers expressed

their willingness to take care of their daughters' children (the mothers' grandchildren) in case the participants were too ill to look after their own children.

Daughters have strong feelings of responsibility to care for their mothers and are expected to contribute more to their mother's household than their brothers. Married women will even send money to their mothers without their husbands' knowledge (Mathis 2011: 845). The participants felt their mothers were their confidants and had close emotional bonds with their mothers. The participants therefore wished to regain their health in order to take care of their mothers.

The participants' mothers acknowledged their disease and treatment. Parents of chronically sick children seek information about their children's disease and prospects. They are also interested in their children's treatment process and the possible complications of any therapy. It is essential for parents to know how they must take care of their children (Kilicarslan-Toruner & Akgun-Citak 2013: 180). The participants' mothers were informed by either the dialysis team or their sick daughters about the expectation that the participants should not get pregnant while receiving kidney dialysis. Once the reasons had been explained to them, the mothers were understanding and supportive. The knowledge mothers had gained enabled them to respect and accept the arrangement because they understood that pregnancy during dialysis treatment would endanger the life of their daughter as well as that of the unborn child.

Kidney dialysis confronts a patient's family with the possibility of dying (Ekelund & Andersson 2010: 33). The mothers of the participants tried to put their daughters at ease about their childbearing prospects. They constantly assured their daughters that their lives were more important than having children. This supported the participants in 'being-for-onself' and they could focus on themselves, their disease and treatment. Although the mothers also wished to have grandchildren, they were more concerned about their daughters' health. It is reported in other studies that spirituality plays a significant role in the parents' personal ways of coping in times when their child/children struggle with chronic diseases. Allen and Marshall (2010: 236), for example, state spirituality and spiritual beliefs are personal resources which are highly related to ways of coping among

parents of children with chronic diseases. The mothers of the participants prayed for their daughters to have the stability of their own family could provide their daughters (the participants).

Because the participants were of reproductive age, the future families-in-law of those who were in relationships expected the participants to bear children. This demand for grandchildren is related to the value of children in African communities and society as confirmed by Dyer (2007: 69): “Children secure conjugal ties, offer social security, assist with labour, confer social status, secure rights of property and inheritance, provide community through re-incarnation and maintaining the family lineage, and satisfy emotional needs.” Married women are therefore obliged to bear children to perpetuate the families-in-law’s future bloodline (Sofolahan & Airhihenbuwa 2013: 274).

When women in Africa experience challenges to bear children they turn to their mothers for support (Holloos et al. 2009: 2067). Their belief that they will “always have the support of their mothers” indicates the daughters’ conviction that their own parents (particularly mothers in this instance) are usually more understanding than their husbands’ parents (Naab 2014: 97). The participants in this study experienced their mothers as supportive and understanding. The mothers’ ongoing encouragement and assistance was a poignant aspect of the mother-daughter relationship in this study because the daughters were chronically sick and pregnancy had to be avoided during the dialysis treatment. The mothers in this study were aware of the demoralising consequences of childless unions in African culture; they dreaded the possibility that their daughters could be rejected by their future families-in-law or stigmatised as being “barren”, but they stood by the participants and supported them through the ordeal of dialysis treatment.

The study findings show the participants’ own families were prepared to wait for grandchildren until it was safe for them to bear children whereas the future in-laws pressed them for grandchildren. Conversely, the future in-laws’ demands made no allowance for the possible negative consequences pregnancy could have on the participant’s life and health. Harassment and rejection from their future families-in-law were reported by the participants. In societies where it is viewed as a woman’s duty to bear children for their

families-in-law, it is not uncommon for women to be harassed and abused if they are unable to comply with this expectation. Childless women in Northern Ghana reported mistreatment from their mothers-in-law (Tabong & Adongo 2013: 4) and in rural Côte d'Ivoire childless women confirmed they experienced abuse from their families-in-law (Gupta et al. 2012: 1061). In fact, the Côte d'Ivoire study found childless women were extremely vulnerable for in-law abuse; they would use physical violence to force a daughter-in-law to have children thereby taking away her right to make her own decision on whether she wanted a child (or more children) (Gupta et al. 2012: 1061).

The mothers also wished for grandchildren; they desired secure and steady relationships, marriage and children for their daughters as it would allay their own fears about their daughters' future. They knew if their chronically sick daughters could have children they would provide the personal and financial assistance their mother would need in the future. In African cultures having children is necessary for the economic survival of the family. Children do some chores at home and when they are old enough they also contribute to the income of the family (Kaler et al. 2012: 136). In other words, if women do not bear children, they do not secure an income for the family (Dyer & Patel 2012: 106) or ensure that caregivers are available for the elderly family members (Evens et al. 2015: 379). According to Van Balen and Bos (2009: 107), in some African societies – especially in poor-resourced areas and communities – childlessness has detrimental effects on the economic life of the family because all members of the family, children included, contribute to the finances.

Children also contribute to the survival of their fathers' family (Mathis 2011: 842). Consequently, the finding that future families-in-law of the participants were more concerned about the childlessness of the participants than the participants own families, may perhaps be understandable from the in-law's point of view. However, it is a negligible view when measured against how potentially fatal a pregnancy can be for the future daughter-in-law on dialysis treatment. The culture of the husband's traditional African family prescribes that the core duty of a daughter-in-law is to provide offspring. Those who do not bear children are accused of immoral action according to traditional African beliefs (Naab 2014: 96). They are thus rejected by the family-in-law (Dhont et al. 2011: 626) on all

levels including having no access to the assets of their families-in-law or that of a deceased husband (Sofolahan & Airhihenbuwa 2013: 274).

Dhont et al. (2011: 626) established that in a traditional African urban population in Rwanda, the growth of the family is closely linked with the replacement of the deceased. As noted before, continuing the family lineage is pivotal in African culture. Because children are vital for the survival of families, the pre-eminent expectation from daughters-in-law is to contribute to the growth of the families of their in-laws and those who bear children are respected. More importantly, producing sons is the foremost expectation (Lambert & Rossi 2014: 30). Having male children is essential in traditional African cultures because they are seen as potential family leaders (Naab 2014: 95). It also has legal consequences because, according to customary law, male members inherit the land and the family money (Van Balen & Bos 2009: 107).

Consequently, as Naab (2014: 99) states, childlessness affects not only the couple but the whole family. Naab's (2014) statement reinforces the earlier finding of Kaler et al. (2012: 134) that reproductive decisions are seldom taken in isolation by the couple as the costs and benefits of children involve the whole family. Still, a woman is prohibited from making an independent decision regarding childbearing without her husband's as well as his family's input (Evens et al. 2015: 382). Furthermore, if a partner/husband does not support his wife/partner who, for some reason, has to postpone bearing children, marital as well as familial problems may develop (Naab 2014: 96). Members of the extended family are affected by the couple's marriage because having children is necessary for the whole family's existence. It is therefore common practice for extended families to interfere with a couple's decisions about having children (Naab 2014: 97).

Childless African women often experience the destruction of loving relationships by families-in-law because of their inability to bear children. When a family-in-law does not accept a wife of one of the sons, marital instability may result (Van Balen & Bos 2009: 116-117). Even when couples are able to manage the consequences of childlessness within their union, a poor relationship with the women's in-laws may over time cause marital problems (Dhont et al. 2011: 625; Fledderjohann 2012: 4). Under pressure from their

families, husbands may divorce their childless wives (Sofolahan & Airhihenbuwa 2013: 274).

Tabong and Adongo (2013: 7 of 10) note one of the fears an African childless woman lives with, is that her mother-in-law may introduce her husband to another woman who can have children. Indeed, Ibisomi and Mudege (2014: 68) expound if the husband chooses not to divorce his childless wife, he may be forced by his family to marry a second wife. This custom then also limits men's choice of wives to what is acceptable (having childbearing wives) for his family (Ibisomi & Mudege 2014: 68). According to traditional African cultural beliefs, voluntarily union with women who cannot have children is not an option for African men. It is believed that no sensible man will stay with a childless wife out of his own free will and therefore the woman is usually the one who is accused of having bewitched him should he decide to stay with her (Naab 2014: 95). Taking other wives may be demanded and seen as a solution for the childlessness of the couple. The family-in-law might be pleased with a childless wife who supports her husband in getting another wife (Naab 2014: 97).

From a religious and cultural viewpoint, African women believe marriage is meant to last forever and divorce is not an option. They are not supposed to return to their family home but should stay at their in-law's place until they die (Mbatha 2011: 34). Once married, wives become part of their husbands' families and are dependent on them for life. They are expected to contribute to their family-in-law's lineage and the children they bear form part of their husband's family lineage (Mathis 2011: 842). The participants relied on their future families-in-law for support in times of being sick. However, the participants were rejected by their future in-laws. A study in Uganda revealed that when daughters-in-law get sick and cannot bear children, their in-laws often abandon them (Whyte & Whyte 2004: 89).

Childless women with more educated and affluent families reported more support and less pressure to have children because the families did not need children for economic sustenance (Tabong & Adongo 2013: 5 of 10). Having alternative insurance strategies such as a pension plan and laws that govern inheritance practices to protect wives, reduce

women's dependence on children and grandchildren for care (Lambert & Rossi 2014: 30). It gives childless women the opportunity to make a living despite the hardship and pain they experience due to being childless.

4.2.2 Living with cultural transition

The demands the participants experienced to bear children were determined by their traditional African cultural background. In the traditional African culture, womanhood is associated with motherhood (Greil, Slouson-Blevins & McQuillan 2010: 145). Contrary to the cultural expectations of some of the families, the dialysis team required the participants not to become pregnant while receiving long-term kidney dialysis treatment because of the health risks it involved for them as well as their unborn infants (Piccoli et al. 2010: 69). To cope with these conflicting expectations necessitated the participants to live in cultural transition.

4.2.2.1 Own cultural transition

Cultural practices are socially transferred through generations from older members of the community or society to newcomers. It takes place through instruction of the new members by the older members and through observation by the new members of the practices of the cultural group. The older members make sure that the norms, values, and beliefs are internalised by new members (Kashima et al. 2015: 122). The cultural identity of members is continually created and moulded according to the expectations of the group (Usborne & de la Sablonnière 2014: 442) and influences the way individual members is perceived by other members (Schaan et al. 2015: 5 of 13).

Cultural systems are not fixed but in transition as “ever changing constructions that emerge from interactions between individuals, communities and larger ideologies and institutional practices” (Kirmayer 2001: 22). Because new members can initiate new practices (Kashima et al. 2015: 122), the cultural identify of individuals may differ from that of the group (Usborne & de la Sablonnière 2014: 442).

The participants acquired cultural beliefs through interaction with their own families and the members of the community. They were also exposed to an allopathic healthcare system that supports specific beliefs regarding health and the promotion of health different to those of the cultural group. The participants were taught by the dialysis team that adherence to dialysis treatment could save their lives while they were waiting for transplants. One of the requirements for adherence was, however, the postponement of becoming pregnant. The participants made an informed choice to adhere to the advice of the dialysis team. In the process they had to disregard or change their traditional African cultural beliefs. They found themselves in the midst of a cultural transition. They opted to adhere to treatment and 'being-for-oneself' thereby not abiding by the traditional African cultural expectations which emphasised 'being-for-others' by getting pregnant. This decision was in contrast to the beliefs of their cultural group.

Acculturation takes place when people with different beliefs interact on a continuous basis and get used to the beliefs of the others to the extent that they modify their own beliefs (Redfield, Linton & Herskovits 1936: 149–152 cited in Sam & Berry 2010: 473). People either adopt the beliefs of others or change their own beliefs due to the interaction they have with people from other groups. Acculturation necessitates people to adapt psychologically and culturally to their new situation (Sam & Berry 2010: 473). Participants interact on a daily basis with westernised health care system which fosters contemporary practices. Therefore the participants had to adapt to the unfamiliar culture associated with their medical care and the expectation not to become pregnant which differed significantly from the expectations of the culture they had been born and raised in.

The participants grew up in families and a society which traditionally link motherhood to womanhood and marriage. Having children is viewed as a requirement for acknowledgement of women as adults and thus as valued members of their society (Hollo et al. 2009: 2068). Schaan et al. (2015: 7) confirm the belief that in some cultures womanhood is defined by motherhood and taking care of the family. Not having children is a visible way of showing non-compliance to the cultural norms of womanhood.

As younger members of their cultural group, the participants had different views on the importance of traditions. Young people respect some of the old traditions, but also embrace more modern customs (Bohman, van Wyk & Ekman 2009: 451-452). The younger generation of African women want to achieve education and employment goals as well as financial freedom before having children (Moore 2013: 162). These women are not reliant on motherhood as their only measure of personal value in society. They view motherhood as only one of their roles along with developing themselves (Moore 2013: 169) and asserting their right to excel in their careers and even set up self-governing households (Mathis 2011: 847).

Some participants in this study challenged cultural transition by exploring alternative methods of having children without being pregnant themselves, for example, adoption or surrogate pregnancy. In traditional African culture systems, having biological children is considered pivotal for continuing the family ancestry. Only biological children are allowed to carry the family's surname and inherit property. As a result, adoption is not accepted and childless couples are expected to rather help raise other children in the family (Naab 2014: 96).

4.2.2.2 Cultural transition of family members and partners

According to traditional African culture, older members of the cultural group expect their children and grandchildren to respect them and the cultural beliefs which they represent (Bohman, van Wyk & Ekman 2009: 451). It is important for them to transfer traditional African culture to younger members of the cultural group to ensure that the latter will uphold the norms and beliefs (Bohman, van Wyk & Ekman 2009: 451). When the elders become aware of acculturation, they attempt to re-instill the traditional African culture's inherited norms and beliefs. This is demonstrated in the re-installment of virginity testing practices by older women in rural KwaZulu-Natal in South Africa to regenerate their role as guardians of young girls (Mathis 2011: 847).

Younger members of the cultural group, who find modern-day living conditions far different from their older family members' experiences, may find some traditional African cultural beliefs unsuitable to their living conditions (Bohman, van Wyk & Ekman 2009: 452). The

participants wished to fulfill the cultural expectations of the future families-in-law to provide them with grandchildren, but could not due to the prescriptions of the dialysis team. The traditional African cultural beliefs of the future families-in-law were thus unsuitable for the living conditions of the participants. Some of the participants' partners understood the prescriptions of the dialysis team in that the traditional African cultural values regarding childbearing could not be adhered to. Unfortunately, their traditional African cultural positions were inferior to that of the older generations and the partners could thus not convince their parents to support instead of reject the participants.

According to Ibisomi and Mudege (2014: 67), childless couples in traditional African culture are mistrusted by society and occupy inferior positions in the family. In traditional African culture it is assumed that all people want to bear children (Ibisomi & Mudege 2014: 65) because mother- and fatherhood determine the position of people in the family (Mathis 2011: 842). Moreover, motherhood gives a woman status in society (Sofolahan & Airhihenbuwa 2013: 274). Childless women are thus not considered as valuable members of society and experience disrespect. In traditional African culture, once women have children, they are respected and are referred to as the 'mother of so and so' (called by the name of their children) (Schaan et al. 2015: 5). Their position as child bearers and their legacy continue after death as they are remembered through their connection with their children (Kaler et al. 2012: 136). Women who do not bear children are seen as inferior in traditional African culture as they do not provide offspring to uphold the traditions, beliefs and rituals of the group (Schaan et al. 2015: 5).

The participants realised the importance of the cultural beliefs of their future families-in-law when these refused to continue with dowry negotiations without the participants having demonstrated their fertility. A dowry or 'bride price' ('ilobolo' or commonly known as *lobola*) is paid by the future husband and his family to the bride's family for her reproductive and productive contribution to her new husband and his family. The inherited practice of *lobola* is deeply embedded in the fabric of traditional African culture. This is evidenced by the fact that, in spite of the cultural transition of the modern African society, it is still widely practised in the southern parts of Africa (Mbatha 2011: 32). *Lobola* is paid to acknowledge the role of the bride's parents in raising her; it also forms the basis for the groom's family to claim the children born out of the union as part of their ancestry (Mathis 2011: 842).

Although many African people no longer adhere to all traditional African cultural practices, the dowry is still paid as a sign of respect to older people of the cultural group. It also serves as a sign of the commitment of the groom towards the bride (Rudwick & Posel 2014: 132-133). Unfortunately, the *lobola* system places pressure on young women to provide grandchildren and when they cannot, as in the case of the participants, they are often blamed for not keeping to the agreement between the two families. It impedes the women's reproductive autonomy and places childless women at risk of intimate partner violence and abuse by families-in-law (Horne, Dodoo & Dodoo 2013: 513). Women may be regarded as property and thus be at risk of being abused (Mbatha 2011: 32).

If women do not live up to traditional African cultural expectations and bear children, older members of the group may interpret it as a violation of social norms (Dyer et al. 2004: 964). They may even get blamed for the infidelity of their husbands (Sofolahan & Airhihenbuwa 2013: 273). In traditional African cultural groups, the extramarital relationships of men who are married to women who cannot or do not want to have children, are encouraged in an attempt to gain grandchildren for the family (Ibisomi & Mudege 2014: 68, Tabong & Adongo 2013: 6 of 10). Such adultery is then viewed as a culturally acceptable way to solve the problem of childlessness (de Kok 2009: 211). In fact, the childless wife is oftentimes praised by her in-laws if she supports her husband to have children with other women (Naab 2014: 97). Should a polygynous marriage ensue due to the first wife's inability to bear children, she will be considered inferior to the wives (or wife) who bear(s) grandchildren for the family (Mbatha 2011: 36).

Some participants in this study experienced that their partners demanded sexual intercourse without a condom in an attempt to force them to get pregnant. It placed the participants' lives at risk. For the participants it created the impression that their partners were not concerned about their health, but about the expectations of their families to contribute grandchildren to extend the family. The cultural transition the participants experienced was not shared by all partners. According to a study by London, Orner and Myer (2007: 18), men who are desperate to have children may force their partners to conceive despite the possible dire consequences (including a decreased life expectancy) pregnancy may have on the women's health. Men may view CKD as a condition which can

be treated; they will therefore have little concern for their partner and her health and will only focus on their own need to have children (Ekelund & Andersson 2010: 31).

Under extreme traditional African cultural circumstances, childless women may be considered as evil (Ibisomi & Mudege 2014: 68) or even as witches who might steal children (Tabong & Adongo 2013: 4). It is believed that only traditional healers can cure them (Naab 2014: 98). Although the participants in the study did not believe that traditional healers could cure their CKD and thus end their childlessness, they were encouraged by family members to consult such healers. In some traditional African cultures, traditional healers are consulted as sole providers of healthcare or in combination with allopathic healthcare (van Wyk 2009: 16). Ivey and Myers (2008: 67) found in some instances, when traditional healers prescribed rituals to be performed, the performance of these rituals did indeed contribute to the psychological support of their patients.

Due to the cultural transition the participants experienced, they did not consult traditional healers. They tried to adhere to the prescriptions of the dialysis team in spite of the pressure from family members to visit traditional healers. They tried not to offend the people in their cultural groups who adhered to traditional practices while at the same time trying not to jeopardise their own health. According to Sam and Berry (2010: 478), people should be able to adapt to changing circumstances. The participants were reared in traditional African cultural societies, but were exposed to allopathic healthcare on a regular basis because of their illness. They had to adapt to a hospital environment. Once they had kidney transplants, their circumstances would again change: there would be no need to visit the dialysis unit on a regular basis, and they would hopefully conceive and bear children thereby fulfilling traditional African cultural expectations. Cultural transition is demonstrated when people become flexible in order to adapt to changes in their living circumstances (Bohman, van Wyk & Ekman 2009: 451).

Some family members accepted the childlessness of the participants and were more concerned about the health of the participants. It was none of the participants' decision not to have children; they had no choice but to adhere to the advice of the dialysis team if they wanted to stay alive and possibly have children in the future after having successful kidney

transplants. According to Ibisomi and Mudege (2014: 65), traditional African people are more tolerant towards childless people when the childlessness is involuntary.

Cultural transition is enhanced by an increase in the educational level of the cultural group. Although cultural transition leads to smaller families (Colleran et al. 2014: 3), the value of women is not determined solely by the number of their offspring, but also by their educational and career achievements (Tabong & Adongo 2013: 8 of 10). Such achievements may protect a childless woman from stigmatisation (Donkor & Sandall 2007: 1689). The participants did not consider their childlessness as indicative of their position in society and as detrimental to their happiness. They believed they were valuable and that they could still experience happiness. Naab (2014: 96) confirms this positive attitude by stating it is not only children that determine the value and happiness of people.

4.2.3 Attempts to be composed by living in the present and hoping for the future

By 'being-for-oneself' the participants had to cope with the stressors associated with kidney dialysis which includes not being in the position to conceive and give birth. In 'being-for-oneself' and 'being-for-others' they tried to appear composed despite the emotional pain they experienced. Kidney dialysis patients experience their future as unclear (Ekelund & Andersson 2010: 33). They are only sure of today. The participants therefore focused on the present while they remained hopeful about the future.

4.2.3.1 Avoiding conflict with self and others

Conflicting expectations concerning pregnancy when receiving long-term kidney dialysis, as experienced by the participants, resulted in relationship instability, spousal adultery, and rejection from in-law members. According to Fatoye et al. (2008: 209), the emotional stress associated with childlessness of women who desire to bear children is increased by conflict with their future family-in-law. High levels of anxiety, shame and guilt experienced by such childless women have been reported in emotionally conflicting situations like these (Naab, Brown & Heidrich 2013: 136). The participants also experienced added stress

caused by the consequences and side effects of kidney dialysis. The treatment is time-consuming and limits the mobility of patients (Ahmad & Al Nazly 2015: 481-482).

Patients with ESRD need to adjust to long-term treatment; they have to accept the chronicity of the disease and the impact it has on their lives (Schipper & Abma 2011: 3191). The participants in this study had to accept the restrictions on childbearing and opted to avoid conflict regarding the expectations of their families and the dialysis team. Some of the participants isolated themselves from their families and partners. Patients with kidney disorder also often experience sexual dysfunction (Schipper & Abma 2011: 3192) and this may be a possible reason why some participants tried to isolate themselves from possible partners. Patients with sexual disorders feel ashamed and often do not discuss it with the dialysis team (Lew-Starowicz & Gellert 2009: 1070-1071).

Childless women tend to avoid discussing their challenges; they tend to view it as a secret which should only be shared with very close family members (Pedro 2015: 53-55). In the study the participants reverted to avoiding situations in which their childlessness could be discussed to prevent conflict. They did not want to defend their support of the dialysis team's prescriptions. They also wanted to avoid painful situations caused by the rejection of them by family members as well as their partners. Their attempts to avoid conflict unfortunately derived them from sources of possible support. Patients with chronic illnesses need support from their significant others to cope with the demands of long-term poor health and treatment (Schipper & Abma 2011: 3190). Absence of support from others may have detrimental effects on the psychological well-being of people.

Without support, patients with life-threatening illnesses are more inclined to use avoidance or emotion-focused coping strategies including denial and self-blame (Hundt et al. 2015: 1192). Denial and avoidance strategies are useful to the participants who cannot engage in more advanced coping strategies. They are often unable to use active coping strategies because of their disease and symptoms that limit physical activity. The treatment and limitations associated with kidney dialysis and the complications surrounding conflicting expectations regarding pregnancy might have been overwhelming for the participants. They blamed themselves for previously not complying with prescribed treatment which

could have contributed to their kidney failure. They also blamed themselves for not having had children before getting sick.

Illness intrusiveness is determined by a person's physical health as well as psychosocial aspects (Hundt et al. 2015: 1193). Patients who sense a loss of control over their health experience more illness intrusiveness and may not employ self-management behaviours that could reduce disease-related outcomes (Hundt et al. 2015: 1192). The participants, being unable to control their situation, experienced external locus of control from the dialysis team and their families. They employed denial and avoidance strategies to cope with the expectations from both sides (dialysis team and family). Welch and Austin (2001: 204) explain there is a link between avoidance coping strategies and the occurrence of depression. These authors also found that when psychosocial stressors increase, people tend to isolate themselves further which results in more severe depression. Dialysis patients often show signs of depression (Silva et al. 2014: 548; Andrade, Sesso & Diniz 2015: 59). Increased levels of anxiety and depression are linked to suicidal ideation and decreased quality of life in kidney dialysis patients (Chen et al. 2010: 258.e3).

According to Nowak, Wańkiewicz and Laudanski (2015: 1803), avoidance can be used by patients with kidney dialysis to temporarily help them to not feel overwhelmed by constant worry about their treatment and associated consequences. Avoidance coping are used by people who feel unable to deal with their problems (Welch & Austin 2001: 205); but, it only relieves stress on a short-term basis. Women with childbearing problems use avoidance coping strategies by not discussing the problem with others (Donkor & Sandall 2009: 89). Kidney dialysis patients use avoidance strategies in combination with denial as coping strategies (Nowak, Wańkiewicz & Laudanski 2015: 1803). Avoidance is more often used by people with a low educational level (Nowak, Wańkiewicz & Laudanski 2015: 1803) and is predictive of destructive emotions and lower scores for healthy long-term mental functioning (Ruiz de Alegría-Fernández de Retana, Basabe-Barañano & Saracho-Rotaeché 2013: 352). Denial as a coping strategy has been found to limit patients' understanding of their treatment; denial prevents meaningful participation in procuring a living kidney donor (Marlow et al. 2014: 8).

4.2.2.3 Dealing with emotional pain

The participants described experiencing severe emotional pain. Childlessness has profound psychological consequences resulting in emotional stress and experiences of loneliness, worry, and symptoms of depression (Fledderjohann 2012: 7). The participants reported extended periods of sadness and crying as a result of people's reactions to their childlessness. Considerable time was spent thinking about childbearing and sleeping problems were reported. Emotional turmoil was further caused by the contradictory expectations of their own families, future in-law families, partners, and the dialysis team. The emotional pain caused by childlessness is aggravated by concerns about possible relationship problems and social stigmatisation (Fledderjohann 2012: 4).

The emotional pain of the participants was increased by uncertainty about whether they would get kidney transplants and be able to conceive. They also felt the dialysis team provided inadequate support and that some families were unreasonable by expecting them to produce grandchildren while they were still trying to cope with the challenges and demands of treatment. People who need to cope with the challenges of childlessness require adequate information from the health team and optimal support from family members (Pedro & Andipatin 2014: 334). The participants did not receive fully detailed explanations from the dialysis team about the consequences they could experience if they became pregnant while on kidney dialysis treatment. Additionally, the information they received from different sources was often contradictory.

The participants' partners received no information from the dialysis team. This is quite unacceptable as childlessness does not only affect women, but also their partners and families (Fledderjohann 2012: 5, Naab 2014: 97). Naab (2014: 99) emphasises that all relevant parties should be involved in health education. Thus, in the context of this study Naab's (2014) assertion included all the patients with CKD who were on kidney dialysis treatment as well as their partners, families and families-in-law. Without proper knowledge some of the participants were exposed to emotional pain caused by family members who did not understand the reasons for their childlessness. They persisted in expecting the participants to get pregnant according to their own traditional African culture.

Much of the emotional pain that the participants experienced was caused by the way they regarded and coped with the experience. A few blamed themselves for their childlessness. They postponed getting pregnant as they first wanted to finish their education and become financially independent. Should they not have done that, they could have had children before they became ill. Childless women tend to blame God, others, and also themselves for not having children and for the sadness, feelings of loss, and emotional pain they experience because of their childlessness (Pedro & Andipatin 2014: 333-334). Some of the participants viewed their childlessness as unfair and they were upset by the negative reactions of others towards them. They had to cope with their own grief as well as with the rejection they experienced from others. People are often very insensitive to the extreme emotional pain that childlessness may cause (Pedro & Andipatin 2014: 335).

Marital concerns were reported by the participants. They felt guilty because of the consequences their dialysis treatment had for their partners who wished to have children. Kidney dialysis patients are anxious about the impact of their ailment on the functioning of their families. They desire support for their families and are concerned that they could be a burden for them (Ekelund & Andersson 2010: 33).

The participants were expected to cope with the effect of their disease and treatment on themselves and their families and, at the same time, also with the effect of their childlessness on the people close to them. When people have to cope with multiple causes of stress, professional support is required (Ekelund & Andersson 2010: 31). Unfortunately, the participants did not receive such support and had to cope with their own emotional pain as well as that of their partners and families. The dialysis unit where the study was conducted does not have a permanent psychologist. Physicians have to write a consultation letter for patients to be evaluated by a hospital psychologist. None of the participants reported having received psychological support from a hospital psychologist regarding the phenomenon. When insufficient support is received, people who have to cope with multiple stressors tend to develop symptoms of depression and may even have suicidal thoughts (van Der Horst & McLaren 2005: 522). In traditional African cultural society, the cause of psychological reactions such as depressive symptoms may be

viewed as supernatural. People who live with depressive symptoms could be labelled as “crazy” and they should be avoided by other members of the cultural group (Naab 2014: 98). Unfortunately, no professional psychological support is sought in these circumstances for these “crazy” people who are, in fact, in dire need of a professionals’ care.

Emotional pain is eased with sufficient support from the health team and the significant others (Steuber & High 2015: 1368). Suicidal thoughts are prevented when people feel accepted and supported by others (Andrade, Sesso & Diniz 2015: 60). Without support and acceptance the emotional pain may become too much to cope with. Some of the participants considered suicide as a means to stop the pain. One of them threatened to drink too much water to escape the pain she experienced. Patients on kidney dialysis are warned about a fluid overload and the dangers of pulmonary oedema. The mentioned participant hoped that by drinking too much water she could cause a fluid overload and death.

The participants who tried to suppress thoughts about suicide did it to save their family members more pain. They also wanted to be available for their family should they need them. A few expressed their desire to live long enough to take care of their mothers when they are aged. In traditional African culture, daughters take care of their mothers in old age (Mathis 2011: 845). Some of the participants felt that although they suffered from emotional pain, they still had reason to be thankful; these positive thoughts prevented them from actually trying to commit suicide. According to Kleiman et al. (2013: 598), the prevalence of suicide is low among people who find reasons to be grateful despite living in gruelling and strenuous circumstances.

Emotional pain does not always lead to hopelessness as some of the participants experienced. They managed to find some meaning in coping with their emotional suffering and experienced emotional growth. They appreciated the love and support they received from some of their family members in spite of the rejection from others. These participants managed to cope with negative situations. People who are able to obviate emotional pain and suffering, can succeed in living enriched lives; they can experience the feeling that their lives have meaning (O’Donnell et al. 2014: 48). Some of the participants were

fortunate to have the support of their families and partners. From this support they gained the strength to cope with family members who rejected them due to their childlessness.

4.3.3.3 Living with the hope for a kidney transplant

The participants were hopeful for the possibility of pregnancy after a kidney transplant. Some recounted they were advised by the dialysis team to wait at least one year after having received a kidney transplant before getting pregnant provided that their kidney function is stable. This advice is in line with the KDIGO Clinical Practice Guidelines for the Care of Kidney Transplant Recipients (2009: S107) which stipulates women need to first consult with their transplant physician before they get pregnant because immune suppression medication needs to be adapted in preparation for a safer pregnancy and an improved outcome.

The possibility of pregnancy after having a kidney transplant gave participants, their partners and family members much hope of having children thereby resolving the conflicting expectations they were experiencing during the kidney dialysis treatment. Hope provides people experiencing trauma such as kidney dialysis and restricted fertility perspective; it makes them realise and understand that their life is still of significance and has a purpose. Hope helps them to assert themselves, to believe that they can cope with stressors and negative experiences (Tutton, Seers & Langstaff 2009: 122).

Exploring the experiences of patients getting long-term kidney dialysis, Moran, Scott and Darbyshire (2010: 504) identified a framework known as, 'Waiting for a kidney transplant'. This framework comprises three themes, namely: '*living in hope*', '*uncertainty*' and '*being on hold*'. The first theme, '*living in hope*' for transplants, gives the patients on long-term kidney dialysis specific points to focus on – these focus points include that patients view kidney dialysis as a temporary problem; they must try to stay focused on passing time until they receive transplants. Embracing these focus points helps the patient to stay positive, it encourages him or her to continue staying emotionally and physically strong to fight the disease, and enhances the belief that escape from the restraints placed on them by their

disease and treatment is possible. The 'average' waiting time for kidney transplants is interpreted by patients as the 'actual' waiting time (Moran, Scott & Darbyshire 2010: 504).

The second theme, '*uncertainty*' is when the hope for a kidney transplant turns into uncertainty and despair when the 'expected' date for the transplant has passed. The patient on dialysis then views her or his life as '*being on hold*' (the third theme) and tends to become more sensitive to the restrictions of kidney diseases and dialysis (Moran, Scott & Darbyshire 2010: 504-505). The participants in this study experienced the waiting period for a transplant as a source of stress. They were told by the dialysis team to be available for a transplant on short notice when a donor kidney becomes available. Such arrangements restrict people's freedom to plan their own lives (Ekelund & Andersson 2010: 31) and cause feelings of uncertainty.

Dialysis patients who are waiting for kidney transplants are reported to have less life satisfaction compared to those who are not waiting for transplants. This is attributed to uncertainty about the transplant procedures and tension caused by the long waiting time (Lin et al. 2010: 764). The participants all hoped to get transplants and found the waiting period extremely stressful. They were aware of the shortage of cadaver organ donors and also knew the dialysis team generally encourages kidney donations from living family members. Although the participants mentioned family members who were willing to donate kidneys, the prospect had not materialised for any of them. According to Ekelund and Andersson (2010: 33), patients find it difficult to ask a relative to donate a kidney, but they nevertheless live with the hope that a family member who is a suitable donor will volunteer to give one of her or his kidneys for a transplant.

The realisation that kidney dialysis is not a short-term problem, but can be indefinite, restricts patients' future outlook because they are living a life '*being on hold*' all the time (Moran, Scott & Darbyshire 2010: 504). The current study participants' experience was that their prospects to bear children were 'on hold' while they waited for transplants. They feared they might no longer be fertile by the time they get transplants and thus hoped that the transplants would be done before they turned 35 years old. This link between becoming pregnant and believing after a certain age they might be infertile is consistent

with the findings of Alhassan, Ziblim and Muntaka (2014: 3 of 6). These authors found in Ghana the prevalence of depression increases when childless women get older. Of note in the Ghana study is that depression peaked in 35-year-old childless women and stabilised at age 40 (Alhassan, Ziblim & Muntaka 2014: 4 of 6). The uncertainty of the unpredictable waiting time for a kidney and, after transplantation, again ensuring enough time (at least 1 year) for adequate functioning of the transplanted kidney left the current participants and their significant family members moving to and fro between hope and despair.

4.3 SUMMARY

In this chapter a theoretical discussion of the findings was presented to create an improved understanding of the experience of living with conflicting expectations as described by the participants. The substantiating constituents namely: living with contradictory expectations from their mothers and future families-in-law; living with cultural transition; and attempts to be composed by living in the present and hoping for the future were discussed with reference to literature. In the next chapter a summary of the findings, limitations and conclusions is presented.

CHAPTER 5

SUMMARY OF FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

5.1 INTRODUCTION

Female patients' experience of conflicting expectations concerning pregnancy when getting long-term kidney dialysis was presented in four chapters. The first chapter comprised of the introduction, rationale, background information and significance of the study. Chapter 2 presented the constructivist paradigmatic perspective and the phenomenological research approach that underpinned the study. In Chapter 3 the findings of the study were described. In Chapter 4 a theoretical discussion of the findings of the study was presented directed by an extensive literature review to provide deeper understanding of the findings. In Chapter 5 a summary of the findings, limitations, recommendations and conclusions drawn from the study findings are presented.

5.2 SUMMARY OF THE FINDINGS

The objectives of the study were to:

- explore and describe the experiences of female patients of the expectations of their family regarding them getting pregnant during kidney dialysis;
- explore and describe the experiences of female patients of the expectations of the dialysis team regarding them not getting pregnant during kidney dialysis;
- explore and describe the experiences of female patients of the conflicting expectations between their family and the dialysis team regarding them getting or not getting pregnant during kidney dialysis.

To achieve the objectives, data were obtained through individual unstructured in-depth interviews with eight women of reproductive age who were receiving kidney dialysis and who had expressed the need to have children.

The interviews revealed that the essence of the participants' experiences were ways of **“being-for-oneself” and ‘being-for-others’ in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis”**. This was supported by the following constituents: living with contradictory expectations from their mothers and future families-in-law; living with cultural transition; and attempts to be composed by living in the present and hoping for the future. A summary of the essence and the constituents are presented next.

5.2.1 The essence: ‘being-for-oneself’ and ‘being-for-others’ in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis

Using the descriptive phenomenological method the researcher found the essence of the experience was exemplified in ways of ‘being-for-oneself’ and ‘being-for-others’ in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis’. Seen from an existential viewpoint, patients getting long-term kidney dialysis are responsible for their choices and actions towards themselves and also towards other people. ‘Being-for-oneself’ represented the participants’ experience of the phenomenon: their daily struggle to survive on a psychological, societal and personal level because of their chronic kidney disease; the stringent treatment regimen; and adapting to the undetermined period of avoiding pregnancy. ‘Being-for-others’ represented the experience the participants had of other people’s expectations regarding them getting pregnant or avoiding pregnancy. Other people that influenced the participants’ experience of the phenomenon included the dialysis team and significant others, namely the participants’ mothers as well as previous and present partners and the partners’ family.

The expectation of the dialysis team was that participants should not get pregnant while receiving kidney dialysis due to the detrimental effect a pregnancy can have on their own health as well as that of their unborn child. In contrast, their family members expected them to bear children. These contradictory expectations placed demands on them as ‘being-for-others’ which they could not satisfy. This caused conflict in their ‘being-for-oneself’ because of their eagerness to meet the demands of both groups.

5.2.2 Living with contradictory expectations from their mothers and future families-in-law

The participants experienced because they were of reproductive age, their mothers and future families-in-law wished for them to bear grandchildren. Their mothers accepted their pregnancy limitation and supported their 'being-for-oneself' whereas their future families-in-law demanded grandchildren and did not support their 'being-for-oneself' but placed the burden of 'being-for-others' on them.

Being chronically ill (CKD) and receiving ongoing treatment (kidney dialysis) the participants needed support from their family members. Mothers and grandmothers are the main home caregivers for children and grandchildren in African communities. Women feel indebted to take care of their mothers and grandmothers in return for the care they had received.

The future families-in-law were unaccommodating of the participants' circumstances and rejected them as future daughters-in-law. When women get married they form part and are supposed to contribute to their husbands' families. Grandchildren similarly form part of the husband's family. The expectation for daughters-in-law to provide the husband and his family with grandchildren is a fundamental cultural norm in traditional African families. The tenet is that the grandchildren will eventually be responsible for the grandparents' and parents' economic security, provide a social and emotional sanctuary, and continue the family lineage. Women who cannot bear children are not accepted as future daughters-in-law and attempts are made to break up relationships which may lead to marriage. This leaves childless women vulnerable to divorce, mistreatment by the families-in-law, and being dispossessed.

5.2.3 Living with cultural transition

The participants grew up with cultural expectations that link womanhood to childbearing. Cultural transition was necessitated by the participants' disease process, exposure to the biomedical model of care, and their inability to comply with traditional African cultural expectations to bear children. They demonstrated cultural transition by making the

informed choice to postpone pregnancy until after a kidney transplant or by considering alternative methods of having children.

Taking into account the widely multicultural environment in South Africa, acculturation is either fortuitous or intentional. In the traditional African patriarchal culture the expectation of a woman is to bear children; however, acculturation allows her to make their own choices without societal expectations dictating her life. For women who adopt cultural transition, it includes being liberated from traditional African cultural expectations of bearing children and getting married by pursuing their own goals; for example, through education and earning an income which emphasises their 'being-for-oneseff'. Cultural transition was supported by some family members and partners who accepted the pregnancy limitation and supported the participants and their 'being-for-oneseff'.

However, future families-in-law who held on to traditional African cultural beliefs placed demands on the participants' 'being-for-others' that they could not comply with. The former refused to continue dowry negotiations without the participants demonstrating their fertility. Childless women are considered inferior to childbearing wives. The participants feared these cultural attitudes and beliefs could lead to polygyny or divorce once they were married. Acceptance of involuntary childlessness is enhanced by the educational level of cultural groups and the income generating achievements of childless women.

5.2.4 Attempts to be composed by living in the present and hoping for the future

To protect themselves, the participants attempted to avoid conflict within their emotional self and with others by not discussing their pregnancy limitation. Denial and avoidance strategies are used by people who experience an external locus of control such as the conflicting expectations of the dialysis team and family members. Avoidance strategies provide temporary relief from stressors, but such strategies also prevent individuals from exploring healthier coping strategies. Avoidance of conflict prevented the participants from getting support from their family members during their challenging experience.

The participants experienced emotional pain related to the effect of childlessness on themselves as well as on their mothers, partners and supporting family members. The

consequences of childlessness are associated with fear, blame, depression and suicidal thoughts. Women's experiences of childlessness and kidney dialysis are affected by their partners and family members; therefore, the latter need to also be involved in treatment, health education and support systems. Supportive family members and finding reasons for their suffering contributed towards the participants' ability to gain emotional strength.

The possibility of pregnancy after having a kidney transplant gave participants, their partners and their family members the hope of having children in the future and resolving the conflict in expectations they were experiencing in the present time. Conversely, living with hope for kidney transplants place restrictions on dialysis patients' ability to plan for the future. The uncertainty associated with the unpredictable waiting time for a kidney transplant together with the one-year waiting period after a transplant before attempting to get pregnant, was stressful. Feeling as though their fertile years were passing by the participants and their significant family members were living between hope and despair.

5.3 LIMITATIONS OF THE STUDY

The findings were derived from qualitative interviews with eight childless women, of reproductive age, receiving long-term kidney dialysis on an outpatient basis at a level 3 hospital (an academic hospital) in Gauteng, South-Africa. These female patients' experiences may differ from those of women receiving treatment in other settings.

The researcher and supervisors are from Western culture and, although the researcher attempted to stay with the participants' experiences, some misunderstanding of cultural issues might have occurred.

5.4 RECOMMENDATIONS

The researcher recommends that the reproductive intentions and desires of women of reproductive age receiving long-term kidney dialysis be taken into account when they are informed about the dialysis team's expectations not to become pregnant until after it has been ascertained that they have a well-functioning transplanted kidney. The women's family and cultural background should be considered by the dialysis team; recognition of their traditional African heritage will strengthen female patients' resolve to adhere to and

cope better with the dialysis teams' expectations. Practice should be improved and support systems reinforced by involving these women's partners and family members in their care and informing also them of the dialysis team's expectations.

Further research should be conducted on the conflicting expectations concerning pregnancy when getting long-term kidney dialysis to develop practice guidelines. Such guidelines will enable the dialysis team to support women and their families to deal with the disease and treatment as well as it's the consequences.

5.5 CONCLUSION

The set objectives of this study were achieved and the research question duly answered.

The purpose of the study was to explore and describe female patients' experiences of the conflicting expectations concerning pregnancy when getting long-term kidney dialysis. The study findings disclosed the essence (meaning) of the experience was: **“being-for-oneseelf’ and ‘being-for-others’ in order to live with conflicting expectations regarding pregnancy when getting long-term kidney dialysis”**. The essence was supported by the following constituents (meaning units): living with contradictory expectations from their mothers and future families-in-law; living with cultural transition; and attempts to be composed by living in the present and hoping for the future.

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ANNEXURE A:

**FACULTY OF HEALTH SCIENCES UNIVERSITY OF PRETORIA ETHICAL
COMMITTEE APPROVAL**

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 20 Oct 2016.
- IRB 0000 2235 IORG0001762 Approved dd 13/04/2011 and Expires 13/04/2014.



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

3/10/2013

**Approval Certificate
New Application**

Ethics Reference No.: 358/2013

Title Female patients experience of conflicting expectations concerning pregnancy when getting long-term kidney dialysis. **Dept:** Nursing Science **Hospital:** Steve Biko Academic Hospital

Dear Ms HC Coetzee

The **New Application** as supported by documents specified in your cover letter for your research received on the **29 August 2013**, was approved by the Faculty of Health Sciences Research Ethics Committee on the **2/10/2013**.

Please note the following about your ethics approval:

- Ethics Approval is valid for **1 Year**.
- Please remember to use your protocol number (**358/2013**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:

- The ethics approval is conditional on the receipt of 6 monthly written Progress Reports, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

We wish you the best with your research.

Yours sincerely



Dr R Sommers; MBChB; MMed (Int); MPharmD.

Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

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ANNEXURE B:

STEVE BIKO ACADEMIC HOSPITAL PERMISSION TO CONDUCT STUDY

Permission to do Research and access Records / Files / Data base/ interview patients at the Steve Biko Academic Hospital

To: Chief Executive Officer/Information Officer
Steve Biko Academic_Hospital

From: The Investigator

Dr E Kenoshi

Ms HC Coetzee

Re:Permission to do the following research at Steve Biko Academic Hospital

I am the principal researcher working in the Hemodialysis Unit, Department of Nephrology at Steve Biko Academic Hospital. I am requesting permission to conduct a study on the Hospital grounds that involves interviews with patient and access to patient records.

The title of the study is: Female patients' experience of conflicting expectations concerning pregnancy when getting long-term kidney dialysis.

I intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature.

I furthermore request in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000 that I be granted access to clinical records, files and databases.

I undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Yours sincerely



Signature of the Principle Investigator


Permission to do the research study at this hospital and to access the information as requested, is hereby approved.

Chief Executive Officer

Steve Biko Academic Hospital

DR ME KENOSHI
CHIEF EXECUTIVE OFFICER
STEVE BIKO
ACADEMIC HOSPITAL

Dr



Signature of the CEO

9/11/2014

Hospital Official Stamp

ANNEXURE C:

INFORMATION LEAFLET AND INFORMED CONSENT

TITLE OF THE STUDY:

“FEMALE PATIENTS’ EXPERIENCES OF CONFLICTING EXPECTATIONS CONCERNING PREGNANCY WHEN GETTING LONG-TERM KIDNEY DIALYSIS”

Dear Participant

1. INTRODUCTION

You are invited to participate in a research study. This brochure will assist with giving you the relevant information to help you decide to participate in this particular study. It is important to understand what the study entails before you can make a decision to participate. Should this brochure fail to provide all the information you need to know, feel free to ask the researcher.

2. THE NATURE AND PURPOSE OF THIS STUDY

The purpose of the study is to describe female patients’ experiences of the conflicting expectations that their partners/husbands and other family members have regarding them getting pregnant while the dialysis team expects them not to get pregnant while they are on dialysis. You as a female of child bearing age who are on kidney dialysis is a very important source of information as you might have experienced the same conflicting expectations and are thus approached to take part in this study.

3. EXPLANATION OF PROCEDURES TO BE FOLLOWED

The participants in this study will comprise of female patients between 18 and 45 years, who is receiving kidney dialysis (haemodialysis or peritoneal dialysis) for a minimum of 1 year. Approximately 5 participants will be selected. Information will be collected by the researcher herself in the form of interviews, conducted in English. Interviews will be voice recorded, and later typed to be studied. Two or three interviews may be necessary to clarify and confirm what was discussed. An interview will last 30 – 60 minutes. Interviews will take place in a place of your choice, on appointment. Participation is voluntary and if you do not wish to participate it will not influence your treatment. If you wish to withdraw from the study at any time, or wish to withhold information, you can do so without explanation or any consequences for your treatment.

4. RISK AND DISCOMFORT INVOLVED

Possible risks for participants are emotional discomfort from talking about their experiences. You will be free to stop the interview at any time should you find it difficult to talk about the expectations that you are exposed to by family who want you to get pregnant and the dialysis team who do not want you to be pregnant.

5. POSSIBLE BENEFITS OF THIS STUDY

A possible benefit of participating could be an opportunity to talk to somebody who is interested in your experiences. The results of the study will also enable the dialysis team to improve healthcare to female patients of reproductive age who want to have children while they are on dialysis. At the end of the study I will provide you with a copy of the findings.

6. WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time during the interview without giving any reason. Your withdrawal will not affect you in any way.

7. HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria and the Gauteng Department of Health Research Committee. Copies of the approval letters are available if you wish to have one.

8. INFORMATION AND CONTACT PERSON

The contact person for the study is Mrs Cecile Coetzee. If you have any questions about the study please contact her at 082 *** ****. Alternatively you may contact her supervisor Prof Neltjie van Wyk at cell 082 *** ****.

9. COMPENSATION

Your participation is voluntary. No compensation will be given for your participation.

10. CONFIDENTIALITY

All information that you give will be kept strictly confidential. Once the information has been analysed no one will be able to identify you. Research reports and articles in scientific journals will not include any information that may identify you.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me about the nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above written information (Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the study, including personal details, will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect me in any way.

I have received a signed copy of this informed consent agreement.

Participant's name(Please print)

Participant's signature: Date.....

Investigator's name(Please print)

Investigator's signature Date.....

Witness's Name(Please print)

Witness's signatureDate.....

VERBAL INFORMED CONSENT

I, the undersigned, have read and have fully explained the participant information leaflet, which explains the nature, process, risks, discomforts and benefits of the study to the participant whom I have asked to participate in the study.

The participant indicates that s/he understands that the results of the study, including personal details regarding the interview will be anonymously processed into a research report. The participant indicates that s/he has had time to ask questions and has no objection to participate in the interview. S/he understands that there is no penalty should s/he wish to discontinue with the study and his/her withdrawal will not affect her/him in any way. I hereby certify that the client has agreed to participate in this study.

Participant's Name(Please print)

Person seeking consent (Please print)

Signature.....Date.....

Witness's name(Please print)

Signature Date.....

ANNEXURE D:

UNSTRUCTURED INTERVIEW GUIDE

UNSTRUCTURED INTERVIEW GUIDE

How do you experience the expectations of your husband/partner and other family members that you should get pregnant while the doctors and nurses tell you that you should not get pregnant while you are on kidney dialysis?

The probing questions will be determined by the participant's answers.

ANNEXURE E:

SAMPLE OF AN INTERVIEW TRANSCRIPT

TRANSCRIPTION: Interview 1

INTERVIEWER: Welcome. Thank you for giving me the opportunity to talk to you. Uhm... I want to start with this question: how do you experience the expectations of your family members, your dad and your sisters, uhm... that you must have a baby, while doctors and sisters, hospital staff tell you to wait, while you're on dialysis, not to get pregnant...? Uhm, how do your family value children, grandchildren...?

PARTICIPANT: They do value children. They have their own children also, this is first.

INTERVIEWER: Mmm.

PARTICIPANT: But, they understand that I cannot have a child, because I'm still sick.

INTERVIEWER: Mmmhmm.

PARTICIPANT: They... I did explain to them... even the doctors before, they did explain to them. And then, my other sister, who is a nurse, she also explained to them that. She knows better than me...

INTERVIEWER: Mmm.

PARTICIPANT: That, she did explain to them, that they shouldn't expect this. They should be supportive of her always.

INTERVIEWER: So from the start, with your first dialysis...

PARTICIPANT: Mmm.

INTERVIEWER: ...starting already they got the facts.

PARTICIPANT: Yes. Yes.

INTERVIEWER: The right information from the start.

PARTICIPANT: Yes. From the start. They were so supportive about it.

INTERVIEWER: Have you talked to your parents about pregnancy?

PARTICIPANT: Yeah. I-I wished to have a child, while my mom was still alive.

INTERVIEWER: Mmm.

PARTICIPANT: I did explain... I did talk to her... that one day if I get a kidney, I will make a baby at least one.

INTERVIEWER: Mmm.

PARTICIPANT: Mmm. So she was agreeing with me, but she said that: you should wait first and ask the doctors. Go to the hospital first and ask the doctors for advice.

INTERVIEWER: Mmm.

PARTICIPANT: If you are ready.

INTERVIEWER: So, they are very sensible about this...? Understanding?

PARTICIPANT: Yes.

INTERVIEWER: Supporting you?

PARTICIPANT: Yes, they are sensible.

INTERVIEWER: So, they were not putting pressure on you, asking you, when... when... when..?

PARTICIPANT: No pressure ... mm hmmm, no pressure... they understand.

INTERVIEWER: Okay. That's very good.... Your current boyfriend, how did you explain this to him?

PARTICIPANT: Before we got involved. Because he is uhm ... younger than me, that I didn't say...

INTERVIEWER: Mmm.

PARTICIPANT: His younger than me, he is 27...

INTERVIEWER: Mmm.

PARTICIPANT: And I am 37...

INTERVIEWER: Mmm.

PARTICIPANT: ...so 10 years difference. So I explained to him before we got involved, that I don't want to get involved with younger boyfriend. Because I'm older and then I'm sick. I did explain my situation.

INTERVIEWER: Mmm.

PARTICIPANT: That I have a kidney disease with SLE {*Systemic Lupus Erythematosus*}. Sometimes, I don't feel well. I can be at the hospital and I get admitted for even 3 months and that he saw he did experience that. Yeah. So, he said, no problem. Its God's ... it is only God who knows. Because he is very ... he believe very much in God.

INTERVIEWER: Mmm... Does he have children?

PARTICIPANT: No. Not at all. He is fresh from school. From university...

INTERVIEWER: [Laugh]

PARTICIPANT: Then he went to work at place* after that he came to School* then that is where he met me.

INTERVIEWER: Okay. How did you explain this ... the ... the problem with pregnancy to him and then when you had a transplant that you were still too sick...?

PARTICIPANT: Mmm... because I met him after ... after the transplant. When I got the transplant.

INTERVIEWER: Mmmhmm.

PARTICIPANT: Then I told him that we should wait first, because it is still fresh.

INTERVIEWER: Mmhmm.

PARTICIPANT: And I had this Mirena for prevention. {*Intrauterine delivery system used as contraception*}

INTERVIEWER: Mmhmm.

PARTICIPANT: And I couldn't make a baby for now. But, when I'm fine, after 2 years, we will go to the hospital and talk to the doctors together. So that, they can test us for HIV aids and everything and tell us if and when we are ready. So he agreed. But... that failed, because I had this disease of the UTI's and the infections, the hydronephrosis and my kidney then failed. So, I couldn't have a baby. So he understood. And he was so supportive. And then I told him that I am going to ... before ... I was so stressed when I got the ... when I found out that ...I'm going back to the dialysis. I thought he is going to run away from me. But, when they told me that ... while I was in hospital, I told him that I'm going back to the dialysis. Then this is the situation that I am not supposed to have a baby. I must be clean. When we go to his home, we can only spend a week because of the {*dialysis*} solutions that I'm carrying and the cleanliness.

INTERVIEWER: Mmm.

PARTICIPANT: So I explained the situation to him. But he is so supportive. He understood.

INTERVIEWER: Mmm. He is still young. Do you think...?

PARTICIPANT: Otherwise, yes. He's still young, because... But I don't know why he doesn't decide now.... because now, we are going for marriage preparations. For the marriage preparations at the church.

INTERVIEWER: Mmm.

PARTICIPANT: He's talking about taking out lobola during August month, now.

INTERVIEWER: Mmm.

PARTICIPANT: He doesn't go back on his word. I don't know why. I thought he is going to go back on his word. Because I get sick. During the night, before I sleep I have this ear

problem. Every day I have to-to -to concentrate on this ear problem. Sometime, it's this SLE, I'm in pain, every time...

INTERVIEWER: And still...

PARTICIPANT: But he is still understanding.

INTERVIEWER: Shoe.

PARTICIPANT: Understanding.

INTERVIEWER: Uhm... were you scared to talk about this to him?

PARTICIPANT: Huh-uhh, the problem that I'm not scared. I am very much talkative and explain everything to everybody.

INTERVIEWER: Mmm.

PARTICIPANT: Even to the people, I am not afraid to talk to them about my illness.

INTERVIEWER: Uhm... okay, coming to his family. Did you explain this to them?

PARTICIPANT: To his family?

INTERVIEWER: Yeah.

PARTICIPANT: I did explain this to the mom, because she is the one that I'm close to now. Yeah, she's like my mom now. Yeah, I called her... she.... we call each other every time. Then she ... when I visited their place, I did explain to her and I showed her the operations and everything. Because those are rural people. When they see a big operation like this, then they think that you cannot have a baby.... you are very sick. And I told her the situation. But, my situation is this one that I have a kidney disease and this is the situation, that I cannot have a baby now. I'm still sick, but if I have a chance with a kidney, then I can make a baby. But, if I don't get better then I cannot have a baby. She said that only God knows. Those are her words.

INTERVIEWER: Mmm.

PARTICIPANT: But she understands, because she's also sick. She's got diabetes, she's hypertension and she was ...the- the leg was amputated.

INTERVIEWER: Shh...

PARTICIPANT: Mmm, so.... so this boy, I think my boyfriend, I think he understands better, because the mother is also sick...

INTERVIEWER: He grew up with it.

PARTICIPANT: Yeah. Even the father was sick, he had cancer. Mmm. So I think the experience gives him this... this courage of being with me.

INTERVIEWER: Uhm.... so, back then when you met him and his parents ... his mom... there was still hope...because you had the transplant?

PARTICIPANT: Yeah...yeah

INTERVIEWER: You were hoping after two years...

PARTICIPANT: Mmm.

INTERVIEWER: ... you can have a baby?

PARTICIPANT: To have a baby. Mmm.

INTERVIEWER: Uhm. Do you think that changed,when you were then sick? Did you feel any change in ... disappointment maybe?

PARTICIPANT: From ... from him?

INTERVIEWER: From him, from the family?

PARTICIPANT: Yeah, I think, they are a little disappointed, even if they don't show it to me. But, I think they are disappointed.

INTERVIEWER: Uhm... what makes you think that.

PARTICIPANT: Because the brothers, two, they are from the other wives.... they are making babies out.

INTERVIEWER: Yeah.

PARTICIPANT: They have babies now. Even his sister, she has another baby. So, they are thinking what about him.

INTERVIEWER: Mmm.

PARTICIPANT: Can he make a baby, because you know the rural people they want to have babies. They ... marriage is all about babies. It's not about love.

INTERVIEWER: This, the lobola arrangements ...

PARTICIPANT: Mmm.

INTERVIEWER: ...do you think it's affecting it or its going to affect it?

PARTICIPANT: Affect what?

INTERVIEWER: Uhm... isn't there a thing of you must have a baby before lobola...

PARTICIPANT: Ooh no. No. Even now we are preparing for lobola. He is going to buy the things for the lobola. The money is there.

INTERVIEWER: So, there were no fighting about this?

PARTICIPANT: Mmm- hmm.

INTERVIEWER: Pressure from the other family members...

PARTICIPANT: No.

INTERVIEWER: ...about this?

PARTICIPANT: The thing about my boyfriend... he doesn't listen to other people. When he does a thing he does it, and when he doesn't want it he doesn't. He doesn't listen to the second opinion. Mmm.

INTERVIEWER: That's good. So, at least, because they understand and maybe because of their experience they ...

PARTICIPANT: Mmm.

INTERVIEWER: They are more supportive...

PARTICIPANT: Yeah.

INTERVIEWER: ...off this. And so they're not giving you any pressure.

PARTICIPANT: Uuh-hmm. No. The immediate family doesn't give me any pressure. Unless the ... the rumours from the extended... sisters family... I don't take... I don't care about them.

INTERVIEWER: And his family also... they're not...

PARTICIPANT: Ah, they don't ... they don't care about what they say.

INTERVIEWER: This ex-boyfriend of yours....

PARTICIPANT: Mmm.

INTERVIEWER: What were your experience with him regarding possible pregnancy?

PARTICIPANT: Huh-uhh, I didn't want to make a baby by then, because I had this tube, this PD.

INTERVIEWER: Did you ... did you ...

PARTICIPANT: There was no chance. I never even explained or discussed about a baby with him, because he had so many babies outside.

INTERVIEWER: Did you know about the other babies?

PARTICIPANT: Yeah. Yes.

INTERVIEWER: So was he putting any pressure on you?

PARTICIPANT: No. Not at all. Because he was not staying with me, he only came to visit. We saw each other after some months...

INTERVIEWER: Did you... if you knew you don't want babies with him, why were you together?

PARTICIPANT: I don't know [laugh]. Just...

INTERVIEWER: Did you ... Did you love him or was it just somebody to have?

PARTICIPANT: Yeah, it was just somebody to have ... to have fun.

INTERVIEWER: Mmm.

PARTICIPANT: To go out with. Not somebody you can build ... a relationship...

INTERVIEWER: You weren't picturing a future with him...

PARTICIPANT: And marriage. No, I was not picturing a future with him.

INTERVIEWER: Okay... so you...

PARTICIPANT: He is not the kind of guy that you can put your-your future with him. Huh-uuh...

INTERVIEWER: Uhh...

PARTICIPANT: He's too playful.

INTERVIEWER: Okay. So then, there was no pressure from him for pregnancy?

PARTICIPANT: Mmm- hmm.

INTERVIEWER: His family?

PARTICIPANT: You will start... I did not even meet his family. You see how ...

INTERVIEWER: It was not serious...

PARTICIPANT: Huh-uhm. The mother did not love me. They even phoned me and called me and swear at me. So, I never met his family. He never took me to meet his family.

INTERVIEWER: Were they angry because he was cheating on his...?

PARTICIPANT: I think the mother was angry because he was cheating on the other wife, they knew that girlfriend.

INTERVIEWER: But you didn't know about that...?

PARTICIPANT: No, I did not know.

INTERVIEWER: And then when they swore at you?

PARTICIPANT: Ahh, I just dropped the phone.

INTERVIEWER: You didn't know what it is about?

PARTICIPANT: It was about me leaving this boy. Then I told him: why do you come back to me. Go back to your mother and your other girlfriend. But he insisted on being with me, even with... while I was with this one, with the new one. Ahh. We struggled to take him of ...of ... of...

INTERVIEWER: So, he was still bothering you?

PARTICIPANT: Yeah, he was still bothering me.

INTERVIEWER: Shame.... Okay. So, it seems the whole experience for you, it was better because your family has experience of disease.

PARTICIPANT: Mmm.

INTERVIEWER: Your boyfriend has experience.

PARTICIPANT: Mmm.

INTERVIEWER: You are educated.

PARTICIPANT: Yes.

INTERVIEWER: So, you could handle it...

PARTICIPANT: Yeah.

INTERVIEWER: ...better.

PARTICIPANT: Yeah, I could handle it better.

INTERVIEWER: You have more self-confidence.

PARTICIPANT: Yeah.

INTERVIEWER: That's good.

PARTICIPANT: Mmm.

INTERVIEWER: That's a different experience than I've seen so far.

PARTICIPANT: [Chuckle] Nê.

INTERVIEWER: Mmm. I am very glad for you. Uhm... so at the moment, how do you view your future with your boyfriend after marriage?

PARTICIPANT: Mmm.

INTERVIEWER: The possibility of children?

PARTICIPANT: We have a brighter future, but without any children. I don't think of any children now.

INTERVIEWER: Mmm. Okay....

PARTICIPANT: Yeah. Unless I have another kidney. I'm hoping to have one, I am praying for one.

INTERVIEWER: Uhm... so, if it doesn't happen in time?

PARTICIPANT: If it doesn't happen at any time now.

INTERVIEWER: Mmm.

PARTICIPANT: [Sigh] then, I could die without a baby. Then I think he will marry another wife. After I'm dead.

INTERVIEWER: But, for now he's totally committed to you.

PARTICIPANT: Yeah, he is totally committed to me.

INTERVIEWER: Okay.

PARTICIPANT: I trust him.

INTERVIEWER: Okay. Is there anything else I didn't ask that you think would shed light on this?

PARTICIPANT: Mmm-hmm, I think I gave my whole story.

INTERVIEWER: I also think so. Uhm... is there anything you would like to ask?

PARTICIPANT: No, thank you.

INTERVIEWER: Thank you very much.

ANNEXURE F:

SAMPLE OF BRACKETING INTERVIEW

REFLECTION ON BRACKETING INTERVIEW

During the bracketing interview with co-supervisor Dr. A van der Wath the following issues was discussed for bracketing purposes:

Bracket

Own belief about childlessness, chronic disease and reaction from family

Own experience from working in haemodialysis and transplant unit.

I believe that most women want children

I believe the conflict with family, partner and family in law is stressful for the women

I believe women care more for children than themselves

I believe that in some cultures you cannot get married without having a child to prove your fertility first.

Family does not understand kidney disease, dialysis or forced pregnancy prevention

Consequences of conflict are loneliness and frustration and rejection.

My experience of own childlessness may have contributed to identifying the problem that became the phenomenon of the study. Telling my mother I can't have children was the most difficult part of the experience for me. I also felt I disappointed my friends and family that wanted me to have children. I preferred to discuss my experiences with different councilors along the way and have come to acceptance. I will not hesitate to seek help if the study makes me feel distressed because I know there are a lot of resources available to make my life easier. I think my experience may make it more comfortable for participants to relate their experiences to me because most of them know that I don't have children.

ANNEXURE G:

SAMPLE OF REFLEXIVE JOURNAL

REFLEXIVE JOURNAL - Participant * Interview

The participant says that no one from the dialysis team spoke to her about pregnancy on long-term kidney dialysis. “No, they..... they didn’t get a chance to talk to me about not getting pregnant”. She did not ask for information because “there is a part of me that’s **very shy to go and ask...ask the sisters about it**”. The participant found information about pregnancy on dialysis on Google.

The patient has been on kidney dialysis (HD and PD) for 4 years. How could they not find the time to speak to her?

Initially I thought the participant is too childish for an interview. She is often late for appointments and repeatedly rushed to the emergency unit with complications related to non-compliance with treatment. She sends me SMS messages when she has a problem and I have often assisted her to get the treatment she needed. She has a lot of health problems and is struggling to complete school because of treatment interrupting school attendance.

She heard from other participants that I was interviewing them and asked why I was not interviewing her. I gave her the information and she was very eager to participate. I was pleasantly surprised by how easy the interview went and how positive she approached the situation. It may be that her immature way of looking at problems help her cope with everything she faces.

ANNEXURE H:

SAMPLE OF DESCRIPTIVE NOTE

DESCRIPTIVE NOTES

Context

Participant is a ** year old female receiving long term kidney dialysis for 2 years and 2 months. She started showing signs of kidney failure 3 years before starting kidney dialysis. She has no children.

Actions

Participant said she read and understood the participant information leaflet that was given to her before appointment for interview was made. She signed the informed consent form.

Dialogue

Interview lasted 49 minutes.

Participant appeared eager to talk and did not appear distressed by the interview.

ANNEXURE I:

SAMPLE OF METHODOLOGICAL NOTE

METHODOLOGIC NOTES

Strategies that work

Determine role-players in patient's family.

Determine what information was received from healthcare providers regarding pregnancy and fertility.

Ask for detailed description of particular experience: event when she informed her significant family member (mother).

Things that do not work

Researcher lost the focal point by encouraging participant to talk about disease process. It did seem like participant needed to talk about it. Would it be better to talk about disease process in pre-interview, when obtaining consent for study from participant?

Researcher sometimes did not know what to ask and formulated long confusing questions. Rather reflect and think carefully before asking a question

Researcher used too many "uhm".

New strategies/ instructions about how subsequent observations will be made

Keep the focal point: what and in what way participant experience the phenomenon and what is its meaning. Direct participant towards reflection and even deeper layers of meaning.

Obtain information about the most important role-players in the participant's life during the pre-interview. This will assist in making interview more focused on the focal point instead of spending time trying to figure out where the role-players fit in.

ANNEXURE J:

SAMPLE OF THEORETICAL NOTE

THEORETICAL NOTES

FAMILY

Three main role players in the participant's life affecting her experience of the phenomenon were identified: her mother, a possible future life partner and possible future family in law.

A possible future partner.

The participant has not had a boyfriend since getting sick and is currently still single.

The participant was waiting for marriage before getting pregnant because of the way her mother taught her and set "rules for myself... I should have a baby once I'm married, if I am not I don't have to...". Therefore "for now it's not {an issue} cause I feel that ... I-I can't have a baby if I am not married... unless if I get, should I get married now, while I'm here... That's when I'm gonna start stressing now...".

The thought of a possible future boyfriend or husband is causing distress because of the expectation to have a child that cannot be fulfilled while receiving long-term kidney dialysis: "I feel that...that being involved with someone now... then maybe feeling that you want that person to accept you and maybe they don't accept you and haa I'm gonna feel bad....so that's why to **avoid** those kind of... emotions and all that... I just hold back myself..... but then in terms of relationship it-it's very difficult because you want someone who will love you and who will like treat you like somebody who is just fine but thenyou know it become a... like a... I don't know it's a boundary nyana {small} something that is limiting you cause maybe that person want's.... things and then wena {you} you can't....ei I don't know....Maybe that person might want to have a child... obviously...". Her believe is rooted in cultural expectations: "Especially, us black people... they expect... if they marry... they expect you to bare children for them..."

She plans to explain to her future boyfriend: "I wouldn't... I would make... make I like... I would try and make it clear to him that you know for now... that... like if he doesn't take it.... Me and him ... we can't be ... I would try and emphasize to him, that you know what... I-I we love each other... I know you maybe want to marry me and all that, but please understand that for now...I can't... there is no way that I can fall pregnant and have a baby. I will explain to him... like even the

dangers and all those things... and even still.... He still insist and insist... he wants to have ... have a baby then... me and him... we can't continue... cause if he loves me he has to understand that I can't do something that's gonna will put my life and the baby's in danger.

A transplant (after which pregnancy is a bigger possibility) would change her life "relationship wise".

Possible future Family-in- law

She expects her possible future family in law to put pressure on her to have a baby: "...so it's gonna to be difficult for...the-the-the people... of the in-laws to accept that yeah, for now you can't have children.... Cause they will tell you they want grandchildren and keep on... bugging you We want grandchildren... aah... it will be a huge ... a huge effect... yho a negative one, for sure".

ANNEXURE K:

SAMPLE OF PERSONAL NOTE

PERSONAL NOTES

Researcher personal emotions:

My first interview – did not know what to expect and felt anxious. Participant is very friendly and was eager to talk. She talked a lot about her disease process and experience thereof.

I realized I is dwelling off the focus of the study, but felt guilty to stop the discussion and return to the focal point.

I was anxious of awakening bad feelings in the participant by asking personal questions or things participant has not thought about before. I found comfort in the assurance that the “psychological defense mechanisms” will protect the participant (Peris, 1969 cited in Dahlberg, Dahlberg & Nystöm 2008:204)

Researcher inexperience made me feel like “kid in candy-store” seeing all these interesting things that I wanted to know more about and therefore I lost focus on the phenomenon.

Ethical dilemma

The reason for the participant refusing peritoneal dialysis (PD) was revealed. The participant has problems with veins needed for access in order to preform hemodialysis. Therefore the health care team has been encouraging her to change to PD but she is refusing. If the problem with her veins does not get resolved she will have no choice but to change to PD or possibly die. During the interview the reason why she is refusing became clear: she is afraid the community might think she is pregnant. (During PD two liter of dialysate fluid is infused into the peritoneal cavity and is left there to ultra-filtrate excess fluid, which usually leads to an increase in the volume.

Meanwhile the person continues activities of daily living. In a thin person, like the participant, it would appear like she is pregnant). She is concerned that the community might get the perception that she is pregnant. Not having a child might lead the community to think she aborted and gossip about her, causing her severe distress. The researcher is not allowed to share this information with the healthcare team because as part of study, it must be kept confidential.

Information given in debriefing session

I discussed with the participant the reasons for avoiding pregnancy that according to research pregnancy while receiving long-term kidney dialysis has a high risk for the mother and baby. To

create a safe environment for the fetus an increase kidney dialysis frequency, adjustment of medication and monitoring of blood results is needed. This has practical and financial implications for the pregnant women that must travel to the dialysis center more often or be admitted in hospital over a long period Female patients are encouraged to wait till after they had a kidney transplant when there is less pregnancy risks and plan in cooperation with their healthcare provider.

I gave her opportunity to ask questions and encouraged her to keep asking until she understands. I support her idea of a group and private discussion and providing information in writing for patients.

ANNEXURE L:

DATA ANALYSIS – MEANING UNITS

Participant	Living up to contradictory family expectations (difference between own family and in-laws)		
	Family UNDERSTAND	Family in-law NOT UNDERSTAND	Family/interpersonal CONFLICT
A	A13 MOM: it makes sense ; you can't fall pregnant while you're like... So it was never much of a bigger deal, and then [Mom] never put pressure .		
B	B2 MOM she understands the reason why I can't have children now. It's not affecting her that much because there is a valid reason, why not... B12 [Mom future wish for B] is children... To get married and have children....		
C	C1 GOGO: she normally says, if only it's possible for you to get pregnant, its fine. But, if it's not possible for you to get pregnant, I don't want you to risk your life	C6: FIL: They do act strange sometimes...talking about you behind your back . Or when they do strange things to show that, we don't really appreciate you being around here . Sometimes, they wake up and just be angry and be moody. They don't talk . They just... [ignore you]	C7 BF: Cause when he's[BF] around, they [BF family] fine. They act all nice, but when he is not around they become moody and all this kind of stuff.
D	D1 GOGO: my grandmother understands. She's saying like: you should put your life first ... not uhm... other people...That you have to concentrate on you getting well first.	D2 BFF: We did [explain to boyfriend's mother]... even her sister... we explained everything to them... But then, the mother said: I can't do anything, I don't have a say... so.... I don't think she was [supporting relationship], cause she wanted the grand -the grand s ... the grandchild.	D12 Like they were ... they were fine with me at first, nê.... But when, they found out that I was not able to have children... Then, I can – I could see when I go to his place ... like his mom ... she's somehow... like even when I call: I am coming... No, we not at home [did not want her to visit]
E	<i>Experience: Family, BF and BFFamily was present with loss of pregnancy & hysterectomy.</i>		
F	F2. MOM: she is understanding and she-she's is supporting me.	F9. XBF family: They were also wishing that I can have a baby but I think that they were understanding that I'm sick	
G	G1 FAM: My parents are-are not that kind of people who... who always put pressure on us ... When are we going to have a.... grandchildren or...		
H	H1. FAM: they understand that I cannot have a child, because I'm still sick.		

Living in cultural transition (difference between self, partners and older members in cultural group)		Attempts at gbeing composed by living in the present and hoping for the future	
Partner	Older members rejection	Plan	Defence mechanism
A12 FutureBF Especially, us black people... they expect... if they marry... they expect you to bare children for them, so it's gonna to be difficult for	A12 [Future] it's gonna to be difficult for... people... of the in-laws to accept that yeah, for now you can't have children.... Cause they will tell you they want grandchildren and keep on... bugging you We want grandchildren... aah... it will be a huge ... a huge effect... yho a negative one, for sure	A10 [Tx and Px possibility would change a lot] in terms of relationship wise...	A8 for now it's not {an issue} cause I feel that ... I-I can't have a baby if I am not married....
B12 [future husband] Married & no baby} he loves me and he has to choose now... he has to choose between the family and the wife. So, it's a bad thing... it's a terrible thing... to think about	B9 (Future) Inlaws it'ss very frustrating from their side. Especially, if you're married. You know: why can't this woman have a child, we need grandchildren... B12 [marry & no baby] It frustrates her that they [inlaws] might reject me, or even divorce	B13 We can still manage it and then we can still get pregnant...	Anger at God. Bargianing. Why. Wish you had other illnesses instead of renal failure.
C4 BF: And he was like, okay. Its fine then. The chances are too low and they ... and they said the risks are too high.	C3 FIL: In their {Boyf} family, they believe that you cannot marry a ...a lady or woman who doesn't give you children, because he's not going to extend the family's surname.	C14 BF: And there is also other options of having children. You can also adopt ...we did talk about it, that ... if there is... there won't be any chances after transplant , we can also adopt a child.	Avoid family in law
D1 BF: And I said: no, my boyfriend is very supportive and he will speak to them. But then, he went on and he got this other girl pregnant behind my back and he didn't tell me anything... And then, I find out for myself, then from there I broke up with him.	D1 CULTURE: when you're a woman, you're supposed to have a baby... a child... so that, you can... like they say, a man can't marry without having children. So that's the other problem we have like in our culture. So, because some people they don't understand. Even if you try to explain to them, that: no, I am sick, I can't have children now. They will say that you are not woman enough. If you can't have children, then, you are not supposed to marry our child or something... So,yoh we struggle a lot about that...	D10 TX [will change view of relationship?] Yeah, I think so.	D11 New BF: It's just a fling. [no longterm plans]
		Planning surrogate pregnancy	
F3 XBF:He said that I don't love him. I must fall pregnant, so that I can show him that I love him.	F9. XBF family:They were... was waiting for me to have a baby. They wa-they were not pressurising me.	F15. FBF: I will look for someone that will understand me	F9 Xfam: <i>how they feel about pregnancy and TOP?</i> I didn't ... we didn't tell them. (Avoid conflict by not informing)
G5 FBF: African men...uhm... if you are his woman, they believe that, or if you love them ... they believe you must have a baby.	G5 [Future FIL] I think even their parents ...I think they will ... they will say to their son: we want a grandchildren. So if I-I'm not able to have the children... that will also break my heart.	G5 FBF: Scared ...Cause I have to explain myself and if I can meet someone who wants to have a babies. I have to tell him that I am not allowed because of my condition.	G1 FAM: they don't know... if I will be ... I-I'm not allowed to have a baby (avoid conflict my not talking about it)
H4 BF So I think the experience [of his mother being sick] gives him this... this courage of being with me.	H5 Bfam Can he make a baby, because you know the rural people they want to have babies. They ... marriage is all about babies. It's not about love	H4. BF the problem that I'm not scared. I am very much talkative and explain everything to everybody. H8 BF We have a brighter future, but without any children. I don't think of any children now.	